> “The most effective way to tackle disability poverty is by reducing costs…”

COUNTING THE COST

Claudia Wood
Eugene Grant

DEMOS

Demos is a think-tank focused on power and politics. Our unique approach challenges the traditional, 'ivory tower' model of policymaking by giving a voice to people and communities. We work together with the groups and individuals who are the focus of our research, including them in citizens' juries, deliberative workshops, focus groups and ethnographic research. Through our high quality and socially responsible research, Demos has established itself as the leading independent think-tank in British politics.

In 2010, our work is focused on four programmes: Family and Society; Violence and Extremism; Public Interest and Political Economy. We also have two political research programmes: the Progressive Conservatism Project and Open Left, investigating the future of the centre-Right and centre-Left.

Our work is driven by the goal of a society populated by free, capable, secure and powerful citizens.

Find out more at **www.demos.co.uk**.

First published in 2010

Magdalen House, 136 Tooley Street
London, SE1 2TU, UK

ISBN 978-1-906693-59-6
Copy edited by Susannah Wight
Series design by modernactivity
Typeset by modernactivity

Set in Gotham Rounded
and Baskerville 10

Mixed Sources
Product group from well-managed
forests, controlled sources and
recycled wood or fiber
FSC
www.fsc.org Cert no. CU-COC-804101

COUNTING THE COST

Claudia Wood
Eugene Grant

DEMOS

Contents

Acknowledgments

We are extremely grateful to Scope for funding this project and for their ongoing support. Special thanks go to Marc Bush and Ruth Scott at Scope, for their help, involvement and insight throughout this project. At Demos, we would like to thank Kitty Ussher, for her encouragement and input; Bea Karol Burks and Ralph Scott, for expertly steering this publication to its production and launch; and also Matthew Fraser for his most helpful research assistance. As ever, any omissions or errors remain our own.

Claudia Wood
Eugene Grant
December 2010

Foreword

Disability Living Allowance (DLA) was introduced by the Conservative Government in 1992. Since then it has acted as a 'lifeline' for many disabled people helping to subsidise the extra expenses associated with day to day living in a society that frequently fails to include disabled people or accommodate their needs.

The impact of disability-related costs on disabled people's standard of living is not in doubt. Even a cursory inspection of disabled people's day to day expenditure reveals that disability-related costs are real and often significant. Whether it's paying for a stair lift or a hydraulic bath, the cost of taxis in lieu of inaccessible local public transport systems, or the expense of a sign language interpreter, these extra costs can have a catastrophic effect on disabled people's disposable income, leaving them at much higher risk of poverty and financial exclusion. Indeed researchers have estimated that once disability-related costs are taken into account the numbers of households with a disabled occupant assessed as living in poverty jumps from 23 per cent to between 40 per cent and 60 per cent.

While the practical and symbolic importance of DLA has always been clear to disabled people and their families, this has not always been the case for government or the wider public. Claims that DLA is not well targeted and that claimant numbers are far higher than originally envisaged have made it a target for public spending cuts.

In 2010 every aspect of public spending is coming under close scrutiny. The welfare bill took the brunt of the austerity measures, with the Government's Budget in June announcing cuts to the DLA budget of £1 billion (around 20 per cent) over the coming Parliament. In real terms this could mean hundreds of thousands of people losing their entitlement to DLA. Whilst we should welcome the Government's new emphasis on independent living in their approach to reforming DLA, we must ensure that it does not lose sight of the core aim of the benefit. That is, making a financial contribution towards the additional day-to-day living costs that disabled people incur in their everyday lives.

Counting the Cost is a timely and important contribution to the public debate about the reform of DLA. At an important window in developing policy around the extra costs disabled people face, it shines a light onto the complexities of disabled people's lives and the interdependencies of the direct and indirect costs they face. In doing so, it highlights the inadequacies of focusing on an individual's level of impairment in estimating additional expenditure and makes a strong case for re-examining how we think about, and measure, disability-related costs.

This report also reminds us that while Government reforms DLA, it must also invest in accessible infrastructure that will enable us to reduce disability-related cost head on and realise savings through sensible investment, rather than by cutting the finances of the financially marginalised.

Working out how, as a society, we contribute towards the additional costs disabled people face is not easily solved, however it is crucial that at this time of austerity that we get the formula right.

Richard Hawkes
Chief Executive, *Scope*

Executive summary

The link between disability and poverty is well established —high levels of unemployment, and unstable and low paid employment among the disabled population, means disabled people have lower incomes than average and are disproportionately likely to live below the poverty threshold and be dependent on benefits for a large proportion of their income.[1] Increased unemployment and a range of welfare and public service cuts following the economic downturn has only exacerbated the situation, with disability benefit claimants set to lose £9 billion in benefits over the course of the next parliament.[2]

However, these standard measures of (income) poverty only tell half the story, as while disabled people have lower incomes, they also have *higher costs*. In what Amartya Sen called the 'conversion disadvantage', many disabled people need to spend more than non-disabled people to achieve the same standard of living.[3] This can include anything from increased electricity bills associated with running medical equipment and doing laundry more often, to increased transport costs and specialist clothing, to having to buy more expensive ready-prepared food which is easier to cook.

By including both reduced income and their higher costs of living, the number of disabled people estimated to be living in poverty increases significantly: while 17.9 per cent of individuals in the UK reside in households below the poverty line, this proportion increases to 23.1 per cent for households with a disabled member.[4] However, when *the additional costs of disability* are taken into account, this proportion jumps to 47.4 per cent of families with a disabled member living below the poverty line.[5] Elsewhere, estimates for the impact of disability costs are even higher. Some studies suggest that when accounting for these extra costs, over half of disabled people in the UK could be living in poverty.[6] Others put this figure at almost 60 per cent.[7]

The fact that the number of disabled people living in poverty increases by such a significant margin when disability-associated costs are accounted for suggests current calculations of disability poverty — which *do not* account for such costs — are a significant underestimate.

However, there is little consensus on the size of the 'conversion disadvantage'. Although there have been a number of attempts to quantify disability costs, the estimations vary considerably — from as little as £7.24 to as much as £1,513 per week.[8] There are two principal reasons for the size of this discrepancy: first, there are differences between studies on how to measure disability itself (functional need arising from impairment, impairment itself, or a 'severity scale', and so on), and second, there are subsequent differences in how costs are then attributed to this — ranging from individual reported spending, through to costs attributed to standards of living being set by groups of disabled people.

Although this issue might hitherto have been academically interesting, it is now highly relevant politically. A number of policy reforms are taking place which will be significantly influenced by the way in which the additional costs of living as a disabled person are quantified and measured. This will include, without doubt, the implementation of recommendations from Frank Field's recent review of child poverty, which commented: 'disability remains one of the most significant indicators of greater chances of living in poverty';[9] and, perhaps most significantly, the imminent reform whereby Disability Living Allowance (DLA) will be replaced by the Personal Independence Payment (PIP).[10]

DLA is unique in that it is a non-means-tested, non-ring-fenced benefit designed to contribute towards the costs of being a disabled person — the 'conversion cost'. It is said to be the only benefit premised on the 'social mode' of disability — an understanding that disability is actually rooted in *social and environmental factors* which render a person's condition or impairment 'disabling'. DLA is given to disabled people in recognition that it is these social and environmental factors which drive a person's disability costs — not just the condition or impairment — and it is aimed at compensating for these. Around 3 million (1.8 million working age) disabled people currently receive DLA at an average award of around £70 per week, split into two separately assessed components — care and mobility.[11] Research suggests that DLA is used by disabled people in countless ways, including buying gifts for family and friends in order to maintain informal care networks[12] and is often used to help keep people in employment, as it can be spent on household support or childcare, for example.[13]

Yet in an attempt to cut £18 billion from the welfare budget, the government has proposed a raft of reforms and cuts to DLA and other benefits.[14] Modelling carried out by Demos earlier this year estimated disabled benefit claimants would lose £9 billion in support over the course of this parliament.[15] In December 2010, the government announced DLA would be replaced by the PIP. Those currently claiming DLA will be reassessed for eligibility for the PIP with a new 'objective' test looking at the impact of a person's impairment or condition from 2013. Unlike DLA, eligibility for PIP will be based on having an impairment or condition for at least 12 months, with those in hospital or residential care automatically ineligible. People receiving the benefit will also be periodically reassessed.[16] The government has previously stated that it hoped to cut the costs and caseload of DLA by 20 per cent — in other words, we might expect that around a fifth of those currently claiming DLA may be found ineligible on reassessment for the new benefit.[17]

The government has stated, in the consultation for the proposed new PIP, that:

> *We remain committed to the social model of disability. The new assessment will not be based solely on the medical model of disability and focused entirely on an individual's impairment, but will instead focus on the ability of an individual to carry out a range of key activities necessary for everyday life.*[18]

However, the proposed assessment could still prove problematic — a test measuring the functional impact of a person's disability may not be able to take into account the disabling social and environmental factors which the DLA and its successor seeks to compensate for.

Two people with similar disabilities may be assessed as having equal 'functional impact' on their lives, but could have widely different disability costs — one might be unemployed, in unsuitable rented accommodation, reliant on public transport, with no family and friends for support. The other may be in work, with their own suitably adapted car and home, with a good social network. Their lives, and disability-related costs, are very different, but they could be entitled to the same level of benefit using a test exclusively measuring the impact of a condition or impairment.

So although the current DLA system is criticised for being based on a 'deficit' model (focusing on what people cannot do) and administratively complex, it is possible that the proposed reform could constitute a regressive step by targeting the benefit at those with this greatest health and care needs, rather than the most prohibitive disability costs. The two are not always the same.

Identifying the drivers of disability costs

Conversion costs are very significant and when taken into account reveal that many more disabled people live in poverty than assumed using income only poverty measures. As several benefits, including Housing Benefit, Employment Support Allowance and others are set to be cut, so disabled people are likely to see a significant decrease in their income over the course of the next parliament. In light of these two facts, it is vital that the forthcoming reform of DLA is implemented carefully to ensure large numbers of disabled people are not pushed further into poverty. This means establishing a thorough and accurate assessment regime to ensure the new PIP helps those with the most prohibitive disability-related costs. However, the evidence base to achieve this is relatively weak, and the proposed assessment method — an objective test looking at the functional impact of a disability or condition — may not be adequate.

With this in mind, this report seeks to add to the evidence base with new primary research, designed to shed light on a fundamental question — *how are disability costs generated?* From this, we are able to answer subsequent questions, such as: *Can we identify a single proxy for disability costs?* And *if not, what are the key drivers of costs?*

Although it is beyond the remit of this report to come up with a definitive solution to measuring disability costs, we are able to confirm that a test relying on functional impact may generate inaccurate estimations of disability costs. We are also able to identify a variety of factors that come into play in a person's life that can increase or decrease their 'conversion cost' and which ought to be recognised in an assessment of any benefit designed to compensate people for such costs.

Our findings

Our analysis of a survey of 845 disabled people raises significant questions for the reform of DLA. We asked people to estimate their disability-related costs in 19 separate cost areas, as well as estimate their relative spending in another 14 categories less directly linked to disability. We asked people how much extra care and support they needed (measured in hours per week) as a proxy for functional impact of disability, alongside a series of other questions about their housing, employment, transport and benefits.

We found that need for care and support did not correlate to disability-related costs. Only in two cost categories — specialist clothing and equipment — was there a link. Other important costs — transport, childcare, household tasks, parking — were unrelated. When we averaged the costs of each need group, we found that those needing the most care *did* spend more than those needing none at all, but those needing a little care spent more than those needing a moderate amount. More importantly, the range of costs were so large in each need group that average values were almost meaningless—for a very large number of the sample, need for care and disability-related costs were wholly unrelated.

However, this does not mean we were able to isolate another single factor (such as age, housing status and so on) which *absolutely* accounted for a person's disability costs. We found, like need for care, that most other factors linked to a small range of cost categories. For example, those relying on public transport had higher disability costs overall than those with their own car, but their costs were higher primarily in transport cost categories. Mode of transport did not affect other types of spending. That said, some factors—like suitability of housing—had a broader impact on costs, with those in unsuitable housing spending more in a number of different areas ranging from childcare to home adaptations and utilities. We found a direct linear correlation between suitability of housing and disability spending.

We also found evidence to suggest that disability spending increases with available resources. Those on higher levels of DLA and those employed full time spent more overall than those on lower level DLA and unemployed. The types of spending suggest this is likely to be driven not by actual costs, but by ability to spend. For example, those on all levels of DLA spent similar amounts on the 'necessities of life' like heating and food. But when it came to social activities, those on higher DLA spent more—suggesting that with increased income comes increased spending on 'non-essential' items. When it came to employment status, those employed full time spent more overall, but this was only in a small number of key areas—childcare, house tasks and specialist equipment. We can assume these areas play an important role in keeping employed people in work. Unemployed people on the other hand had higher spending in other areas, including transport and utilities. This is likely to be symptomatic of being at home more and using more heating and electricity.

Overall, no single factor can be used as an adequate proxy for total disability cost—not need for care and support, nor transport used, nor employment or housing status.

Each factor has a role to play in generating different types of costs which contribute to a person's total spending. We found that a person with the following characteristics would most likely have the highest disability spending:

- unsuitable accommodation
- private rented accommodation
- reliance on public transport
- no informal support from family and friends
- requiring higher levels of care and support
- unemployed
- living in London
- receiving Jobseeker's Allowance
- no savings, in debt and no bank account

Importantly, this person might not experience the same level of 'functional impact' from their impairment or health condition as other disabled people according to an objective test looking at this aspect of disabled people's spending. Indeed, receiving JSA would suggest this person was ineligible for disability-related out-of-work benefits and therefore 'fit to work'. But this person would have higher costs: our survey found that those receiving Jobseeker's Allowance (JSA), as a group, had higher costs than those needing the highest level of support (28 hours or more per week). In the proposed reform to DLA, however, none of the factors listed above would be considered, even though they make a real difference to costs. While it is suggested that use of equipment and adaptations might be taken into account alongside the functional impact of a person's condition or impairment, this is just one of several possible factors that come into play. Therefore this person, with lower functional impact, may well receive lower levels of the new PIP than others who have lower costs.

Implications for Personal Independence Payment and disability poverty in the long term

Our findings suggest that the proposed reform for DLA assessment will be too narrow to take full account of people's disability costs and award the new PIP accordingly. Any 'single proxy' assessment—whether based on functional impact of disability, age or housing status—will never capture more than a small range of costs, leaving those people with high costs, but low scores in this one single proxy, particularly at risk. In the specific case of the proposed objective assessment, this means those experiencing a low functional impact of disability, but high costs, will lose out. Conversely, those experiencing high functional impact but relative low costs will do well. Although helping those with high care and support needs is laudable, *it is not the original purpose of the DLA*. DLA was designed to contribute towards disability-related costs. Those with higher costs, regardless of the complexity of their condition or impairment, should receive more. The government has stated that the new PIP will 'be targeted at those disabled people who face the greatest challenges to leading independent lives'.[19]

It is difficult to determine if this is in reference to the impact of a disabled person's condition of impairment, or in reference to prohibitive costs. However, targeting the PIP at those experiencing a higher impact of their condition or impairment could turn the new benefit into a health and care budget by implication—giving it to those with the highest health and care costs to compensate for them. This seems to be implied by the government's stated plan to reassess the PIP 'if an individual's condition has deteriorated or improved'.[20]

This undermines the principle of the PIP as a non-ring-fenced benefit: helping those in work to stay in work, helping others to maintain social networks and inclusion, helping others to remain active and independent. Although the government says it will ensure there is no overlap between PIP and adult social care,[21] it is clearly the role of the health and social care services—through the use of personal and individual budgets—to allocate resources to those disabled people with the greatest need to meet their health and care costs.

We recommend the proposed the PIP reform be considered in light of our findings, and that an assessment procedure must have the following characteristics if the government hopes to maintain the PIP as an effective tool to compensate for disability costs in their broadest sense. The PIP must be:

- *Multi-dimensional*—the assessment must consider more than one driver of disability costs and not rely on one general proxy, as no one factor is accurate enough. The larger the number of factors considered, the more accurate the assessment will be at identifying high-cost individuals and targeting the PIP accordingly. However, thoroughness must be balanced with the potential administrative complexity.
- *User friendly and co-produced*—a multi-dimensional assessment need not be more complex and administratively costly than a single proxy assessment. Co-produced, multi-agency assessments have been pioneered in social care, where disabled and vulnerable people can provide an accurate, holistic account of their needs in an engaging and intuitive way without it becoming prohibitively complex. This co-production approach would lend itself well to a multi-dimensional the PIP assessment.
- *Flexible to employment status*—unemployed and employed disabled people may have very different types of disability costs, but it is clear they both have costs, and both need DLA. For employed disabled people, DLA can be vital in helping them stay in work as it can help fund additional support at home or with childcare that makes working feasible. The new PIP must remain sensitive to this fact and able to recognise and target both types of cost.

Implications for disability poverty over the longer term

Our findings suggest disability costs are driven by a variety of factors—including some we might call internal (such as complexity of condition or impairment, and age) and some we might describe as external (suitability of housing, access to transport and employment status). Although the government is unable to intervene or significantly change these internal factors, it is well within the government's capacity to affect the external ones. In this respect, our findings should be seen as welcome news, as many of the drivers of disability costs are external. This means that disability costs can be reduced significantly by properly targeted policy reform and strategic investment.

By affecting change in these external factors, the government could both reduce the amount of DLA (and later PIP) people need, and, in reducing disability costs in the longer term, drive down rates of disability poverty.

The four key external factors most conducive to government intervention are housing, transport, employment and product and service markets.

Housing

Investment in suitable accommodation for disabled people is key to reducing ongoing disability costs. Home adaptations and equipment are significant areas of spending, as are utilities, and these increase as suitability of housing declines. Building new homes to Lifetime Homes Standard, ensuring social housing keeps registers of adapted accommodation, and encouraging home ownership or shared ownership would all be effective methods of reducing disability costs in these areas.

Transport

Those relying on public transport have significantly higher costs than those with cars, not only because of their spending on public transport, but also because they have to spend more on private transport when public transport is not suitable or accessible. Capital investment in station improvements and replacement of rolling stock (trains, buses, trams) is already under way—ensuring these forms of transport are accessible for disabled people is a simple and logical step. Ensuring the Motability Scheme—to give disabled people access to a car when they need it—is available to more disabled people would also drive down disability costs.

Employment

Although improving employment rates among disabled people will not eradicate disability costs (as there is a disability cost associated with maintaining employment), it would reduce the significant costs associated with being disabled and unemployed, which are more likely to be borne by state benefits. Increasing employment levels among disabled people would also have a significant impact on the economy—increasing disabled people's employment rate (currently at around 50 per cent) to the national average of 75 per cent would boost the country's GDP by about £13 billion.[22] A more personalised and targeted welfare to work regime would prove effective in helping disabled people build their capabilities, move into work and stay there.[23]

Product and service markets

Specialist equipment, clothing, food and non-prescription medicine and medical products are significant areas of spending for disabled people. Many of these products are not free from the NHS so must be purchased privately. Several of our survey respondents felt they were being 'ripped off', because of lack of competition and choice, so everyday products labelled 'disabled' were far more costly than those without this label. The government ought to ensure the disability product market is affordable for disabled people, and consider how it could encourage competition from other specialist and non-specialist providers in the commercial and third sector—for example, by applying the Equalities Act 2010 to manufactured goods.

Concluding thoughts

The findings of our report have significant implications for the proposed Personal Independence Payment. With the current proposed assessment procedure, the government risks targeting the PIP incorrectly—helping those experiencing the highest functional impact of their impairment or condition, not necessarily those with the highest costs. The original premise of the DLA was to help those with the highest costs, and the PIP must follow this principle. It can only do this by using a more accurate measure of disability cost. As there is no single proxy for cost, this inevitably means adoption of a multi-dimensional assessment, which will need to be balanced carefully with administrative complexity. We feel lessons could be learnt from social care assessments in this respect.

However, our findings have longer-term implications—they pave the way for a potential reduction in PIP and more sustainable solution to disability poverty. The government's current solution to reducing disability poverty is to focus on increasing employment among disabled people, to both reduce benefits dependency and increase income.[24] But we must bear in mind that disability poverty is a dual phenomenon—driven by lower incomes and higher costs. In the current economic climate, where jobs are harder to come by, increasing disabled people's incomes through greater employment will be a challenge. Moreover, this would do nothing to improve the situation of those who cannot work. It may be, therefore, that the government could reduce disability poverty more effectively, and for larger numbers of people, by reducing disability costs rather than focusing exclusively on increasing income. The findings of our report show that this is not as difficult as it might seem. Disability costs are not solely generated by factors the government cannot change—such as impairment, condition or age. They are driven by a range of environmental factors which, with the right intervention, could reduce disability costs significantly. Such interventions do not always require large sums of capital investment—rather strategic decisions being taken during existing investment strategies, for example, in transport or new-build homes.

1 Introduction

The connection between disability and low income has been well established over a number of years.[25] Disabled people remain at a disproportionate risk of living in poverty, as they are more likely to be unemployed or in low paid work (in part because of lower levels of qualifications within the disabled population). In 2004 around 50 per cent of disabled households were situated in the bottom two quintiles of income distribution, in contrast to 30 per cent of all other households.[26] Further research published that year estimated 29 per cent of disabled households lived with incomes below 60 per cent of the median — the poverty line — compared with 17 per cent of non-disabled households.[27] This inequality has remained relatively stable over recent years. In 2008 figures suggested around 30 per cent of disabled people lived in relative poverty, compared with 16 per cent of non-disabled people.[28] Recent government estimates are a little more conservative — citing 2008/09 data from the Households Below Average Income (HBAI),[29] Minister for Disabled People Maria Miller MP recently reported that 23 per cent (3.9 million) of individuals living in households with at least one disabled member lived in relative poverty, in contrast to 16 per cent of those in families with no disabled members.[30]

The current economic climate has no doubt exacerbated disability poverty, with a combination of increased risk of unemployment,[31] and cuts to welfare and public services, which are disproportionately affecting disabled people. Original analysis by Demos, released earlier this year, estimated that the 3.6 million disabled people receiving disability-related benefits would see a subsequent loss in income over the course of the current Parliament of £9 billion.[32]

Yet although the connection between disability and poverty is significant, current figures—such as those presented above—only capture half of the picture. This is because, at present, poverty measures primarily focus on disabled people's lower incomes, and do not account for the additional, often prohibitive, costs disabled people face as a result of living with an impairment.[33] Disabled people experience a dual disadvantage—lower income and higher costs. The Nobel prize-winning economist Amartya Sen described this as an 'earnings disadvantage' (the effect of disability on an individual's ability to earn an income) and a 'conversion disadvantage' (the effect of disability on an individual's ability to convert this income into a good standard of living). Disability-related costs are a fundamental feature of this second (conversion) disadvantage. These might include buying certain foods for specialist dietary requirements, adapting accommodation to make it accessible, higher utility bills from constantly running nebulisers, oxygen tents and other specialist equipment, paying for private transport if public transport is inaccessible, and so on.

Such costs have a profound impact on disabled people's disposable income, but fall below the radar of current standardised measures of disability, which focus entirely on differences in income. Therefore these measures significantly underestimate disabled people's financial wellbeing. Kuklys's study, cited by Sen, showed that while 17.9 per cent of individuals in the UK reside in households below the poverty line, this proportion increases to 23.1 per cent for households with a disabled member.[34] However, when *the additional costs of disability* were taken into account, there were 47.4 per cent of families with a disabled member living below the poverty line.[35] Elsewhere, estimates for the impact of disability costs are even higher. Some studies suggest that when accounting for these extra costs, over half of disabled people in the UK could be living in poverty.[36] Others put this figure at almost 60 per cent.[37] Such significant discrepancies highlight the inadequacy of using current poverty measures as tools to assess disability poverty. As Sen points out, 'the constant use of income-based views of poverty can distract attention from the full rigour of social deprivation' experienced by disabled people.[38] In short, the fact that the number of disabled people living in poverty increases by such a significant margin when disability-associated costs are accounted for suggests current calculations of disability poverty—which *do not* account for such costs—are a worrying underestimate. That is not to say attempts at quantifying these costs have not been made—an issue we explore below.

What are disability-related costs?

A multitude of additional costs arise from living with an impairment or health condition, and these have been categorised in different ways, including Tibble's six-cost framework (see box 1), as well as alternative distinctions between disability-created and disability-enhanced revenue costs,[39] and disability-enhanced capital costs to describe the extra costs incurred by having a legitimate need for items that non-disabled people might otherwise consider to be a luxury—remote-controlled lights, electric can openers, or intercom systems, for example.[40]

Box 1

The different costs of disability

Many attempts have been made to map and categorise the different types of cost incurred from living with a disability. These include:

- *special costs of goods and services needed by disabled people but not by non-disabled people (eg buying medicines or paying for personal care services)*
- *additional costs of goods and services needed by both disabled and non-disabled people, but which disabled people need more (eg higher heating and electricity bills as a result of running specialist medical equipment)*
- *one-off costs of goods and services that only need to be bought once (eg buying an occupant-controlled indoor–outdoor wheelchair)*

- *recurrent costs (maintaining said wheelchair, buying replacement batteries, etc)*
- *extra special or additional costs that are higher for disabled people than they are for non-disabled people (eg life assurance, motor insurance)*
- *reduced costs of goods, services and activities that disabled people are likely to spend less on than non-disabled people (eg holidays abroad).* [41]

These various definitions aside, there is no doubt disability-related costs can be substantial: a walking frame can cost around £90, a mobility scooter can cost £2,199, and an electric wheelchair £7,295.[42] Other items essential to daily living, like specialist beds and bedding, may have to be paid for privately.[43] Specialist shoes often cost over £100. Even everyday items can be more expensive — difficulties in cooking (chopping, lifting pans) can necessitate increased spending on ready prepared meals, while being at home most of the time, with limited mobility, leads to increased heating and electricity bills. Disabled people may also need to pay for practical support: disability often affects an individual's ability to carry out day-to-day activities such as shopping, and shopping online incurs delivery charges, while shopping carried out by social services can cost disabled people up to £11 each time.[44]

He needs pads and bibs occasionally but is not eligible for these on NHS. The house and his room in halls need to be kept more heated due to his status as a wheelchair user — not generating much body heat. If he requires many items of specialist equipment — for example cutlery, cups, clothing — these are not funded and have to be purchased. Holidays are more expensive due to the type of accommodation and travel required — spontaneity and last minute deals are not an option! I could go on!
Survey respondent

Other things cost more on a 'little and often' basis. Just one example: because I need to get my milk in single-pint cartons (because I have trouble lifting and pouring) and I need to get it delivered by the milkman (because I can't get to the shops unaided) I pay about 60p per pint, compared to the 30p per pint paid by someone who can go to the shop and buy a 4-pint bottle. OK, that's only about £80 a year but there's loads of little things like this, too tedious to document, and they add up fast!
Survey respondent

It is also important to bear in mind the distinction between realised costs (what a disabled person actually spends on meeting disability-related needs) and potential costs (what they would spend had they sufficient income to do so). Unsurprisingly, there is a direct connection between disability expenditure and disposable income — in some instances, the amount of expenditure rises with the amount available to spend.[45] As Hyman rightly points out, 'the 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"'.[46]

Meeting these costs: state support and welfare benefits

States should ensure that the provision of support takes into account the costs frequently incurred by persons with disabilities and their families as a result of the disability.[47]

Disproportionately high levels of unemployment and entrenched disadvantage in the labour market means disabled people are more likely than non-disabled people to be dependent on benefits for a large proportion of their income.[48] And yet, once disability-related costs are factored in, many recipients of disability benefits — even those receiving the maximum level of all available benefits, and who have no personal assistance costs — still experience significant shortfalls in income. A study commissioned by the Joseph Rowntree Foundation conducted five focus groups of disabled people who identified themselves as having:

- low–medium support and or mobility needs
- medium–high support and or mobility needs
- needs that are intermittent or fluctuate over time from relatively negligible needs to medium or high support and/or mobility needs
- needs arising from hearing impairments[49]

Participants in these groups then drew up costed lists of items and resources needed to maintain a standard of living agreed to be acceptable by the group—their 'budget standard'.[50] Table 1 compares the weekly costs accorded to 'budget standards' for disabled people with different levels of need, alongside the maximum benefits these people could receive (including DLA and the then available Income Support and Incapacity Benefit, as well as full Housing Benefit and Council Tax Benefit).

Table 1 **Maximum benefits compared with disabled person budget standards, excluding personal assistance costs (to nearest £)**

	Total amount of benefits payable per week (£)	Disabled person budget standard per week (£)	Unmet costs per week (£)
High–medium needs	235	467	232
Intermittent needs	90	298	208
Low–medium needs	79	279	200
Hearing impairment needs	110	310	200
Visual impairment needs	110	310	200

Source: Smith et al[51]

As can be seen from table 1, the maximum benefit levels meet only 28 per cent of costs incurred by those with low–medium needs, 30 per cent of costs incurred by those with fluctuating or intermittent needs, 35 per cent of costs associated with hearing and visual impairments, and 50 per cent of costs connected with high–medium needs.[52]

In addition to this shortfall, many items essential for managing a variety of conditions are not provided by the state, or acquiring them through statutory services is prohibitively difficult or takes too long. As a result, many disabled people are often left having to pay for vital items, equipment and services themselves.[53] These might include indoor hoists, specialist beds and bedding.[54] Those with particular nutritional requirements may need to buy certain food types and supplements, which are not provided on prescription and can cost around £15–20 per month.[55] Indeed, those under 60 and with non-exempt conditions pay £7.20 per item in England for prescribed medicines.[56] The exemption of prescription charges for those with long-term conditions proposed by the previous Labour government was dropped by the current government in its recent spending review.[57]

Covering costs: the role of Disability Living Allowance

The primary—indeed the only—benefit specifically designed to contribute to the additional costs of living with a disability is Disability Living Allowance (DLA).[58] In this respect, DLA (see box 2) is unique in design by virtue of being based on the 'social model' of disability, which recognises the wider social, physical and economic factors that all play a central role in a person's disability. Similar but more specific models, like those adopted by institutions like the World Health Organisation, explicitly recognise disability to be a dynamic process involving the interaction between a person's impairment and their personal characteristics, as well as their social and physical environments. The 'medical model', on the other hand, posits that a person's impairment and their health conditions are alone the cause of disability.[59] The shift away from the medical model to the social model of disability has been heralded as ‘one of the most significant intellectual and political developments of the last ten years’ and has transformed the very meaning of disability.[60]

Box 2

Disability Living Allowance

Introduced by the Conservative Government in 1992 and premised on the social model of disability, Disability Living Allowance (DLA) is a tax-free, non-means-tested benefit designed to make a contribution towards the extra costs of living with a disability. It is premised on the understanding that disabled people spend more than non-disabled people due to disability-related purchases, like personal care, but also seeks to serve as a source of compensation for more generalised extra spending—like the additional expense of food and heating.[61]

Many disabled people in receipt of DLA use it to pay for things like specialist medical equipment and non-prescribed medicines, travel and private transport, personal assistance and fees for residential care.[62] *Some claimants report that without DLA they would be left unable to pay utility bills or to get the proper healthcare they needed.*[63] *Other items and activities bought or subsidised using DLA include:*

- *warden assistance in sheltered accommodation*
- *food supplies and fuel*
- *home maintenance (cleaning, etc)*
- *transport*
- *social activities*
- *gifts and presents for friends and family, in acknowledgement of informal personal care and support.* [64]

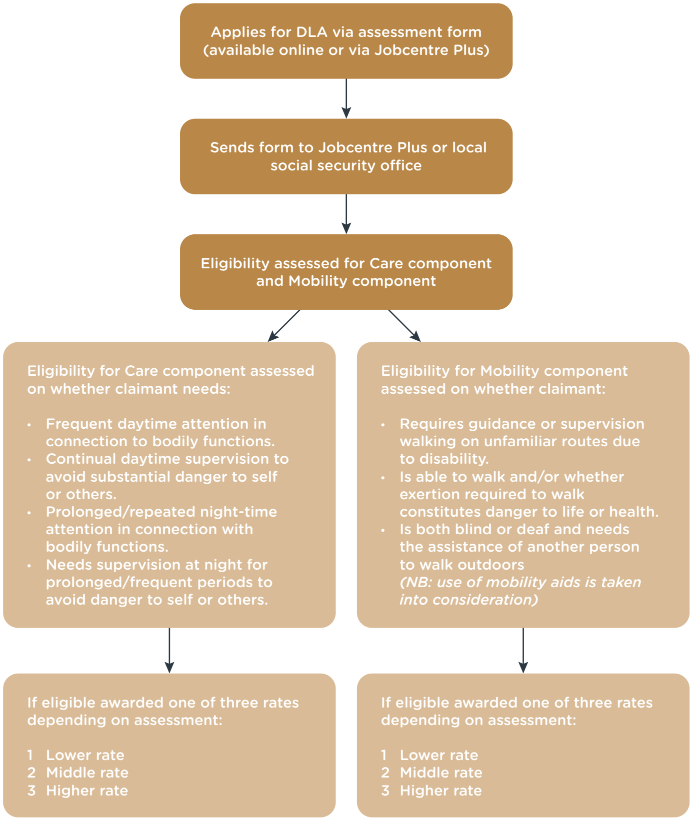
DLA is separated into two components: care and mobility. The care component is divided into three levels of payment: low, middle and higher, while the mobility component is paid at two rates: lower and higher. Eligibility for these components is assessed separately from one another, so people can be paid at different levels for each component.

The average DLA award is around £70 per week, and 3 million people (1.8 million of working age) receive it in 2010. It accounts for about £11 billion of the government’s annual welfare expenditure.[65]

Applying for DLA is an arduous process, which involves filling in a complex 59-page form. Applicants must satisfy a series of ‘disability tests’ under each component.[66] *The tests centre on key definitions—like ‘bodily functions’, ‘continual supervision’ and ‘substantial danger’—used throughout the assessment.*[67] *To qualify for the care component, for example, claimants must show among other things that they require ‘frequent attention’ from others throughout the day, in connection with their bodily functions, or continual supervision to avoid substantial danger to themselves or to others.*[68] *Similar ‘tests’ are used to assess the level of attention or supervision an individual is likely to need during the night, as well as during the day.*[69] *To be eligible for the lower rate of the care component, a disabled person has to show that they need help with everyday routines and activities like washing, getting dressed, eating or attending to personal hygiene.*[70] *To be entitled to the lower rate of the mobility component, claimants need to show that walking is problematic enough that they require help or assistance out of doors.*[71] *Applicants must provide medical evidence to support their claim, as well as details of their GP.*

Critics have claimed that the DLA assessment process is complex and unwieldy, and focuses on a deficit model of disability (what an individual cannot rather than can do). Nonetheless, it does reflect (if only in part) the social model of disability, in that it seeks to ascertain the personal, social and practical barriers a disabled person experiences as a result of their impairment.

Figure 1 **Claims process for Disability Living Allowance**



Applies for DLA via assessment form (available online or via Jobcentre Plus)

Sends form to Jobcentre Plus or local social security office

Eligibility assessed for Care component and Mobility component

Eligibility for Care component assessed on whether claimant needs:

- Frequent daytime attention in connection to bodily functions.
- Continual daytime supervision to avoid substantial danger to self or others.
- Prolonged/repeated night-time attention in connection with bodily functions.
- Needs supervision at night for prolonged/frequent periods to avoid danger to self or others.

Eligibility for Mobility component assessed on whether claimant:

- Requires guidance or supervision walking on unfamiliar routes due to disability.
- Is able to walk and/or whether exertion required to walk constitutes danger to life or health.
- Is both blind or deaf and needs the assistance of another person to walk outdoors *(NB: use of mobility aids is taken into consideration)*

If eligible awarded one of three rates depending on assessment:

1 Lower rate
2 Middle rate
3 Higher rate

If eligible awarded one of three rates depending on assessment:

1 Lower rate
2 Middle rate
3 Higher rate

The introduction of the Personal Independence Payment

In a bid to drive down welfare expenditure, the government announced in June 2010 that it would be changing the DLA assessment regime and eligibility criteria for future applicants of DLA and would begin a process of reassessing current claimants to reduce DLA costs by 20 per cent, and save the government over £1 billion by 2014/15.[72] However, in December 2010, a more ambitious reform was announced — DLA is set to be scrapped and replaced by the new Personal Independence Payment (PIP).

The PIP differs from the DLA in a number of important ways. First, it will be unavailable to those in hospital or residential care. According to the October spending review, a similar reform (removing the mobility component from disabled people living in residential care) would save around £135 million by the end of parliament.[73] Second, it will only be available to those with long term impairments or conditions — so a person must have met the eligibility criteria for a period of six months (the 'qualifying period') and be expected to continue to satisfy the entitlement conditions for at least a further six months (the 'prospective test'). This means that, to be eligible for the benefit, an individual's health condition or impairment must be expected to last a minimum of 12 months. This is concerning for two reasons. First, it implies that a person will need to have been living with a condition or impairment (and shouldering substantial costs as a result) for six months before any compensation can be awarded. Second, it means those who may have significant costs for 10 or 11 months will receive no assistance. Yet the costs of living as a disabled person are potentially so large (see chapter 2) that shouldering such costs for such a period of time could easily wipe out a person's savings or send them into debt.

> *I have a significant amount of debt which I amassed before I was able to claim DLA etc (just to keep paying the bills etc). I am slowly paying this off so there is very little disposable income.*
>
> Survey respondent

Third, the PIP will be subject to reassessment, so that the amount received will be adjusted 'if an individual's condition has deteriorated or improved'.[74] This is important as it relates to the fourth, and most important, difference between DLA and the new PIP—the latter will be assessed according to:

> *a broader, more objective measurement of the impact of an individual's health condition or impairment on everyday activities than those currently captured on the DLA claim form. Our initial proposal is that the assessment should consider activities related to an individual's ability to get around, interact with others, manage personal care and treatment needs, and access food and drink.*[75]

Although the exact nature of this assessment has yet to be determined, the aforementioned reference to reassessment based on 'deterioration or improvement' of a condition, and other references to targeting those with 'greatest challenges to leading independent lives' suggests the government will focus on the impact of impairment almost exclusively. Statements as recent as October 2010 talked of helping 'the most severely disabled people' and that the reforms 'will ensure support is targeted on those with greatest need'.[76] In June 2010 the government stated it would reform the DLA to ensure support is targeted on those 'with the highest medical need'.[77]

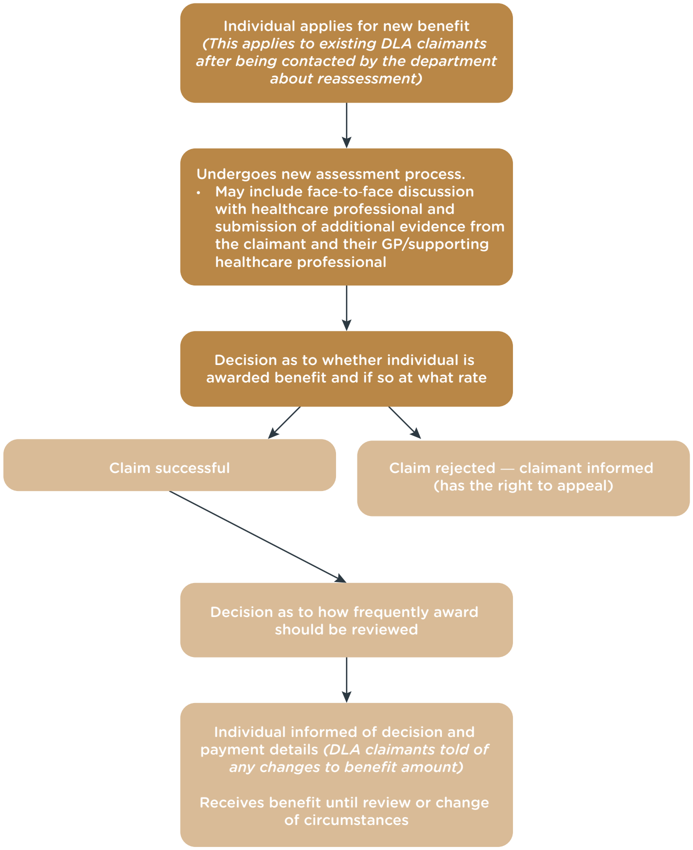
This could be problematic for ensuring PIP is targeted at those with the highest disability-related costs. The Government's statement that 'there is some evidence to suggest that individuals whose impairments have the greatest impact are likely to experience higher costs'[78] is only partly true. As we explain below, this evidence is certainly not conclusive and our own findings presented later in this report demonstrate that the link is tenuous and can only explain some types of disability-related costs. Some conditions or impairments with 'low level' impact can incur very high living costs, and vice versa. Determining the amount of the PIP in this way could therefore result in an ill-suited match between the amount awarded and the costs of living—an issue we explore in more detail later in this report. The government acknowledges that the use of specialist equipment or adaptations might affect disability costs, and states it is 'considering the best way to prioritise support in this situation'.[79] Although it is encouraging that the government recognises more than one factor may affect a person's disability costs, the presence or absence of adaptations is still just one part of a wider, more complex picture.

Even though the proposed new PIP has some weaknesses, particularly in its planned assessment, this does not mean the current DLA should remain unreformed. The current assessment process for DLA is lengthy, opaque and complex, so often people do not know if they are likely to qualify.[80] Some disabled people also do not know what the benefit is for and often assume it is an out-of-work benefit.[81]

However, as several disability-related benefits are now being cut, there is a greater need than ever for an accurate and appropriate assessment for eligibility of DLA (and its successor). DLA currently 'passports' to Carer's Allowance, which can only be claimed if the person being cared for receives the middle or higher rate of the care component of DLA,[82] and the Motability Scheme. More recently, the government has proposed a cap on the total amount of benefits a household can receive, set at around £500 per week.[83] Should any member of the house be receiving DLA, however, the household will be exempt from this cap.[84] Thus eligibility for DLA is now a high stakes issue, with wider disabled household income now dependent on it. There is a risk that a poorly targeted new benefit will push some disabled people further into poverty.

A more focused debate must now begin, therefore, on assessments models that are potentially less burdensome that the current system of testing, but more accurate than the proposed PIP assessment. Some of the alternatives are explored below.

Figure 2 Claims process for Personal Independence Payments



The cost of disability: the need for a multi-dimensional picture

There have been relatively few attempts to estimate the true costs of living with a disability and to quantify the conversion disadvantage.[85] Although much of the research undertaken in recent years has concluded that there are indeed extra costs incurred from disability, no consensus has emerged on exactly how much these are or how to measure them.[86] An overview of the existing evidence and research reveals widespread disagreement over the size of extra costs, what drives and affects these costs, and how these costs should be measured and properly estimated.[87] Much of this disagreement can most likely be attributed to two apparent variables, which we address in turn:

- how to measure level of need arising from disability
- how to measure the costs resulting from these needs

Measuring level of need arising from disability

Determining a disabled person's level of need arising from their impairment is a key factor in ascertaining the true costs of living with a disability. However, there are various ways in which this can be done, three of which are outlined below, each with strengths and limitations.

Specific types of impairment

This type of analysis focuses specifically on a certain type of disability or impairment. Some studies, such as Hyman's, have focused solely on additional disability-related costs as experienced by wheelchair users (although not necessarily restricted to the use of a wheelchair).[88] Others examined disability costs facing households with a member who had learning disabilities.[89] While such an approach may be beneficial in providing estimates for certain types of impairment, it risks homogenising a group whose needs, financial circumstances and access to informal networks of support — all of which can impact on the costs of living with a disability—could be very diverse. In short, it may be difficult to properly account for diversity of need within the group. This is apparent in the significant variation between estimated costs for these groups. Hyman's study of wheelchair users, for example, found that among this group the total extra expenditure on disability-related needs ranged from less than 20 per cent of total household income to more than 60 per cent.[90] In a similar vein, studies focused on households with a member with learning disabilities showed such costs to vary from 0.3 per cent to 47.6 per cent of weekly household income.[91] Furthermore, focusing on a type of impairment is more closely aligned with the medical model of disability, which focuses specifically on impairment itself as the cause of disability and driver of disability-related costs. It does little to reflect the diversity of circumstances and resulting costs that can be found with broad and heterogeneous impairment groups.

Self-identification of need

Studies focusing on need arising from impairment, rather than the impairment itself, include Smith et al's study for the Joseph Rowntree Foundation. Following a preliminary consultation with disabled people, academics and professionals, disabled people were recruited to the study on the basis of needs resulting from their impairment, rather than the nature of their impairment.[92] Participants were asked to identify their own needs, and were then allocated to one of five different groups, those with:

- low–medium support and or mobility needs
- medium–high support and or mobility needs
- needs that fluctuate over time from relatively negligible to medium or high support and or mobility needs
- needs arising from hearing impairments
- needs arising from visual impairments

Participants completed various forms of instrumentation (diaries recording consumption, purchases and activities; questionnaire on items owned) in order to estimate the costs of each need group. The possible limitations of such an approach include the risk that participants may have inflated or underestimated their level of need, and thus be allocated to an inappropriate group, which would skew the results. The results may also be exposed to a significant degree of subjective bias, which could compromise objectivity. Nonetheless, the argument that disabled people are themselves 'experts' and so best placed to identify and understand their own needs and costs resulting from disability is a compelling one.[93] Similar approaches have already been successfully adopted across social care with the emergence of the personalisation agenda, and the use of self-assessments of need for care and support and subsequent allocation of care funding.[94]

Scale of severity

Some studies attempt to categorise disabled people and their perceived level of need on a numerical scale—the Office of Population, Censuses and Surveys (OPCS) studies being perhaps the best known in this respect. The 1988 OPCS study classified disabled people according to a constructed scale of 1 to 10 representing the severity of the impairment and its 'functional impact', with 1 being the least disabled and 10 the most severely disabled (box 3).[95] Over 2 million people were then assigned to categories 1 and 2; 2.7 million to categories 3 to 6; about 882,000 to categories 7 and 8; and 575,000 to categories 9 and 10.[96] A follow-up study, published by the Disablement Income Group that same year in response to the OPCS study, used a similar scale, but focused on disabled people in categories 3 to 10.[97]

The greatest strength of adopting this approach is that the results are easy to quantify and based on a linear scale; however, there are some serious shortcomings. Studies like the OPCS allegedly adopted a very low threshold of disability, which led to very high prevalence.[99] They also employed definitions of disability in the low categories, which were based on rather ambiguous and contestable terms such as 'behaviour' or 'disfigurement'.[99] This meant that the largest number of those surveyed ended up in the lowest categories, and 'led to many [disabled people] in each category reporting no extra cost on account of disability'.[100] Studies published in response to the OPCS survey used receipt of Disability Living Allowance and Attendance Allowance as a proxy for level of need, and revealed the costs of disability to be much higher than initially indicated by the OPCS.[101] A second flaw of this method is that the process of categorising members of the sample to a selected group is inherently subjective—indeed, the categories themselves could be said to be somewhat arbitrary.

Finally, and perhaps most importantly, focusing on the functional impact of an individual's impairment again relies on the medical model of disability. This means that applying severity as a proxy for cost will not properly account for the social or environmental factors, which can drive up the costs of disability, or recognise that severity and cost do not always coincide. Both will lead to incorrect assumptions and inaccurate results.

Measuring the costs arising from disability

In the previous section we considered the various approaches used to interpret need arising from disability. Once this level of need has been established, cost must then be attributed to it. There are four predominant methods of attributing cost:

- the subjective approach
- the budget standards approach
- the comparative approach
- the standards of living approach.

The subjective approach

Studies adopting this approach ask disabled people to estimate their additional disability-incurred expenditure so as to measure how much disabled people spend as a result of being disabled. Estimates of extra costs are then calculated from respondents' answers. This approach is especially valuable because it recognises that disabled people are best placed to identify the additional costs they incur. As a result,

studies are likely to produce more accurate assessments of special costs—items purchased by disabled people only because of their disability (eg medical equipment).[102] However, this approach can be problematic as it measures actual expenditure, as opposed to whether the amount spent is sufficient to meet that person's needs.[103] Consequently, this may produce underestimates of costs as spending is constrained by income—it is very possible that a household on a low income may have low levels of disability spending, but still have high levels of need which go unmet as a result of income constraints.[104] Respondents are not asked what they would spend *were the resources available.* Should the 'subjective cost' approach be combined with a 'subjective need' approach to measuring disability (see previous section on measuring disability), there would be no objective or control measure with which to confirm the results. This would make it almost impossible to roll out this approach nationwide as a measure for DLA.

The budget standards approach

This is somewhat similar to the subjective approach in that disabled people are asked directly to state what their needs are.[105] However, rather than answer by identifying actual expenditure, participants are asked to develop lists of items they need to achieve a certain standing of living.[106] Smith et al's study used such an approach. As outlined above, this study took the self-defined 'needs based' approach to measuring disability, grouping people by need arising from impairment rather than the impairment itself. Each need group was then asked to compile a list of items essential to maintaining a standard of living judged acceptable based on consultation with disabled people and other experts. Such lists were then costed and these costs formed the basis for a 'budget standard'.[107]

Analysis showed that the single, most expensive area of the budget for all groups but the low–medium support and/or mobility needs category was paying for the costs of personal care or assistance (this included interpreters for deaf people and accompaniment for people with visual impairments). Such costs made up between 11–72 per cent of budget totals. Weekly costs to meet needs varied widely from about £1,500 for people with medium–high level needs, to around £400 for people with low–medium level or fluctuating needs.[108] Fundamentally, their analysis led Smith et al to conclude that an individual's level of need is more important in determining extra disability costs than the type of impairment they may have.

The weaknesses of a budget standards methodology include the lack of a 'control' budget standard for non-disabled people, making it difficult to determine how the costs identified differ from those of non-disabled people. Even if a control were to be developed, say, based on the average non-disabled household expenditure, this would assume that average expenditure properly meets the needs of non-disabled people.[109] Finally, the pre-determined standard of living on which to base costs is aspirational and highly subjective. While it can be developed with extensive consultation and focus groups of disabled households to verify its suitability, it is neither wholly objective nor replicable as goal to be achieved by DLA payments, for example, unless established as a national benchmark. This would be an extremely challenging (though not impossible) task for policymakers.

The comparative approach

Comparative expenditure approaches involve comparing patterns of spending by disabled people with 'similar' non-disabled people, to identify where disabled and non-disabled people's priorities differ from each other. Using income as a controlled factor, this approach seeks to determine how much both groups spend on individual items so as to establish differences between spending priorities. The particular strength of this method is that it measures what groups *actually* spend on goods and services, rather than additionally spend, which may in turn increase the accuracy of the data collected.

However, this means such studies often fail to produce an overall estimate of additional costs, but rather solely compare spending patterns between different groups. Indeed, there is no isolation of disability as a key variable in this approach. A disabled household may in fact spend more on items for reasons that have nothing to do with disability. Also, as Tibble pointed out, the accuracy of some studies may be compromised by comparing expenditure per household rather than per individual.[110] This could mean that extra household spending on items on behalf of an individual with a disability are disguised by reduced household spending on other items. Furthermore, assessing what such households actually spend may mean that this method then fails to pick up on budgetary constraints, which limit the ability of disabled people to cover additional costs required to meet their needs. Finally, as a wider principle, this approach can also risk making unfair comparisons—for example, by comparing a household in which an individual is out of work because of their impairment with a household in which an individual is unemployed for a totally different reason.

The standards of living approach

The standards of living approach operates on the assumption that disabled people experience lower standards of living than non-disabled people, because they divert money and resources to goods and services as a result of their disability.[111] This type of approach uses survey data to examine standards of living between disabled and non-disabled people, whereby standards of living are assessed by measuring ownership of certain goods.[112] Such goods might include items like video and CD players; mobile phones; household appliances like dishwashers, tumble dryers and microwaves; and access to a motor vehicle.[113] 'Equivalence' scales are then produced in order to show how much greater disabled people's incomes must be to attain the same standard of living as non-disabled people. However, some studies using this approach have stopped short of producing overall estimates of additional costs; instead they solely compared differences in spending between disabled and non-disabled people on particular items and areas.[114]

One weakness of this is that there is likely to be much variation of opinion on what items or areas of expenditure are integral to a certain standard of living. Some households may decide that owning a computer is more essential than some other disability costs like extra heating.[115] Rather than show disability-related expenditure, this approach may be limited to measuring how households choose to budget. Finally, it is unclear whether such an approach takes proper account of less tangible — but equally valuable — goods such as access to social activities or informal networks of support.

Box 3

The OPCS severity scale model — the limitations of a medical approach to quantifying disability costs

As outlined above, the 1988 OPCS survey used a scale from 1 to 10 to identify the 'functional impact' of impairment. Respondents were categorised to a group depending on the apparent severity of their impairment, 1 being the lowest and 10 the highest. Groups 1 to 2 were the largest; over 1 million disabled people were estimated to be in group 1. Then, using this scale, researchers employed the 'subjective approach' outlined above to attribute cost to need. Around 10,000 disabled people were questioned on their additional expenditure in particular areas. From this data, each group was assigned an average cost of disability (2001 prices). The results showed the costs were £7.24 for those with 'low' severity (categories 1 and 2); £13.09 for those with 'moderate' severity (categories 5 and 6); and £20.59 for those with 'severe' severity (categories 9 and 10). Ultimately, the results of this study suggest that as severity of impairment rises, so too do the costs of disability.[116]

Studies like the one by Zaidi and Burchardt (2003) went further by assigning to this scale a flat-rate percentage increase, representing the assumed additional costs incurred by living with a disability.[117] *This approach creates a linear connection between level of impairment and additional costs, with each point scored on the scale of severity equating to an additional cost of between 3 per cent and 4.5 per cent of income per person depending on living circumstances.*[118] *So, disability costs would be 6–9 per cent of income for an individual who scored two points on the severity scale; 9–13 per cent for individuals scoring three points, and so on.*[119] *Overall, this study concluded the median severity score for a working age disabled person to be £7.85, and so the average costs of disability to be between 24 per cent and 35 per cent of income.*[120] *Disability organisations have used these figures to conclude that, on average, a disabled person of working age faces additional costs of more than 25 per cent above normal expenditure for non-disabled people.*[121]

Although the findings of the OPCS survey and subsequent studies suggest there is a direct correlation between severity of impairment and the costs of disability, the results were strongly influenced by the type of questions asked to identify costs. These were narrowly focused on areas of health and social care service expenditure — those most likely to be affected by impairment — and paid no attention to broader practical, social and personal costs (such as housing costs, utilities, social costs and so on). Therefore the OPCS survey is limited in demonstrating primarily that medical and care costs rise with impairment, as one would expect. Furthermore, as a technical point, the results of the OPCS survey are likely to have been seriously compromised because when people were unable to provide an estimate for a particular cost, an average of other people's estimates was then substituted for theirs.[122]

Different approaches, different estimates

From the above review of existing evidence and available literature, it is clear there is a very wide variety of methods and approaches in measuring disability or need, and then attributing costs to them. Unsurprisingly, this has led to large discrepancies in the estimations of the extra costs of living with a disability. As table 2 shows, this estimation varies from as little as £7.24 to as much as £1,513 a week, and uses both actual amounts (£ sterling) and a percentage of income.

Table 2 **Estimates of overall extra costs of disability**

Study	Estimate of overall extra costs	Variable(s) by which estimates are broken down
Martin and White (1988)	Range from £7.24 to £20.59 a week	Severity level
Disablement Income Group (1988)	£81.06 a week (at 2001 prices—from Zaidi and Burchardt)	None
Dobson and Middleton (1998)	£99.15 a week for a disabled child but budget standards estimate minimum budgets to be £117.95 to £170.68 a week	Age group and type of impairment
Matthews and Truscott (1990)	No overall costs—instead study produced estimates of differences in spending on particular items	
Jones and O'Donnell (1995)	No overall costs—instead study produced estimates of differences in spending on particular items	
Philips (1993)	Estimated the cost of a package of care for a severely disabled person at £250 a week	
Zaidi and Burchardt (2003)	Between 11 per cent and 69 per cent of income	Severity level and household type
Smith et al (2004)	Range from around £389 to around £1513 a week	Level of need or type of impairment

Source: Tibble, 2005[123]

Lack of consensus — the implications for the Personal Independence Payment

With this wide variety of findings comes a lack of consensus about the best ways of measuring level of need and determining the actual costs of disability.[124] No single approach has been identified as producing the most accurate depiction of disabled people's extra expenditure[125] and lack of agreement is apparent across international as well as domestic studies.[126]

Consequently, eligibility for and rates of welfare benefits like DLA and social care and support services provided by the state have been predicated on limited evidence, and the extent to which these benefits are enabling people to meet additional costs remains unclear.[127] However, the research that does exist indicates that often DLA does not allow disabled people to fully meet the extra costs of living with a disability.[128] It is important to remember, however, that DLA is supposed to serve as a *contribution towards* the extra costs of disability, not to cover them fully. That said, and despite differing methods and estimated costs, the existing evidence suggests that DLA as it stands is not sufficient.[129] Indeed, as noted in a recent DWP paper, very little is known about the difference receiving DLA makes to disabled people's lives.[130] Disability organisations have called for the development of an accepted standard calculation of the costs of disability and a full-scale, evidence-based review of DLA to ensure it meets the purposes for which it was designed.[131] Given the imminent replacement of the DLA with the new PIP, such a review would seem all the more vital.

Indeed, the implications of the uncertainty surrounding the extent of disability-related costs—and, by extension, disability poverty—and the efficacy of DLA in assessing and meeting these costs has never been more significant. The recession exacerbated disability poverty; in recent years disabled people have found it increasingly difficult to manage on their income, accrue savings and meet basic universal living costs like utility bills. Prospects of securing and sustaining employment in a post-recession labour market are especially bleak for disabled people, who are already disadvantaged when trying to find work. DLA constitutes the primary regular and reliable source of income for claimants who have sought work but found it difficult to maintain regular employment, while all other earnings and benefits have stopped and started.[132] Following the fallout from the financial crisis, the government is undertaking a most ambitious programme of welfare reform—the most radical for over 50 years—and DLA is undergoing significant reform as a result. Such changes may well have serious consequences for disability poverty, at a time when the government is—via the Field Review—seeking to reconfigure its approach to poverty and multiple deprivation in Britain to consider wider and more sensitive measures of poverty beyond a crude assessment of income.[133] Now would seem the perfect time to better articulate the causes of disability poverty and include them in such broader measures.

Within the consultation documents for the PIP, the government has outlined its intention to introduce an objective assessment of need, which will use the impact of an impairment or condition as a proxy of cost.[134] Yet significant questions arise on reviewing the existing evidence base as to whether this would be adequate and generate accurate results on which to distribute PIP resources. The government has emphasised its commitment to the social model of disability and the PIP will remain a benefit premised on this model. It would seem logical, therefore, that such a benefit should take into account *social and environmental factors* and their impact on disability-related costs, in keeping with the social model on which it is premised.

And yet questions remain as to whether an unreformed DLA is still fit for purpose. As we have outlined above, the assessment of DLA is currently complex and poorly understood. Its two components—mobility and care—are limited in their ability to capture the range of disability-related costs. Nearly 50 per cent of DLA claims are rejected, but of the cases that are appealed, 54 per cent are overturned in the appellant's favour.[135] That so many appeals are found in favour of the appellant (44 per cent in 2007/08; 51 per cent in 2008/09) raises serious 'questions about the quality of the

original decisions made'.[136] Furthermore, the framework used by the DLA to establish rates of benefit has been informed by studies using the OPCS scale of severity, which, as noted above, may not properly reflect an individual's needs arising from that impairment. The DLA's links to this model possibly undermine its credibility as a 'social model' benefit, and the government cites this as one reason for the introduction of the PIP to replace it.[137] However, swapping 'severity of impairment/condition' (DLA) for 'functional impact of impairment/condition' (PIP) seems a relatively small change—one which still does not take into account social and environmental cost drivers.

So although many feel the DLA is due for reform, the proposed PIP, with its objective test of functional impact, may not prove any more accurate. What should be used in its place, however, remains open to debate. Chapter 2 seeks to further this debate by providing greater clarity on the different drivers of disability costs, including but not exclusively the functional impact of disability or condition. In doing so we will not be able to develop a foolproof new methodology for measuring disability and quantifying the associated costs, but should be able to provide greater insight into the relative weight of different factors—medical, social and environmental—in influencing the costs of living with a disability.

This, in turn, could have two very important implications. In the short term, the PIP assessment procedure could be made far more accurate if it were to measure these wider factors. The proposed PIP assessment would be far narrower and less thorough by comparison. In the longer term, the measurement and reduction of disability poverty might be rendered more effective, as the real drivers of the conversion cost could be targeted. We will revisit each of these points in the conclusion of this paper, once we have established in chapter 2 what factors influence disability costs.

2 Analysis of our findings

This chapter seeks to fill some of the gaps in understanding identified in chapter 1 by analysing new primary data from a survey of 845 disabled people or their relatives. It is clear from the review of available studies outlined above that there is no single 'cost of disability' — this cost varies widely from person to person. Our survey will not provide a definitive answer to this question where others have been unable to do so. However, in the following analysis, we hope to provide greater clarity on *the most accurate way* of measuring disability costs by identifying the most important drivers of those costs. The most accurate assessment of disability costs will, therefore, be those which take into account all of these drivers.

Our methodology

Scope, in partnership with ComRes, distributed an online questionnaire to disabled people and their families. Scope received 845 completed questionnaires and passed the raw numerical data to Demos for analysis. In the questionnaire people were asked to estimate their daily costs in 19 separate areas related to their disability. This follows the 'subjective' approach outlined above. They were also asked to estimate how much they spend relative to non-disabled families in 14 areas that might be described as indirect disability costs, such as utilities and holidays, following the comparative approach outlined above. A series of further questions solicited information on a wide variety of variables related to people's social networks, family life, housing and employment status, as well as background data — their age, ethnicity, and nature and severity of their disability.

The object of the analysis was to link these variables to direct and indirect costs, to establish which of the variables identified in the survey (severity of disability, age, social and family life, accommodation and transport factors and so on) were most closely linked to daily living costs. Using a variety of correlation methods we were able to determine which factors were most closely related to increased costs, and therefore identify the most important cost drivers.

Measuring impairment or condition

There is no established methodology for estimating the complexity of a person's condition or impairment in a simple single question format—estimating this would require a whole new questionnaire similar to the OPCS severity scale survey outlined above. As this was not feasible within the time frame of the project, we considered alternatives. We decided that relying on people's self-defined complexity (having them rate their condition from 1 to 10) would skew the results, so we decided to ask people how many hours of personal care and support they needed each week (this could be met by social care or informal carers) as a proxy for the functional impact of their impairment or condition.

In the survey we also asked about their eligibility for DLA and, if eligible, what levels within the mobility and care component. By comparing current eligibility and level of each DLA component with actual disability costs, our survey was able to establish how accurate the *current* DLA test is at measuring and covering disability costs—a vital question to be addressed before this benefit is replaced.

Demographic breakdown

The sample was made up of 845 people, of whom 74 per cent were disabled and 26 per cent were relatives and friends filling the survey in on behalf of a disabled person. Of those filling the survey in on behalf of someone else, 93 per cent were the parents of a disabled person. The ages of those answering the survey ranged from 1 to 90, with an average age of 49; 92 per cent described themselves as White British; 31 per cent were unemployed; 21 per cent were students; and just 10 per cent worked full time, while 8 per cent worked part time.

When broken down by impairment, the single largest group (66 per cent) described themselves as mobility impaired, 61 per cent described themselves as physically impaired more generally, followed by 38 per cent who described themselves as having a long-term medical condition (eg MS, epilepsy). More than a quarter (28 per cent) had a developmental condition, like cerebral palsy. However, most of those we surveyed (80 percent) reported having more than one condition or impairment and 16 per cent reported having five or more. For example, many reported having a physical impairment, a mobility impairment, a speech, language and communication impairment, a developmental condition such as cerebral palsy or dyspraxia, and a learning disability. This made it impossible for us to analyse costs based on a particular condition or impairment—the level of overlap was too great to isolate and identify one costly impairment or condition. This in itself has implications for future assessments of the DLA's successor, the PIP, as it suggests segmentation of the disabled population into particular diagnostic groups would fail to take into account large costs being generated elsewhere. For example, the PIP might focus on the functional impact of a wheelchair user, but fail to recognise the costs of their mental health condition.

As outlined above, there is no single, established measure to quantify level of need or complexity of disability. However, one of the proxies we used in this survey was the number of hours of care and support per week people reported they needed (provided either by family and friends or by social care services). The largest proportion of our sample (44 per cent) reported they needed 28 hours a week or more personal care and support; other amounts of personal care and support respondents needed each week were:

- 7–14 hours (18 per cent)
- less than 7 hours (14 per cent)
- 15–28 hours (13 per cent)
- no additional care and support (10 per cent)

What do the data tell us about disability costs?

Understandably, the data provide a complex picture of disability costs. No single variable proved to be strongly linked to total expenditure, but some variables were linked to individual groups of costs, for example, the type of transport a disabled person has affects how much they spend on transport costs, fuel and parking. Disabled people who live in unsuitable housing have to spend more on adaptations and childcare. Some variables influenced a broader array of costs, however; for example, those who do not have a bank account and receive Jobseeker's Allowance (JSA) have to spend more on several different costs including utilities, home help and transport. Thus disabled people in these circumstances spend more in total overall.

Interestingly, our proxy for level of need (number of hours of care needed per week) did *not* correlate to total costs. Although average spending was higher for those with the highest care need (28 hours or more per week), and lowest for those with no additional care need, those with 7–14 hours of need spent less than those with less than 7 hours need. More importantly, the number of outlying values smoothed by these averages was very large indeed — therefore, the costs of a very large number of people did not relate to the amount of care they needed at all. The only areas of spending where there was a (small, and just statistically significant) link to hours of need was in specialist clothing and equipment costs.

A similar trend emerged with the DLA care component. Although those receiving the higher level spent more overall, their spending was only really higher in four of the 19 areas — specialist equipment, food and clothing, and therapy. This is not surprising as we found a stronger link between DLA received and number of hours of care needed per week than between DLA and total costs.

Another trend we saw was in some cases people spent according to their available resources. This led to a particularly complex interaction between costs and employment. Those who were unemployed — particularly those on JSA — spent more than other groups in a number of areas, and also estimated their indirect spending costs to be higher. The qualitative data collected as part of the survey included many comments relating to the fact that being unemployed meant staying at home all day, therefore paying more for utilities, house tasks, home support and so on. This was further confirmed by the fact that those on Working Tax Credit (WTC) spent less overall than disabled people on unemployment benefits. However, when we considered all employed people (not just those on WTC), we found that actually those who were employed full time *spent more overall* than unemployed groups. This suggests that as incomes rise, so can spending. Those on WTC may spend less, but being eligible for WTC would imply the recipient had a lower income than other employed people.

Our findings relating to DLA support this hypothesis. Estimated spending on the necessities of life (food, household goods, utilities) was fairly similar by those on the low, middle and high care components — whereas those with the high rate of care component spent more on social activities. This suggests that once the basics are covered, additional income is spent on building and maintaining social networks and inclusion.

These findings raise a number of difficult issues for DLA reform and the wider objective of combating disability poverty. It is almost certainly impossible to untangle a 'magic formula' of different lifestyle factors that will predict disability costs and award DLA (and PIP) according to this. Every person we surveyed had a unique combination of factors which impacted on their costs. Attempting to identify and quantify each of them to generate a perfectly accurate PIP rate would be phenomenally costly and administratively complex. Nonetheless, and although we would not recommend this extreme approach, our analysis does show, before all else, that one single proxy measure of cost (be it functional impact, as per current proposals for PIP, or one of any other of the factors we used in our survey) will be wholly inadequate as an estimate and predictor of disability-related costs. At most, a single measure may help predict a single or small group of types of costs, but the principle on which DLA is founded is that it contributes to the costs of disability *in the broadest sense*. The social model recognises the disability characteristics of the environment and social structures, so we should consider carefully how to balance the need to take into account a holistic and broad range of costs, while not generating such a finely grained assessment procedure that it becomes difficult to administer and access.

In the following sections, we consider the primary variables that our survey identified as having the most significant impact on disability costs, either in the 19 direct cost areas, where we asked people to estimate monthly spend, or in the 14 indirect cost areas, where we asked people to estimate how much they spend in relation to non-disabled people.

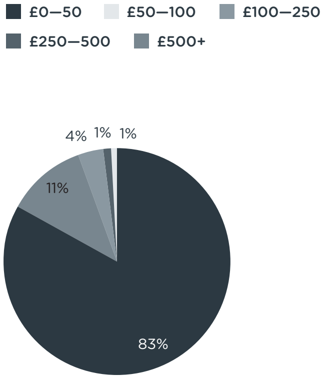
How much are people spending?

There were 19 categories of direct disability costs:

1. specialist food
2. specialist equipment
3. specialist clothing
4. therapy
5. hygiene products
6. doctor's fees
7. dentist's fees
8. optician's fees
9. prescription medicine or products
10. non-prescription medicine or products
11. private medical insurance
12. public transport
13. private hire transport
14. car parking at hospital or clinic
15. car parking at work
16. car parking for leisure
17. house tasks
18. childcare
19. gifts to family and friends

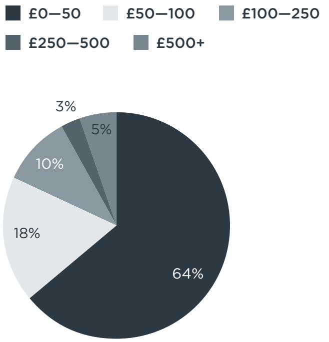
Most people (83 per cent) spent up to £50 per month in each area they selected, though 102 people were spending £250–500 per month in each area, and 67 people were spending £500 or more per month. In total, our highest spender estimated they spent around £3,400 per month, but the average across the sample was around £800–1,550 per month (figure 3).

Figure 3 How much do you spend each month (average of all disability-related costs)?



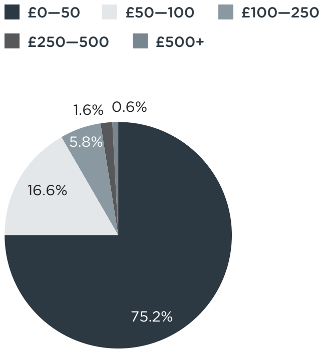
However, this general figure hides large differences in expenditure on specific types of cost. For example, specialist equipment proved to be a very large single cost, and a large proportion of people spent much more on this than on other categories of expenditure (figure 4). The types of specialist equipment identified varied widely, from bedding, gloves, bath hoists and audio books to the costs associated with maintaining and charging mobility scooters, wheelchairs, hearing aids and sensory alarms.

Figure 4 How much do you spend each month on specialist equipment?



Similarly, specialist transport was also identified as a large monthly expense (figure 5).

Figure 5 How much do you spend each month on specialist transport?



How much do people spend relative to non-disabled people?

Without a control sample, we are unable to establish whether disabled people spend more than non-disabled people on some of these 19 cost areas. We can assume that spending on specialist equipment, therapy and medication costs will be higher for disabled than non-disabled people; however, the comparative expenditure on less specific costs (eg utilities and childcare) is less easy to establish. In the absence of a control sample, the survey adopted the comparative approach and asked people if they spent more, on 14 'less specific' costs than non-disabled people as a result of their disability. The options ranged from 'a lot more' to 'a lot less' and the 14 indirect disability cost areas were:

1. electricity
2. gas
3. water
4. telephone
5. fuel for car
6. laundry

7 local community, activity or leisure centres
8 sports and interest clubs
9 cinema, theatre, comedy and entertainment
10 pubs and clubs
11 holidays (in the UK)
12 holidays (abroad)
13 childcare
14 food, drink and other household items

Most people surveyed did not think they spent less in any cost area than non-disabled people. Many of what we might call the 'necessities of life' — heating, fuel for transport, food drink and household goods — were almost universally seen as much more expensive for disabled than non-disabled people:

Anything that has the label DISABLED on it costs more — from batteries for my mobility scooter to socks with non-elastic tops — £5 a pair instead of £5 for 3 for 'normal ones'. Most of the time I feel it is a big con — just being charged a lot extra because there is a need. More and more companies are jumping on the disabled bandwagon — from the cost of special forks or bowls to walking sticks.
Survey respondent

As I spend 95 per cent of my time at home because of my disability I spend significantly more on heating. I feel cold more than average person because of inability to move very much and moving very slowly…
Survey respondent

I have to spend more for going anywhere — either a car (more expensive to accommodate wheelchair and automatic) or a taxi is essential to go anywhere… Because I can't go out to most shops, [I do] virtually all shopping on the internet and therefore pay for delivery on many occasions — all grocery shopping done in this way and generally costs delivery charge… All speciality disability-related items are expensive — both because of small sales and because of lack of choice — eg anything to do with wheelchair, mobility aids, special clothing for wheelchair.
Survey respondent

I can't go to local fruit and veg shop for better deals so am captive to the supermarket prices, which often charge more for less.
Survey respondent

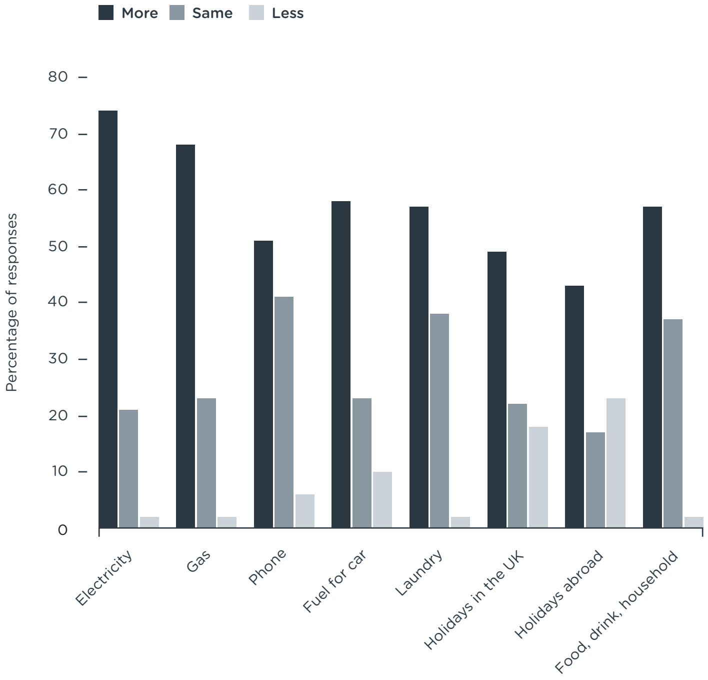
Holidays were seen as somewhat more expensive, but for leisure activities and childcare, opinions were more varied — with some thinking these things were a little more expensive, and a small number thinking these areas cost them a little less.

This could be explained by the fact that non-disabled people may go out less, therefore have lower socialising costs, or it may simply be that no additional costs are associated with going to the pub or cinema (additional transport costs might be reflected in increased fuel costs instead):

I don't have much of a social life because I am too tired to go out after work or at the weekend, so I suppose I save money because I don't go to pubs or nightclubs… If I had more money I could get taxis to go out; I have a car but finding parking near places that I want to go is so hard, even with a blue badge I sometimes can't find anywhere to park.
Survey respondent

The difference in expenditure on childcare is harder to explain. One might assume that disabled parents would need more childcare, and therefore have higher costs than non-disabled people. However there are many possible explanations for why this is not the case — one might be that disabled parents may have non-disabled partners who take responsibility for childcare, therefore costs are not any higher. Disabled people may also have fewer children on average (therefore lower costs). Figure 6 shows the goods and services that disabled people thought they spent much more on than non-disabled people.

Figure 6 **Areas where disabled people feel they spend much more than non-disabled people**



Drivers of disability-related costs — establishing the relationship between cost and lifestyle factors

Although the above data provide an insight into the levels and types of costs disabled people have to meet, it does not enable us to identify what might be driving these costs or what factors might be most closely associated with higher costs. The following section addresses this question. We have considered the following variables:

- need or functional impairment
- receipt of DLA
- receipt of other benefits
- employment status
- source of care and support
- housing
- transport
- other factors.

We looked for a link between each of these and disability-related spending and estimations of indirect costs. We go through each one in turn in the following sections.

Variable 1 — Need or functional impact of condition or impairment

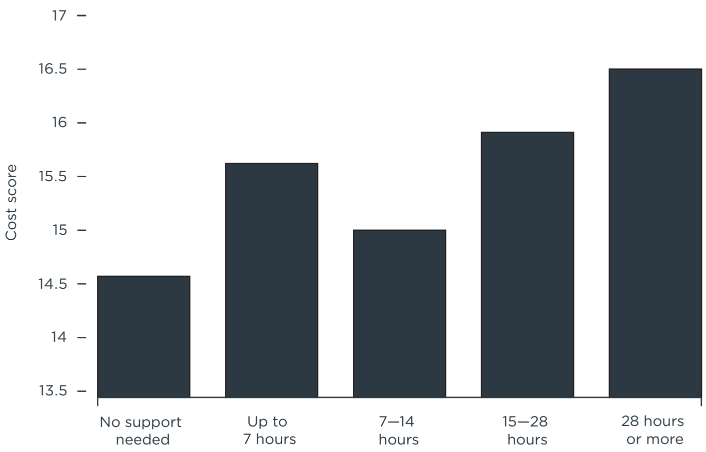
- The correlation between the hours of care and support people say they need each week and the amount people spend in *total* is not statistically significant.
- Spending on specialist clothing and equipment were the only two categories related to need.
- Only when costs are averaged by need group is there a link, but this is non-linear.
- There are very large differences in costs within need groups, making averaged costs misleading.
- There is a moderate relationship between need and estimation of indirect costs spent relative to non-disabled groups.

When total costs (a method we explain above) were *averaged* for each need group, we found that those with no need for support had an average score of 14.6 (spending between £730 and £1,435 per month), with those with the highest need (28 hours or more) having an average cost score of 16.5, spending on average £825–1,575. This is not an entirely linear trend, however, as those reporting needing less than 7 hours of care had a higher cost score than those needing 7–14 hours of care. This means the former group spent between £785 and £1,535 per month, while the latter spent £750 to £1,500 (figure 7).

Moreover, the actual (and more accurate) relationship between *all* people's scores and costs is very low (r=0.07). This suggests that there are large numbers of outlying values which are smoothed by averaging the scores — this is confirmed by the fact that the variation in people's reported costs within each need group were high (between sd=7.4 and 8.8), with the widest variation in costs for those needing the highest number of hours care.

In other words, for very many people, and particularly those with the highest needs, level of need does not in any way relate to disability costs. This is significant as this measure — number of hours of care and support needed per week — is a proxy for the functional impact of a condition or impairment (as need for support relates to limits of functional ability and ability to live independently). The new PIP, replacing DLA, intends to use 'impact of condition or impairment' as a way of deciding eligibility for the PIP and at what level. Our findings suggest such an assessment measure will be inaccurate.

Figure 7 Average cost score by need group



Estimated spending and need (hours per week)

Our second measure — estimations of spending relative to non-disabled people in indirect cost areas — showed that there was a very small correlation between need and spending more on average relative to non-disabled people (r=0.224). In other words, people with more complex needs are more likely than those with less complex needs to feel they spend more than non-disabled people in the 14 cost categories we identified.

This was particularly the case for laundry costs (r=0.33) and electricity costs (r=0.31). However, as the link was very small, there are numerous exceptions to this general trend, including the fact that those needing 7–14 hours of care per week feel they spend the least on childcare (less than those with lower *and* higher needs).

In fact, there were just five of the 14 indirect disability costs where there is a linear correlation between low need and perceived lower spending and high need and higher spending:

- electricity costs (though the two groups needing the most care have the same estimation of cost)
- petrol or diesel costs (though the two groups needing the least care have the same estimation of cost)
- laundry costs (need groups are most divergent in their estimations here)
- holiday costs (with fairly significant differences between the no need group and 28 hours or more need group)
- household good costs (though the differences between need groups was very small, with most thinking they spent a bit more or about the same).

Variable 2—Receipt of Disability Living Allowance

- The DLA care component is more closely related to the need for care than total disability costs.
- Average total costs do have a linear relationship with the rate of DLA care component, but this is primarily driven by increased spending in four areas—specialist clothing, equipment, food and therapy.
- In the other 15 areas, there was almost no relationship between the level of DLA component received and level of spending.
- There are very large differences in costs within DLA groups, making averaged costs misleading.
- Evidence also suggests differences in DLA group spending might be a result of differences in available resources, and not different costs per se.

We found there was a moderate link (r=0.373) between the number of hours of care a person needed and the level of DLA care component they received (though not in the mobility component received, suggesting that this component of the benefit is not well targeted).

This suggests that for the care component at least, the level of DLA received reflects need for care or complexity of condition. However, as we have seen above, need for care does not determine disability costs, which is what DLA was designed for.

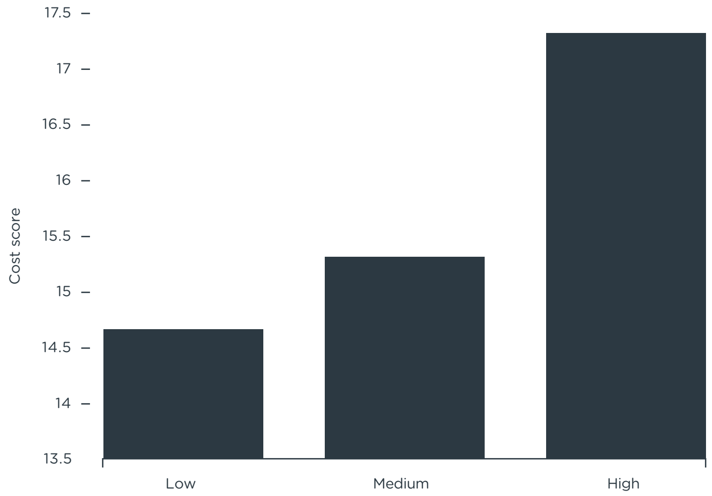
As figure 6 shows, people's average costs were strongly linked to the level of DLA care component received (r=0.98), with the low group having an average 'cost score'[138] of 14.6, which translated to spending £725–1,450 per month. The middle group had an average cost score of 15.5, spending £775–1,550 per month, while the high group had a cost score of 17.1, spending £850–1,600 per month. However, these differences were driven primarily in just four areas: specialist clothing, equipment, food and therapy. This is understandable given that need is linked to care-related spending, and DLA is linked to need.

However, when looking at the entire sample, the link between DLA received and cost of disability was almost non-existent (r=0.12), which means that DLA does not match the costs of large numbers of people in the sample. This is because costs varied so widely within DLA groups that averages become less meaningful. Figures 8 and 9 demonstrate this point. Figure 8 shows the linear relationship of average cost within each DLA group, and the scatter chart of figure 9 shows the entire sample in three groups.

As figure 7 shows, there is no correlation between total cost and DLA care component, with the majority of groups clustered around the 0 to 25 cost score, which translated to £0 to £1,250–2,500.

Overall, these data therefore suggest that DLA more accurately reflects need for care (with a whole sample correlation between need and DLA of r=0.373) rather than cost (with a whole sample correlation between DLA and cost of r=0.12). This suggests current DLA assessment targets those with greater need, not greater costs—an important point given that DLA is not designed for such a purpose but, ironically, is in line with current proposals for the PIP, which talks about targeting the benefit at those with the greatest need. We might expect that the correlation to need, rather than cost, will increase if current reform proposals go ahead, leaving those experiencing lower impact of their condition or impairment, but high costs, at a particular disadvantage.

Figure 8 **Average cost score by Disability Living Allowance care component eligibility**



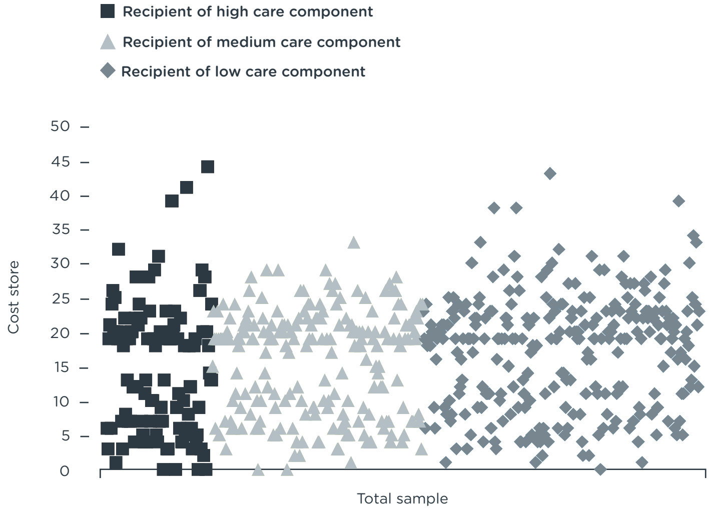
Disability cost and disability spending — the role of resource constraint

It is important to bear in mind that, as with all 'subjective' cost methods, our survey asked people how much they *spent* on a given area, not how much their costs were or how much they would need to spend to meet their needs. It is possible, therefore, that the differences in spending between DLA groups does not demonstrate a difference in living costs, but rather a difference in available resources. Those on the high care component receive £71.40 per week, and those on the low care component receive £18.95 per week. This is a significant difference in the resources available to spend and could well determine how much people spend in a range of areas:

I used to pay for private therapy but I now get it on the NHS. But then my DLA was middle rate and I also got Income Support so I had a bit more money to spare for that. [I] lost middle rate DLA and therefore lost Income Support so had to pay for prescriptions and [am] not able to pay for therapy.

Survey respondent

Figure 9 **Total cost scores by Disability Living Allowance care component — complete sample**



Looking at these data more closely, the hypothesis that spending is related to people's available resources (rather than costs driven by the needs of people with different levels of DLA) in this case seems plausible. When it comes to spending in indirect cost areas, there is more consensus between the three groups on how much they spend in what we might call necessities of life — utilities, household goods and food.

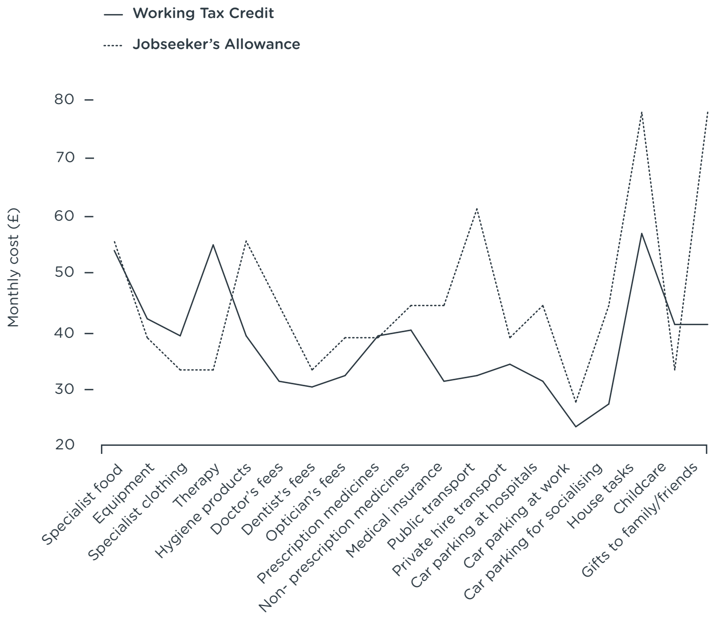
However, there is much more difference of opinion if we look at 'luxury' areas — socialising and holidays. When it comes to socialising, those with high and middle components of DLA feel they spend the same, but there is a clear and significant difference in spending on holidays with those receiving the DLA high component thinking they spend a lot more than those on the middle and low rates. This is significant because it indicates the use of disposable income. One can assume that when resources are constrained, people will spend on their priorities first — utilities, household goods and food. They can only afford to spend money on socialising and holidays if they have extra money. As spending on the 'necessities of life' is fairly similar across all groups, but spending on 'luxuries' differs widely, this suggests that people spend more if they have more, and they can only spend on socialising and holidays if they have higher levels of resources. It may not be the case, therefore, that those receiving the DLA high care component necessarily have higher costs than those receiving low or middle rates:

> *You learn to live within your means and it means you don't do things anymore! You always look for the reduced items when you go shopping and special diets like mine tend to get ignored because you just can't cope with cost.*
> Survey respondent

> *I spend less on leisure and social activities and also on holidays either in the UK or abroad because I don't do any of the above because I don't have the spare money to do these things.*
> Survey respondent

This is important when considering the wider question — what is DLA *for*? Should DLA help people with more than just the basics of life? Should people be able to afford leisure activities and holidays? The government has stated, in its proposals for PIP, that priority will be 'given to those individuals who need to overcome the greatest barriers to living full and active lives'.[139] This would suggest that the new benefit will take into account wider needs, including remaining socially engaged. We discuss this in more detail in the conclusions of this report.

Figure 10 **Spending in 19 cost areas for highest and lowest scoring benefit groups**



Variable 3 — Receipt of other benefits

- As disabled people often claim multiple benefits, it is difficult to determine whether one benefit group has higher costs than another.
- Nonetheless, those receiving JSA have significantly higher costs that those on WTC.
- This suggests being unemployed generates costs, but as JSA claimants spend more than those on ESA and IB, functional need is not a key driver. Being unemployed and unsupported seems to be the most costly scenario.

Many of the disabled people completing the survey receive a variety of benefits. The most common are Housing Benefit (26 per cent), Incapacity Benefit (30 per cent), Income Support (21 per cent) and Employment Support Allowance (6 per cent). A further 12 per cent of those responding to the survey also received Carer's Allowance, though only 28 per cent of them were relatives of disabled people; the rest were disabled people who presumably are also carers themselves.

Many receive more than one benefit, for example, 58 per cent of those receiving Housing Benefit also get Income Support, and 46 per cent received Incapacity Benefit.

On averaging the costs of each benefit group, the groups can be placed in the following order, but with only small differences between their average spending (sd=1.12):

- those receiving Jobseeker's Allowance (£850–1,600 per month)
- those receiving Employment Support Allowance (£780–1,530 per month)
- those on Income Benefit (£749–1,449 per month)
- those receiving Housing Benefit (£744–1,445 per month)
- those with Working Tax Credit (£700–1,450 per month).

Costs in many of the 19 categories varied widely between groups — particularly therapy costs and childcare (where those receiving WTC spend much more than other groups), specialist transport and prescription medicines (where those receiving ESA spend much more), personal hygiene products (where those on IB and HB spend more), and public transport, house tasks and gifts to friends and family (where those on JSA report spend much more).

It is very interesting to note the highest and lowest spenders are those receiving JSA and WTC respectively, as both are what we might call 'low need' groups — those on JSA have been deemed fit to work and not eligible for ESA or IB, while those on WTC are in work (all but one of those receiving WTC were disabled people themselves, not relatives of disabled people).

This would suggest the differences between people in these groups are not related to their capacity to work or functional need, but perhaps related to being unemployed. In the following section we see how being unemployed slightly *reduces* overall spending (probably because of lower available resources), though costs remain high in a number of key areas, including utilities, house tasks, gifts to family and friends, and home help.

It is these areas where those on JSA spend the most, which could be attributed to the fact that being unemployed means spending more time at home and generating a range of costs as a result:

> *Heating and lighting cost a lot more than they did when I was working for the simple reason I am at home.*
> Survey respondent

It is very interesting also that those on ESA and IB — who are also unemployed — have lower costs than those on JSA, in particular spending less on public transport, parking, house tasks, and gifts to family and friends to maintain informal support networks. It could be that the withdrawal of specialist employment support from those on JSA generates additional costs that those on ESA and IB do not have to face.

Variable 4 — Employment status

There are not large differences in costs, but on average, those working full time spend slightly more than those working part time, and in turn, both groups spend slightly more than those who are unemployed.

- This suggests spending increases slightly as income rises.
- However, unemployed people actually have the same or higher costs in more cost areas than those in work, but total amounts of spending are driven higher among employed people because of their higher spending on childcare, house tasks, prescriptions and specialist equipment.

The importance of disposable income

As we have discussed above in relation to DLA spending, it is highly likely that with increased income comes increased spending. So those working full time report spending more than those working part time, and both spend more than those who are unemployed. However, these broad differences in total costs do not paint a full picture. Total spending is higher among those who are employed primarily because of their high spending in four key areas — childcare, house tasks, prescription medicines (which are free for the unemployed) and specialist equipment. In most other areas, unemployed people spend the same or slightly more. As they have a significantly lower income than those who are employed, this suggests unemployed disabled people are in a particularly difficult situation — with much lower income but similar costs.

Disabled people who are employed may have more money to spend on everyday costs as well as on holidays, leisure and other non-essential items. Indeed, disabled people working full time were most likely to say they spent a lot more than non-disabled people on holidays abroad. Clearly unemployed disabled people and part-time workers felt they did not spend as much as non-disabled people because they are simply unable to afford such holidays. This is substantiated by the fact that those on Working Tax Credit — who are lower income earners — spend less than all full-time employed disabled people (£722–1,422 per month compared with £915–1,615 per month).

This again is important when considering DLA's true purpose. When employed, people's costs are higher: does this mean employed disabled people should receive higher rates of DLA? Not necessarily, as they may have chosen these higher costs to improve their wellbeing, because they can afford them from their earned income. So should their DLA be *lower?* Not necessarily either, as the DLA people receive may be vital to supporting them to stay in work. These challenging questions must be considered before a PIP is introduced to replace DLA.

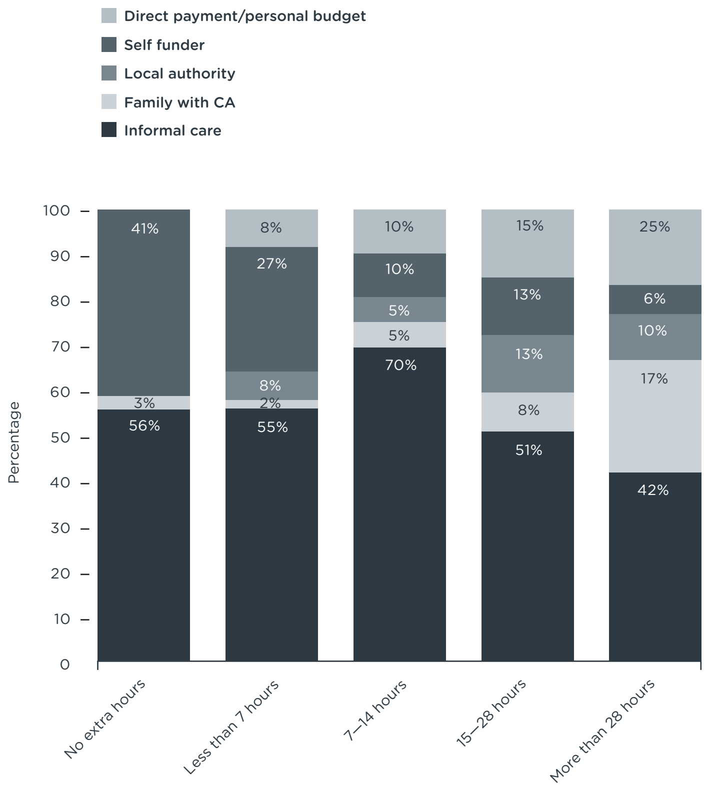
Variable 5 — Source of care and support

- When averaging costs, our findings show those with personal budgets spend the most, and those relying on informal support the least.
- However, average costs are misleading as there was such variation in costs within support groups.
- High spending by those with personal budgets could be explained by this group having more resources available to spend than other groups.

We must bear in mind that current eligibility for council funded care is based on a need assessment and Fairer Access to Care Services (FACS) criteria. In 2010, 80 per cent of local authorities provide care only to those with critical or substantial need as determined by the FACS assessment. One might therefore expect that those receiving local authority funded care, or using a personal budget or direct payment, will (generally, but not always, as social care is also means tested) have higher needs than self-funders or those primarily relying on informal care.

This broadly seems to be the case, with a moderate correlation between those reporting needing more hours of care per week and those receiving local authority funded care or using a personal budget or direct payment (r=0.58). The main exception to this is the reliance of informal care provided by family and friends, which all groups, regardless of hours of care needed, rely on extensively (figure 11).

Figure 11 Level of support (hours per week) broken down by source of support



More than half (59 per cent) of disabled people answering the questionnaire said they relied on their family and friends for most of their support. Even among those using formal care, this reliance was high — 40 per cent of self-funders and 31 per cent of those receiving council funded care said they also relied on family and friends for care and support.

Average total spending of each group places them in the following order of cost:

- those relying on informal care (£793–1,543 per month)
- those being cared for by someone receiving Carer’s Allowance (£819–1,569)
- those paying for their own care and support (£839–1,539)
- those receiving care and support free from the local authority (£843–1,593)
- those receiving a personal budget or direct payment from the local authority to spend on their care (£870–1,620)

However, when the entire sample (not just group averages) was considered, there was no statistically significant link between funding source and level of spending (r=0.07). This confirms earlier findings that average costs are less meaningful here, as differences in costs within support groups are so wide (sd=8.13). In other words, these averages obscure large numbers of people whose source of care funding does not relate to their disability-related spending at all.

Two further points should be borne in mind. The first is that while those with personal budgets and direct payments report spending slightly more on average, this cannot be wholly attributed to higher need or impairment. This is because personal budgets and direct payments are cash sums given to people to meet their care and support needs. This group has *additional resources* to spend that others do not, and this is likely to be reflected in the survey results. Even though people in this group may have higher levels of need than other groups, their increased spending could well be attributed to the fact that they may have more to spend on care and support than other groups:

Direct payments mean I have someone to help with meal planning, food preparation, checking on household tasks. Before I had DPs there were some days when I would be tired or confused enough to end up eating nothing but a bowl of cereal.

Survey respondent

Second, although those relying on informal care spend slightly less on average than other groups, this cannot be wholly explained by low level of need. It is not the case that those in this group spend a lot less in areas that might be associated with lower levels of (medical) need. In fact, they spend the most of all groups in four cost areas, three of which might be described as medical — prescription and non-prescription medication, dentist fees, and gifts to friends and relatives. This last point suggests that informal care is not 'free', but rather needs to be maintained by those who rely on it through positive relationships and social networks:

> *I use my DLA to pay for my ironing and buy gifts for my family who help with cooking and cleaning and doing tasks when I am too tired or my limbs are not fully functioning.*
> Survey respondent

> *Being forced into a position where I am beholden to family and friends for my essential support means that I cannot have an equal friendship with them. I cannot argue or disagree for fear that my care will be withdrawn.*
> Survey respondent

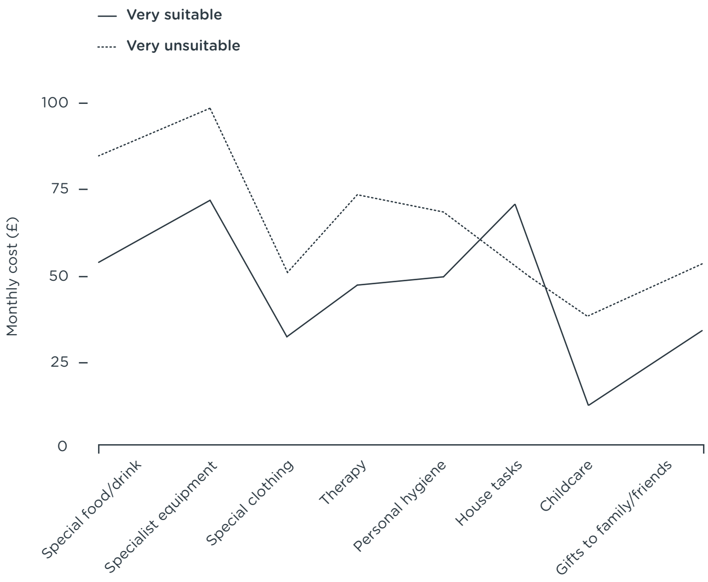
Variable 6 — Housing

- Suitability and type of housing affect a range of disability spending.
- Those in unsuitable housing spend significantly more, particularly on adaptations, specialist food, clothing, utilities and childcare.
- Private rented accommodation is most costly, shared ownership the least.
- Although those in residential care spend the least, this does not take account of residential fees. Those in residential care who still have to pay (leisure etc) feel they spend significantly more than non-disabled people.

There is a moderate and statistically significant link between the suitability of a person's accommodation and their average disability-related costs (r=0.56), with those living in unsuitable accommodation more likely to report higher costs than those with more suitable accommodation.

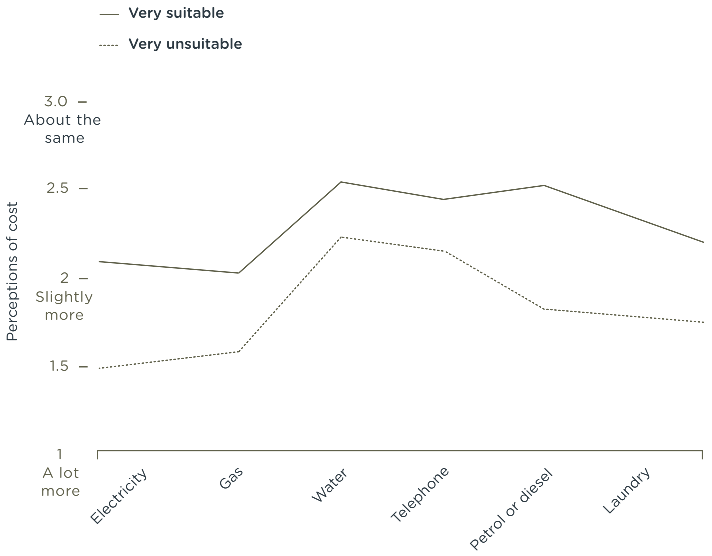
The largest differences in spending were in specialist food, specialist equipment and adaptations, specialist clothing, therapy and personal hygiene product costs, which are all significantly higher for those in unsuitable accommodation. Those in unsuitable accommodation spent on average £80 per month on adaptations compared with £60 per month spent by those in suitable accommodation (figure 12). Those in unsuitable accommodation also spend more on childcare (£15 more per month).

Figure 12 **Average monthly cost per person in very suitable and very unsuitable accommodation**



The data also show a strong direct correlation between suitability of accommodation and estimation of indirect disability costs. The less suitable a person's home, the more they feel they spend on a number of areas relative to non-disabled people. This was particularly marked for most utility costs (including fuel for transport), childcare and food and household goods (figure 13).

Figure 13 **Perceptions of cost relative to non-disabled people, by suitability of accommodation**



We found that all of those living in residential care think it is suitable, and 79 per cent of those living in their own homes think it is suitable, compared with 76 per cent of those living with their families, 74 per cent of those living in social housing, 68 per cent of private renters, and 67 per cent of shared owners who think their living conditions are suitable.

There was a direct and significant relationship between average monthly costs and type of housing, in the following order of monthly cost:

- private renting (£840–1,590)
- living with friends or family(£793–1,543)
- own home ownership (£787–1,537)
- social housing (£776–1,527)
- shared ownership (£729–1,458)
- residential home (£644–1,288).

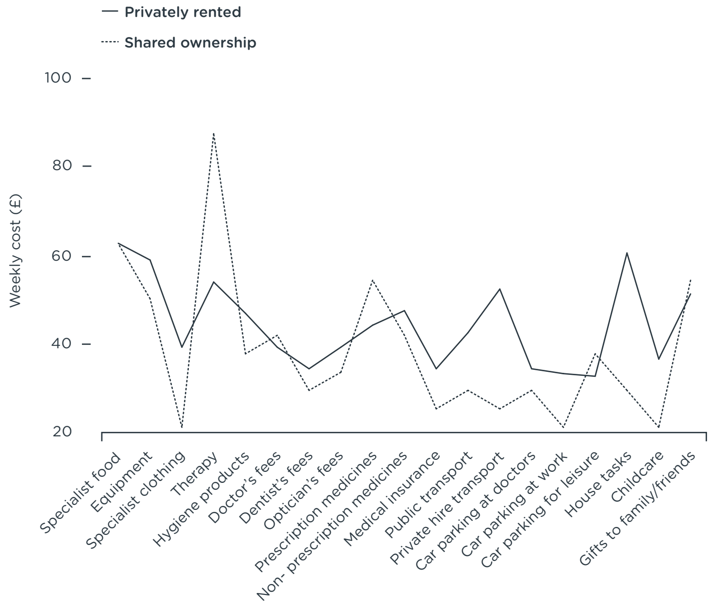
The lower cost for living in residential care homes might be explained by the fact that these costs do not take into account residential fees. We might argue that residential fees, which can be several hundred pounds per week (rightly), cover a variety of costs outlined in the survey including specialist food and medicines, and house tasks. When it came to non-disability-related costs, those in residential care particularly felt they spent more than non-disabled people on holidays and leisure — suggesting that in the areas of spending they remain responsible for, their costs are relatively high. This point is particularly important given that the proposed PIP will not be available to those in residential care.

If we consider the highest and lowest cost non-residential accommodation, we can see there are significant differences in costs of specialist clothing, specialist or private transport and house tasks, where private renters pay more (figure 14). In the case of public transport, private renters pay double — £50 per month on average compared with £25 for those in shared ownership, and three times as much for house tasks — £60 per month compared with £20 for shared owners:

If I did not live with my parents, the money I receive would not be enough to cover the cost of living with a disability.
Survey respondent

Therapy costs are conversely significantly higher for shared owners. This may be attributed to the nature of the condition shared owners have — our survey shows they are disproportionately more likely to have long-term conditions like multiple sclerosis, for example.

Figure 14 **Weekly costs by most and least costly accommodation type**



Variable 7 — Transport

- The type of transport used primarily affected transport and parking costs, but these were significant.
- Public transport users spent the most overall, as they spent highly on public transport, but also on private transport — suggesting public transport does not cover all transport needs.
- Among car users, those with adapted and motability cars spend the most, on specialist equipment and clothing.

As one might expect, the type of transport a person relies on does not affect every type of disability cost. Using public transport, or owning a particular type of car, is unlikely to affect the amounts spent on non-prescription medication, for example. However, it is clear that mode of transport used directly affects a range of transport and parking related costs, which can be significant. (figure 15).

Overall, those mainly relying on public transport had the highest average disability costs. This higher average was driven by substantially higher public transport costs (on average £62.50 per month compared with £35.50 for those relying on private transport and £33 for those with access to a car) and gifts to family and friends to maintain informal networks — presumably reliance on others might be higher for those without their own transport. Interestingly, private hire or specialist transport costs and parking costs were also high for public transport users. This suggests that public transport cannot cover the entirety of this group's transport needs, and therefore additional use of private transport or other people's cars (both incurring costs) is sometimes necessary:

A lot of times if public transport goes down late at night or is overcrowded such that it feels unsafe (worried about falling and getting injured again — two broken bones related to travel by public transport in past three years makes me nervous) [I] end up paying for cabs or minicabs out of my own pocket. Not frequently — but [its] expensive and key to feeling safe. The other reason that I'd take a cab is having to carry heavy groceries

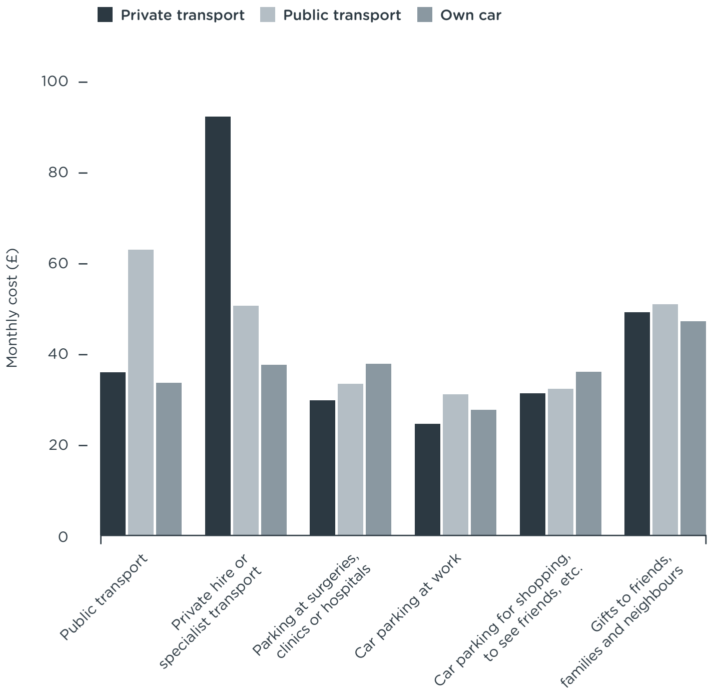
or other awkward purchases—don't have as much strength.
Survey respondent

If I cannot afford taxi fares then I must stay home until I can persuade a friend with a car to give me a lift.
Survey respondent

The next highest spenders were those who mainly used specialist transport. Unsurprisingly, their single largest expense was private transport costs (like dial-a-ride or taxi fares), where they spent on average £90 per month compared with £50 for those relying on public transport and £37.50 a month for those with their own cars, but they had lower public transport and parking costs to offset this.

The lowest spenders were those with access to a car. Although they have slightly higher parking costs, they have significantly lower private and public transport costs—and lower spending overall. Unsurprisingly, those with their own cars feel they spend much more than non-disabled people on petrol or diesel, with those relying on public transport and private transport thinking they spend slightly less than non-disabled people.

Figure 15 Transport related costs for different transport groups



Among those with cars, those with adapted cars spent the most on their disability overall, followed by those with motability cars, those with large cars, and those with standard cars. Unsurprisingly, the higher costs for those with adapted cars was driven by very large spending on specialist equipment—£90 per month for this group compared with £67 for those with motability cars, £63 for those with large cars, and £50 for those with normal cars. These costs may include maintaining adaptations made to the car itself, but it is also likely that someone with a specially adapted car would need to spend on home and other adaptations.

The cost of petrol is so high. I have no alternative to travel by car and I feel unfairly targeted because I have no other choice.
Survey respondent

I had to purchase a large car, purchase hand controls, and hoist — all extremely expensive — and when I come to change my car the extra costs will be needed again.
Survey respondent

This is particularly important in light of proposals for a new PIP assessment to take into account the use of adaptations or equipment. It is certainly welcome that the government recognises that those without equipment or adaptations sometimes have higher costs — as we have seen as it related to people living in unsuitable accommodation. But there is a risk that the PIP assessment regime might view the purchase of equipment as a reason to reduce PIP, because it underestimates the ongoing costs of maintaining and running such items (expenditure on electricity, petrol, batteries and so on), or might fail to recognise that the purchase of equipment is symptomatic of the need for spending on other support, such as house tasks.

Other variables

Savings and debt

Disabled people are known to have a higher risk of indebtedness than non-disabled people, because of their higher levels of unemployment, lower income and higher living costs. They are also less likely to be able to accumulate savings for the same reasons.[140] Our survey found 38 per cent of people reported they were in debt, not including their mortgage. Of those in debt, 64 per cent had credit or store card debt; others owed money to banks (50 per cent), family members (23 per cent), student loan companies (22 per cent), friends (9 per cent) and loan sharks (4 per cent). Nearly half (44 per cent) of those surveyed did not have savings, mostly because they did not have enough money to spare (73 per cent), were unemployed (29 per cent), or had no bank account (5 per cent). Of those who did have savings, 21 per cent had less than £2,000.

Although the differences were very small, on average, those in debt had higher disability costs than those with no debt, while those with no savings reported spending more than those with savings. More interestingly, those who said they did not save because they did not have a bank account reported significantly higher costs overall and in several areas, including specialist food, equipment and clothing, therapy, prescriptions, private transport, house tasks, childcare, and gifts to friends and family. Those in debt to family and friends also reported having higher costs, particularly on childcare, house tasks and private transport.

It is also interesting to note that of the 10 per cent of the sample who reported they worked full time, 44 per cent said they were in debt and 44 per cent also reported they had no savings. These levels are actually higher than the 33 per cent of unemployed people who reported being in debt, and 38 per cent reporting having no savings. This might be a result of being able to access credit (and therefore get into debt in the first place) when employed. This suggests in-work poverty is a significant issue:

I'm not in debt because I can't afford to get into debt — there is no way I [would] consider borrowing money — there's no money left to pay it back.
Survey respondent

Location

There were very small differences in reported costs between disabled people living in urban or rural districts, apart from on three areas: public transport, private transport (where urban dwellers spend on average 24 per cent and 28 per cent more than rural dwellers respectively) and house task costs.

The difference in transport costs may arise from a lack of availability of transport options in rural areas, thereby reducing people's spending on such items by default:

I live in a rural area and rely on my car to get about; I could not propel myself from bus stops to my destination so public transport is not an option even if there were accessible buses on my local route.
Survey respondent

When comparing costs by region, we found Welsh disabled people reported the lowest costs (£690–1,300 per month), and London-based disabled people the highest (£850–1,600 per month). There were ten times more instances of costs being over £500 per month in any given cost area in London than in Wales, for example.

Interestingly, disability costs were almost as high as London in Scotland, Northern Ireland and East of England, while South East England and Yorkshire and Humber were next most expensive. This suggests that the established regional differences in the cost of living does not map directly onto the cost of disability.

Age

Our survey covered a very wide age range, from age 1 to 90, with parents of disabled children filling in the survey on their household costs.

On averaging costs by age group (0–18 years, 18–64 years and 65 plus) a clear link emerged between age and disability costs, with those aged 0–18 (or their families) spending the most (on average about £870–1,650 per month), followed by those aged 18–64 (£784–1,534 per month), then those aged 65 plus spending the least (£733–1,300 per month). Differences in spending are particularly large when it comes to:

- therapy costs, where families of disabled children and young people aged 0–18 spend on average nearly £100 per month, those aged 18–64 spending £65 per month and those aged 65 plus spending £55 per month
- childcare costs, with the 0–18 age group spending on average £77 per month, those aged 18–64 spending £65 per month and those aged 65 plus spending £50 per month

- house tasks, with the 65 plus age group spending the most (£90 per month), followed by those aged 18–64 (£75.50 per month) then those aged 0–18 (£65 per month)
- specialist equipment costs, with the 0–18 age group spending on average £107.50 per month, those aged18–64 spending £77 per month and those aged 65 plus spending £100 per month.

One of our children is a blue badge holder, so that parking in some places costs less if we travel with him. However, we spend a lot on petrol because of our many hospital and therapy appointments. Therapy and specialist assessments are very expensive, and so is specialist equipment. We feel that little things are less expensive for disabled children (like the parking costs) but everything that they really need in order to develop and learn costs a lot.
Survey respondent

Caring for a child with disabilities is always a struggle; utility costs are always higher because they are used more. We find clothing, toys and bedding can also be a big drain financially, as extra is also required here.
Survey respondent

I do notice that lots of equipment does seems to be a lot more expensive than average, when a disability is involved, so called catalogues of special needs equipment is horrendously high, and way out of an average family's budget, where some regular toys just aren't safe or practical to use.
Survey respondent

When it comes to people's estimations of a range of indirect disability costs (utilities, socialising and holidays), young disabled people and their families were most likely to think they spent a lot more than non-disabled people compared with other age groups. This was, unsurprisingly, particularly marked for childcare costs. Those in the working age group (18–64) were most likely to think their costs were closer to non-disabled people in these areas, although they were not the lowest spenders in direct disability costs.

What does this all mean?

It is clear that no one factor—be that the impact of a condition or impairment, accommodation, employment status, mode of transport or age—can explain differences in all day to day costs. The reason for this is that our survey asked disabled people about 19 different cost areas related to their disability and 14 indirect cost areas. This means that some lifestyle factors drive some costs (such as mode of transport and parking or transport costs), while other factors drive other costs. This may seem a methodological flaw on our part, but it is not. We picked these cost areas in an attempt to reflect the diversity of spending a disabled person might have—from care and support costs through to going out to the cinema and parking at work. Our 33 cost areas could, in fact, be hundreds if we were to actually look at the reality of a disabled person's life. Disabled people do not spent all of their available resources on medical and care products and services—this is one element of their lives alongside raising a family, going to work, socialising with friends, and so on. And it is in these other areas where disabled people can incur a 'disability premium' and have to spend more to achieve the same quality of life as non-disabled people. It would be almost impossible to select a single defining factor as a proxy for disability costs. People's lives are too complex for that.

An overview—drivers of disability costs

Table 3 gives an overview of the relationship of different factors to disability costs.

Table 3 **Relationship of different factors to disability costs**

Factor	**Relationship to disability costs**
Functional impact of impairment or condition	Only specialist equipment and clothing costs. When averaged, a non-linear correlation between cost and need, with those needing more than 7 hours of care per week reporting higher costs than those needing 7–14 hours. Large numbers of outlying values—many people having no relationship between need and cost. Linear correlation between need and estimation of indirect cost in 5 of 14 areas.
Receipt of DLA	No correlation based on whole group's costs, linear correlation when costs of each care component group are averaged. Again, large number of outlying values. Evidence that DLA rate received reflects disability spending (level of resource constraint) and not cost per se. Stronger link between DLA and need than DLA and cost.
Other benefits	Low correlation between benefit received and cost. Averaged costs are clearer, with those on WTC spending least, JSA spending most. Contrary to earlier evidence suggesting unemployed spend less than employed. Possibly something specific to JSA driving costs.
Employment status	Those in work spend slightly more than unemployed but only in a small number of key areas. Unemployed people have higher spending in other areas. Evidence to suggest higher spending based on available resources rather than costs per se.
Source of support	Differences between council-funded, self-funded and informal care users very small. Those with personal budgets are the highest spenders, though evidence to suggest this is driven by available resources and not entirely by need. Those relying on informal care spend less, but are high spenders on some medical (need-related) costs.
Housing	Strong correlation between suitability of housing and disability spending. Least suitable housing drives higher costs especially in adaptations, childcare and utilities. Marked differences in spending according to housing type. Private renters have highest costs, with shared ownership least. Residential care report lowest spending overall but costs might be hidden by care home fees.
Transport	Moderate correlation between mode of transport used and transport and parking costs. Those relying on public transport have highest costs, following by private transport, then car users.

We can conclude that a disabled person will have higher disability costs in relation to the number of the following circumstances he or she experiences:

- unsuitable accommodation
- private rented accommodation
- reliance on public transport
- no informal support from family and friends
- requiring a number of hours of care and support
- unemployed
- living in London
- receiving JSA
- no savings, in debt and no bank account.

However, that is not to say that those in work, with their own home and their own car do not also incur significant costs. However, the combination the factors above generates the most costs *as a single individual.* In other words, it is possible that one disabled person could have all of the factors outlined above—they are all compatible and create one plausible scenario. An alternative combination that one person could have, which would also be costly (but not as costly as the scenario above), would be:

- unsuitable accommodation
- home owner
- with own (adapted) car
- no informal support from family and friends
- needing more hours of care and support
- receiving local authority funded care
- living in Northern Ireland
- unemployed, receiving ESA
- no savings, in debt to bank

This scenario again is very plausible, and looks different on paper from the previous scenario, but the data show us that this combination is the second highest generator of costs.

What is most interesting here is that someone living in circumstances identified in the first list has higher costs than someone living in circumstances identified in the second. The factors in the second list would, by their nature, apply to someone with more complex needs—as they would be receiving ESA, not JSA, and local authority funded care—eligibility for both of which is determined by level of need or impairment or condition.

However, as we have seen, the need for more hours per week only correlates to increased costs when those costs are averaged per need group, and even then not fully (as those with up to 7 hours of care report higher spending than those with 7–14 hours). When the full sample is taken into account, there is only a very small correlation in two medical or care costs. In fact, those receiving JSA report higher costs (around £865–1,620 per month) than those saying they need 28 hours of care or more per week (£825–1,575 per month) and those receiving local authority funded care (£840–1,590 per month). As it is unlikely (though not impossible given current welfare reform) that someone with such high needs would be receiving JSA, we chose to make these two factors mutually exclusive and used the most costly variable (JSA) in the first scenario and the second factor (need) in the second scenario.

3 Conclusions and recommendations

Overview

Underlying this report—its analysis and conclusions—are two basic facts: first that the government is intent on radically reforming disability benefits, and indeed the wider welfare system; second that it is doing so at a time when much of the existing evidence base around disability benefits, and Disability Living Allowance (DLA) in particular, is not conclusive enough. The government has proposed a new benefit, the Personal Independence Allowance (PIP), to replace DLA, with a new objective assessment based on the impact of a condition or impairment, and new eligibility criteria (including the need to have a condition or impairment for 12 months or more and not be in hospital or residential care). Yet relatively little is known about the drivers of disability costs, how these differ for different people, to what extent DLA helps people to meet these costs, and more generally how DLA impacts on disabled people's lives.[141]

Our study did not attempt to quantify disability costs, or to come up with a specific formula with which to calculate an overall 'cost of disability'. Instead, we aimed to identify the underlying factors driving these costs and how they differ. While there have been a number of attempts to quantify disability costs, many have focused around the impairment or condition itself as the single driver of cost. Yet, our study has shown that calculating the costs of disability—and, consequently, the appropriate level of DLA—remains much more complex than has often been presumed.

We found that the impact of a condition or impairment is not the best proxy for disability costs, but we were unable to find a single suitable replacement. In fact, every factor we identified, when considered in isolation, was inappropriate as a proxy. In short, no single defining factor can be used as a proxy for disability costs. Ultimately, what this highlights is an urgent need for further work to better establish the extent of disabled people's conversion costs and gain a greater understanding of what drives them and how they are most effectively measured.

Implications for the Personal Independence Payment

This is all the more urgent given the imminent reform of DLA. Our findings have significant implications for the future measurement of DLA's replacement, the PIP, which need to be explored before reform is implemented. The unique characteristic of DLA is that it considers the full range of disability costs and therefore is not ring-fenced — it can be spent on anything a disabled person wants or needs to help them live their lives. However, these data show that currently DLA corresponds more closely to the number of hours of support a person needs per week rather than the costs they incur. In light of this, it would seem a reform of the way DLA is awarded is necessary to more accurately reflect cost rather than support needs.

However, the proposed PIP, using an assessment of the functional impact of a condition or impairment as a single proxy for cost, risks further inaccuracy and ill-targeted payments. The government states its aim is to focus the PIP on 'those disabled people who face the greatest challenges to leading independent lives'[142] but does not specify whether this challenge is financial, or based on the complexity of their impairment or condition. Given that the PIP will 'only be available to people with a long-term health condition or impairment' and will be reassessed 'if an individual's condition has deteriorated or improved'[143] this suggests there will be an almost exclusive focus on the complexity of a person's disability, rather than on broader factors which our findings prove can significantly affect costs.

So, the 'high cost' disabled person with the characteristics listed in chapter 2 might not experience the same impact as a result of their impairments as other disabled people according to the PIP test. Indeed, receiving JSA would suggest this person experienced a lower impact, as they are ineligible for disability-related out-of-work benefits and considered 'fit to work'. But this person would have higher costs. In the PIP regime, however, none of the factors listed above (unsuitable housing, no access to transport, and so on) would be considered (even thought they make a significant difference to costs), and this person, with lower functional impact, may well receive lower levels of DLA than many lower spending counterparts with higher functional impact.

Similarly, if a person on the PIP should lose their job, or their partner dies, or they are moved to less suitable accommodation, their disability-related costs are bound to increase. Yet their PIP will not be reassessed and adjusted to reflect these changes. The entire premise of the PIP — to compensate those with the greatest disability-related costs — will have been undermined.

To accurately target the PIP, therefore, an assessment would have to take into account several different variables, including the impact of their condition or impairment but also housing and employment factors, informal care networks, and so on, if it hoped to establish disability costs (in their widest sense) accurately and compensate for them accordingly. This could prove administratively complex and costly.

An alternative approach could be to redesign the PIP to compensate people for one type of cost — making its assessment more straightforward by default. For example, if the PIP was designed to compensate for transport costs, we could use mode of transport as a single assessment measure as our data show there is a direct relationship between the type of transport used and a person's transport costs. But this would not be an appropriate use of the PIP — disabled people are not defined by the type of transport they use, nor is it the main source of costs in their lives.

Yet the same could be said about the functional impact of an impairment or condition. Need (measured in hours of support per week needed) is not the factor most strongly correlated to total disability costs, or indeed, not most strongly correlated to all medical and care type costs. This would suggest that imminent reforms to the DLA assessment process, which is based on functional ability, will render its successor (PIP) less accurate as a reflection of costs than it is at the moment. Our data show that variation in costs actually grew as needs increased, with those needing 28 hours or more care having the widest variation in reported costs. Therefore if the PIP becomes targeted at those with highest need, the chances of it being inaccurately matched to disability costs also increases. This makes the PIP less effective as a tool to help compensation for disability-related costs.

Moreover, targeting the PIP in this way brings with it a real danger of turning it into a medical or social care benefit by implication—as those experiencing the greatest functional impact of their condition or impairment are likely to prioritise spending on their medical or personal care. This will undermine the unique character of DLA—that as a non-ring-fenced benefit it is spent in hundreds of different ways to suit the needs and aspirations of the person receiving it. the PIP would be awarded while taking little account of disabled people who cope with a plethora of social, environmental and practical factors which increase their cost of living, and would be implicitly intended to cover only those costs generated by impairment or condition.

This then begs a wider question as to whether the current reforms planned for DLA are destined to turn the benefit into just another health and social care allowance, which would then duplicate social care funding and an existing (and very effective) policy innovation: individual budgets. The government has stated that, in implementing the PIP, it 'will consider how the benefit interacts with other forms of support, for example adult social care, and explore whether it is possible to share information at the assessment stage and eliminate areas of overlap'.[144] This suggests that it too has recognised

the risk of duplication between a welfare benefit focused on impairment or condition and social care funding.

We are not recommending, however, that DLA should be exempt from reform—on the contrary, careful reconfiguration could improve the way in which it is targeted and distributed, and improve its efficacy in mitigating disability poverty, and our data shed light on some of its weaknesses:

My DLA no longer covers the costs of my disability, although it used to when I first claimed 10 years ago. This is because the impairment-related costs have increased faster that the rate of DLA—for example petrol, gas and electricity; but also I'm needing additional support—for example chiropody, which I didn't need 10 years ago and do now but can't get on the NHS.

Survey respondent

However, the current proposed reforms have two weaknesses. The first is that this approach is based on the flawed assumption that the functional impact of disability is the predominant driver of disability cost and can therefore be used as a simple proxy. We know this is inaccurate and also risks changing the very nature of the DLA from a benefit premised on the social model of disability into a health or social care allowance. The second is that the approach attempts to isolate one single factor (in this case functional impact, but it could in fact be anything—age, housing status, car ownership) as a proxy for cost.[145] We know this will generate inaccurate and narrow results.

Ultimately, it is not our goal nor is there scope to provide detailed, costed recommendations on how DLA could be reconfigured to address these two weaknesses. We are under no illusions that our study has produced the 'right' answer to how DLA should be reformed. However, if the PIP is to be used as an effective tool to combat disability costs, its assessment regime must have the following characteristics:

- be multi-dimensional and personalised
- have a user-friendly and co-produced assessment process
- be adaptable to employment status.

Multi-dimensional and personalised

A disabled person can face any number of social, practical and environmental obstacles which increase their daily living costs. It stands to reason, therefore, that there are a wide range of disability cost types and that these costs will be driven by different factors.

A single proxy of measure — one centred on the impact of impairment or condition, for example — will only capture a single type of cost and so will always produce only part of an otherwise highly complex picture. A benefit designed to help meet many — not just one — types of costs must, therefore, adopt a more holistic and multi-dimensional approach in order to take into account a range of factors which can increase costs — some of which are identified in chapter 2. The assessment would need to consider, for example, a disabled person's employment status; their accommodation, its style and suitability; their access to transport and what type; and the informal networks of support they may rely on. This is not a simple procedure — being unemployed increases some costs, being employed increases others. More work is needed to better understand the relative weight of these factors.

A user-friendly and co-produced assessment process

The current DLA assessment process has been described by some as a 'bureaucratic struggle'.[146] Indeed, it is highly complex and places a significant administrative burden on the claimant. Its complexity is such that it may even affect accuracy of decision making: in April 2010, the Work and Pensions Select Committee noted that quality of initial decision-making procedures for DLA (and Attendance Allowance) was 'cause for concern' and expressed anxiety that current assessment forms were misunderstood by many claimants.[147] Furthermore, while around half of all claims are refused, there is a high rate of appeals that result in decisions being overturned in favour of the appellant.[148] According to Wollenberg, in 2008/09 51 per cent of appeals were overturned, and 43 per cent were overturned in cases reaching an appeal hearing.[149] This considered, there is a real case for ensuring the future assessment process is more user-friendly so as to reduce the burden placed on claimants, minimise potential misunderstandings, improve accuracy and reduce the number and cost of appeals. How this is best achieved, however, warrants careful consideration — there may be an inherent tension between making the assessment more user-friendly and easy to administer, and making it more accurate and comprehensive (as outlined above).

We do not believe, however, that a single proxy measure like the one proposed by the government for the PIP is necessarily the most user-friendly option, nor do we believe that a more accurate multi-dimensional measure will automatically be more complex. In fact, there is a strong case to suggest that a multi-dimensional, holistic measure will actually be more easily understood, as it will be more reflective of the reality of people's lives. When people talk about their needs, aspirations and outcomes, they do not articulate these in neat service or departmental silos. People will discuss their health, social care, housing, transport and family needs as one seamless package, in a way that makes sense to them, and an assessment procedure based on this will be more intuitively simple than asking people to focus on one element of their lives (the functional impact of their disability) in isolation from other relevant issues. Such an approach has been successfully applied to social care, where personalised, multi-agency, outcomes-based assessments are regularly used with vulnerable and disabled people to great effect. The key to the success of these assessments is co-production — having an interactive assessment where the applicant informs and engages with the eligibility process. Co-production would therefore improve the accuracy of the assessment regime in a way that is compatible with people's understanding of their lives, and also improve people's engagement with (and potentially acceptance of) the assessment's results.

Adaptable to employment status

DLA claimants can claim and work simultaneously. Yet, as the government acknowledges, it is widely perceived to be an out-of-work benefit. However, the government also suggests that 'receiving it [DLA] appears to reduce the likelihood of being in employment, even after allowing for the impact of health conditions or impairments'.[150] This may be so, but such a statement encapsulates the government's narrow focus on people's conditions and impairments: does DLA reduce the likelihood of being in work after allowing for other factors which might influence ability to work such as practical, psychological or social barriers? The government statement implies that the PIP, as DLA's improved replacement, will not disincentivise work but rather 'help many more disabled people to work and enjoy all the advantages that an active working life can bring'.[151] However, there is a very significant difference between 'not disincentivise work' and 'incentivise work'. The government must guard against being tempted to reduce eligibility for the PIP among those who are unemployed, as a tool to incentivise work.

Our findings demonstrate that disability costs are strongly influenced by employment status. On the one hand, unemployed disabled people have high costs in some areas, including public transport and utilities, through dint of being unemployed and at home:

> *I have higher utility bills than others, because I am home all the time; if I was working I would not have to heat the house in the day, or boil the kettle half a dozen times.*
>
> Survey respondent

In fact, in some instances, employment status and receipt of benefits was shown to be a greater driver of disability costs than medical need (as determined by levels of care required). That disabled JSA claimants were found to incur higher disability costs than those receiving 28 hours of care or more a week again underlines the inadequacy of measuring disability costs by care need alone. It is also significant for welfare-to-work policies as it suggests that helping disabled people into employment may in turn help reduce disability costs.

On the other hand, employed disabled people spend more on average overall than unemployed disabled people, driven by high spending on home adaptations, childcare and help with household tasks. In such cases, receipt of DLA might be what keeps people in employment—by allowing them to pay for childcare or for help at home while they work or after they return from work:

> *I use my DLA to pay for my ironing and buy gifts for my family who help with cooking and cleaning and doing tasks when I am too tired or my limbs are not fully functioning, usually at the end of the day having been at work all day!!!*
>
> Survey respondent

Thus DLA is needed and used by employed and unemployed disabled people in different ways, and cannot be reserved exclusively for one group or the other. The PIP should serve to help disabled people in work meet additional costs like therapy or childcare, while enabling those looking for work meet vital expenses such as transport and heating.

Defining and articulating the purpose of the Personal Independence Payment

Our findings highlight a broader and more fundamental question that must be addressed before DLA is replaced by a new benefit and assessment system: what is DLA for?

We have seen that an individual's spending can increase according to the resources they have available. For example, claimants across all three DLA groups had similar patterns of spending on 'necessity' purchases such as utilities, food and household goods, while those receiving the higher rate spent more on purchases like holidays and social activities. This trend is hardly surprising; indeed, it is a basic economic fact that spending is constrained by disposable income (else we accrue significant amounts of debt). Nonetheless, little remains known about the extent to which DLA meets disabled people's needs:

> *Because I have no spare cash I no longer have a social life as I cannot afford to pay my way.*
>
> Survey respondent

> *If I had more money I would go out more, socialise, which I hardly do now due to costs. I would have some holidays and nice new clothes instead of second hand all the time.*
>
> Survey respondent

> *When I don't have enough money to pay for things I really need I have to do without and limit the quality of my life. I'm not talking about luxury items but things that would make the quality of my life the same as the average person.*
>
> Survey respondent

The question is, should the PIP meet 'non-essential' costs or should it be set at a level which promotes independence and social inclusion?

Some might suggest that holidays and leisure are unnecessary luxuries, and should not be funded by the PIP, while others would stress that participating in social activities is paramount to building social capital and remaining socially included and mentally stimulated:[152]

> *DLA is not intended to merely ensure pared-down no-frills bread-and-water survival of the body from one day to the next. It is supposed to help disabled people be able to participate in 'normal life' which should include [being able to afford] long-term necessities such as secure shelter, warmth, healthy food including at least one hot meal a day (I have survived on sandwiches for weeks on end due to benefit screwups but it's hardly advisable!), access to public services like parks and libraries, and social contact with other people.*
>
> Survey respondent

These fundamental questions ought to be addressed before significant changes are made by introducing a new benefit. There is a risk that a new assessment, based on the impact of a condition or impairment, will simply identify social care need; while the PIP is meant to be a contribution towards costs, it is not meant to subsidise or replace social care funding. Moreover, this would also imply that the greater the impact of a person's condition or impairment the greater the benefit they should receive, like social care funding, reserving funds for those with the highest need. Yet the PIP's stated aim is to help people lead 'independent lives', which would surely imply helping those experiencing high cost barriers to independence (but not necessarily impairment or condition-related barriers) to overcome them.

Longer term implications for disability poverty

Although our findings are important in light of DLA reform, there are also implications for the wider question of disability poverty. There are two fundamental points raised in this report that we ought to consider. The first is that disability poverty has a dual cause—lower income and higher costs within the disabled population. The second is that disability costs are driven by a variety of factors, as our findings demonstrate. These factors include some we might call internal (such as complexity of condition or impairment, and age), and some we might describe as external (suitability of housing, access to transport, employment status). Although the government is unable to intervene or significantly change internal factors, it is well within the government's capacity to affect the external ones. In this respect, our findings should be seen as welcome news—as many of the drivers of disability costs are external, disability costs can be reduced significantly by innovative policy reform and strategic investment. This, in turn has two benefits: spending on the PIP could be reduced, and, over the longer term, disability poverty could be reduced.

The following section considers four key 'external' factors that drive disability costs, are conducive to government intervention and could drive down disability poverty:

- employment status
- accommodation
- transport
- external markets.

Employment status

Although improving employment rates among disabled people will not eradicate disability costs (as there is a disability cost associated with maintaining employment), it would reduce the significant costs associated with being disabled and unemployed, which are more likely to be borne by state benefits. Our findings showed that being unemployed increased several costs, including utilities and transport, with those claiming ESA and IB spending more than those on WTC. Those on JSA had higher costs than those needing 28 hours of care a week or more.

Improving employment rates among disabled people would therefore combat disability poverty in two ways—it can improve income, and reduce disability costs. It would produce real returns for government in the long run: increasing disabled people's employment rate (currently at around 50 per cent) to the national average of 75 per cent would boost the country's GDP by about £13 billion.[153]

As outlined in previous Demos research, adopting a more accurate assessment of work readiness, and a more targeted and personalised approach to welfare-to-work support, is the most effective way of ensuring disabled people find and sustain employment.[154]

That said, the PIP should never be seen as a tool to 'incentivise work'. We are not convinced that the receipt of DLA automatically disincentivises people from working as the Government claims, as there are multiple and complex reasons why people do not work in addition to their condition or impairment, which the Government has not taken into account.[155] The PIP must therefore support people both in and out of work, working alongside a more focused welfare to work strategy.

Accommodation

Housing and accommodation are key drivers of disability costs. Our analysis reveals disabled people living in unsuitable accommodation have higher costs overall, and spend particularly highly on equipment and adaptations, utilities and childcare. Spending decreases directly as suitability of accommodation improves.

Yet it has been estimated that around a quarter of disabled people in need of adapted accommodation are living in unsuitable housing.[156] And although disabled people are twice as likely to live in social housing as non-disabled people,[157] research shows that much of the social housing stock is unsuitable for disabled people and much of the housing that is accessible and purpose built is not allocated to those who really need it because social housing landlords often do not keep a record of such properties, or waiting lists are so long that accessible properties cannot be reserved for disabled people.[158]

There are several ways in which such issues could be addressed without prohibitive cost. Ensuring new-build homes meet the Lifetime Homes Standard is a significant step in the right direction, but as fewer new homes are now being built by government, this is having a limited impact. With this in mind, it is vital that private sector home builders adopt the standard. Though this has been integrated into the Code for Sustainable Homes, which should be fully adopted by the private sector by 2013, recent guidance suggests this might be delayed for the most energy efficient homes.[159] Given the significant electricity and heating costs reported by disabled people, outlined in the previous section, this would seem particularly short-sighted. Others have warned that unless effective legislation is put in place to enforce compliance, this is unlikely to generate real change in any case.[160] The provision of suitable housing is vitally important as a means to reduce disability costs over the long term, and to ensure there is appropriate housing for an ageing population. The wider adoption and enforcement of the Lifetime Homes Standard ought therefore to be considered anew.

Finally, the government might want to consider how to encourage the accumulation of assets and home ownership among disabled people. Our survey found that people owning their own homes were most likely to think their house was suitable to their needs, second only to residential care home residents. Those in shared ownership had the lowest reported disability costs, and, at the other end of the spectrum, private renters had the highest. It stands to reason that someone with their own home or in shared ownership is able to adapt it to meet their needs, safe in the knowledge they own the property and are not investing in a landlord's asset, which they may have to move out of.

Ultimately, adopting policy recommendations like those advocated by Wind-Cowie, and Wood and Grant, would allow disabled people who are receiving Housing Benefit to capitalise their benefit, taking a lump sum so as to better enable them to purchase, or part own, their own home.[161] This would not only help provide many disabled people with stable and more suitable accommodation, but over the long term would result in significant savings for government through reduced benefit payments. Efforts to increase disabled homeownership aside, disabled people's disproportionate dependence on social housing could in fact present something of an opportunity for government to reduce disability costs and barriers to participation by improving the current stock of social housing accommodation. Even the simple, low cost step of ensuring existing accessible and suitable social housing is monitored, registered and allocated to those who need it could make a real difference to disabled people:

I need a toilet in the upstairs bathroom, but the housing association says no, we have to go through social services or be re-homed. We don't want to be re-homed as this is our home, we are a family and we have children, so I manage to use the stairs at night time, to the downstairs toilet. One day we would like to afford a plumber to put in a toilet, and a shower, but for now I put up with it because my husband helps me.

Survey respondent

I receive very little support from the local authority, even though they moved me as a priority due to disability and being flat-bound—they moved me into a shared ownership terraced house with bedroom and toilet upstairs, no toilet downstairs, no access for my wheelchair in the house and no access to the kitchen or garden.

Survey respondent

Transport

Those relying on public transport have significantly higher costs than those with cars, because of their spending not only on public transport, but also on private transport when public transport is not suitable or accessible:

> *I don't go out as much as I'd like because I can't afford the transport costs via taxi to go where I want. Travelling around London as a disabled person costs a fortune.*
>
> Survey respondent

> *I pay for taxis when taking bags on the bus/tube would be too difficult or when the route has too many changes or when I don't know how far it is from the nearest bus/tube to where I need to go.*
>
> Survey respondent

Since 2006 transport service providers have been required to make reasonable adjustments to ensure they offer an accessible service to disabled people.[162] However, studies show that because there is inaccessible transport large swathes of the disabled population are unable to get the healthcare they need, attend hospital appointments or see family and friends as often as they would like.[163] Inaccessible transport also has a detrimental effect on employment and economic security: 23 per cent of disabled people have had to refuse a job offer because of inaccessible transport; a further 23 per cent have had to decline a job interview; and 48 per cent are reported to have restricted their choice of jobs for the same reason.[164] A study in 2009 reported that 58 per cent of disabled people found information about transport was inaccessible, 83 per cent encountered negative or unhelpful attitudes from transport staff, 58 per cent found the station or terminal inaccessible, and 64 per cent found the mode of transport inaccessible.[165] Clearly, therefore, requiring transport operators to make 'reasonable adjustments' without rigorous enforcement seems not to have translated into real improvements to accessibility.

Investing in accessible transport infrastructure would, on the other hand, require less enforcement and reliance on transport companies and individual staff to help disabled people. Reasonable adjustments to make up for inaccessible infrastructure would be less necessary. This would help reduce the need for disabled people to rely on costly private transport, lead to greater social inclusion and ensure disabled people could access the healthcare they require when and where they need it. It would also enable many to access job opportunities and sustain employment, which, as shown by the data, would also lead to lower disability costs, and result in significant financial gains for government in the form of higher tax and National Insurance contributions.

Capital investment in station improvements and replacement of rolling stock (trains, buses, trams) is already under way. Ensuring these forms of transport are accessible for disabled people, as and when they are replaced, and as improvement work is being carried out, is a simple step requiring forethought and strategic planning rather than significant amounts of additional investment.

However, it is simply not feasible for many disabled people to use public transport (even accessible public transport). Car ownership, on the other hand, can be an important tool for greater independence and is associated with lower disability costs overall (petrol costs aside). Although the Motability Scheme has its limitations, it is the only scheme to give disabled people access to an adapted car when they need it. Eligibility for the scheme is currently based on having the high mobility component of DLA, but the government might consider how to expand this with the introduction of the PIP—for example, basing eligibility on the higher rates of both of its new components (mobility and daily living), or even extending it to all PIP recipients:

The Motability Scheme is fantastic in terms of providing the vehicle, insurance, tax, servicing etc. Equally the arrangements made for collection/delivery re servicing. Therefore, without receiving my DLA mobility component, I could not cope financially, sourcing relevant vehicles/garages etc.

Survey respondent

External markets

Specialist equipment, clothing, food, and non-prescription medicine and medical products are significant sources of spending for disabled people. Many of these products are not free from the NHS, so must be purchased privately. Several of our survey respondents felt they were being 'ripped off' because of lack of competition and choice, with everyday products labelled 'disabled' being far more costly than mainstream products:

I think certain items are expensive for a disabled person — almost as if the market is sewn up and there is not much competition — and many things would make life a little easier, but I have to go without.

Survey respondent

Items I need because I am disabled are disproportionately expensive. You get the feeling the suppliers know you will need these items and charge in many cases a very high premium. They deny it but I consider that they are milking us.

Survey respondent

Stimulating markets for goods and services by encouraging larger numbers of providers could improve competition, choice and more affordable products. This would have a dual benefit of reducing the costs of disability while stimulating a relatively small industry. A key step would be to extend the Equalities Act 2010 (which replaced the Disability Discrimination Act 1995 in October 2010)[166] to cover manufactured goods. This would ensure that mainstream products which had been slightly adapted for the disability market could not be significantly more expensive, as over-pricing goods would be seen, under the auspices of the act, as restricting accessibility to that good.

The government should also consider how it might help stimulate the supply of goods and services through regeneration and business and enterprise strategies — plans which are already in place to help stimulate the economy, and which often focus on green industries, technology and other well-known growth areas. It may well be that the disability product and service market is another untapped area of economic growth, given the demand for more affordable disability-related products, which the government has not yet considered.

Conclusions

The findings of our report have significant implications for the reform of introduction of the Personal Independence Payment to replace DLA. The current proposals include an assessment to award the PIP according to the functional impact of a condition or impairment — a move which risks targeting the PIP incorrectly — helping those with the greatest health or care need, not necessarily those with the highest costs. Although this is a valid objective, it is not appropriate for the PIP. DLA and its successor are designed to help disabled people with their disability costs, and so naturally, should be targeted at those with higher costs. This can only be achieved by using a more accurate measure of disability cost. As there is no single proxy for cost, this inevitably means the adoption a multi-dimensional assessment, which will need to be balanced carefully with administrative complexity. We feel lessons could be learned from social care assessments in this respect.

However, our findings have longer term implications. They pave the way for a potential reduction in the PIP and more sustainable solutions to reducing disability poverty. The government's current approach to reducing disability poverty is to focus on increasing employment among disabled people, to both reduce benefits dependency and increase income.[167] But we must bear in mind that disability poverty is a dual phenomenon, driven by lower incomes and higher costs. In the current economic climate, where jobs are harder to come by, increasing disabled people's incomes through greater employment will be a challenge. Moreover, it would do nothing to improve the situation of those who cannot work. It may be, therefore, that the government could reduce disability poverty more effectively, and for a larger number of people, by reducing disability costs rather than focusing exclusively on increasing income. The findings of our report show that this is not as difficult as it might seem. Disability costs are not solely generated by factors the government cannot change — such as impairment or condition, or age. They are driven by a range of environmental factors, which with the right intervention could reduce disability costs significantly. Such interventions do not necessarily require large sums of capital investment — rather strategic decisions being taken as part of existing capital investment and regeneration strategies.

Notes

1 N Smith et al, *Disabled People's Cost of Living: more than you would think,* York: Joseph Rowntree Foundation, 2004; E Gore and G Parckar, *Disability and the Downturn,* London: Leonard Cheshire Disability, 2009.

2 C Wood and E Grant, *Destination Unknown,* London: Demos, 2010.

3 A Sen, *The Idea of Justice,* London: Allen Lane, 2009.

4 Ibid.

5 Ibid.

6 Gore, E and Parckar, G, *Disability and the Downturn*, London: Leonard Cheshire Disability, 2009.

7 Smith et al, *Disabled People's Cost of Living.*

8 Ibid.

9 F Field, *The Foundation Years: Preventing poor children becoming poor adults,* London: HM Government, 2010.

10 Dept for Work and Pensions, *Disability Living Allowance Reform,* London: HM Government, 2010.

11 R Ramesh and P Butler, 'Budget 2010 losers: women, disabled and families bear the brunt', *Guardian,* 23 Jun 2010, www.guardian.co.uk/politics/2010/jun/23/budget-2010-losers-women-disabled (accessed Aug 2010).

12 A Corden et al, *The Impact of Disability Living Allowance and Attendance Allowance: Findings from exploratory qualitative research,* DWP Research Report 649, London: Dept for Work and Pensions, 2010.

13 Ibid.

14 'Welfare budget faces further £7bn in cuts', Independent, 20 Oct 2010, www.independent.co.uk/news/uk/politics/welfare-budget-faces-further-7bn-in-cuts-2111788.html (accessed Dec 2010).

15 Wood and Grant, *Destination Unknown.*

16 Dept for Work and Pensions, *Disability Living Allowance Reform.*

17 HM Treasury, *Budget 2010 Policy Costings,* London: HM Treasury and HM Revenue & Customs, 2010.

18 Dept for Work and Pensions, *Disability Living Allowance Reform.*

19 Ibid.

20 Ibid.

21 Ibid.

22 S Evans, Disability, *Skills and Work: Raising our ambitions,* London: Social Market Foundation, 2007.

23 Wood and Grant, *Destination Unknown.*

24 In a recent Demos report, we outlined how the Government's strategy for incentivising work was flawed as inadequate welfare to work support was provided.

25 Smith et al, *Disabled People's Cost of Living.*

26 Ibid.

27 Ibid.

28 G Parckar, *Disability Poverty in the UK,* London: Leonard Cheshire Disability, 2008.

29 HBAI estimates use a standard of living proxy, which adjusts household income to household size and composition.

30 M Miller, *Hansard,* 4 Oct 2010, col 1342W, www.publications.parliament.uk/pa/cm201011/cmhansrd/cm101004/text/101004w0003.htm#1010047000825 (accessed Oct 2010).

31 Gore and Parckar, *Disability and the Downturn.*

32 Wood and Grant, *Destination Unknown.*

33 Gore and Parckar, *Disability and the Downturn.*

34 W Kuklys, *Amartya Sen's Capability Approach: Theoretical insights and empirical applications,* New York: Springer-Verlag, 2005.

35 Sen, *The Idea of Justice.*

36 Gore and Parckar, *Disability and the Downturn.*

37 Smith et al, *Disabled People's Cost of Living.*

38 Sen, *The Idea of Justice.*

39 P Large, 'Paying for the additional costs of disability' in G Dalley (ed), *Disability and social policy,* London: Policy Studies Institute, 1991.

40 Ibid.

41 M Tibble, *Review of Existing Research on the Extra Costs of Disability,* London: Department for Work and Pensions, 2005.

42 Corden et al, *The Impact of Disability Living Allowance and Attendance Allowance;* Mobilityscooter.co.uk, 'Mobility scooters', www.mobilityscooter.co.uk/ (accessed Nov 2010); Mobilityscooter.co.uk, 'Electric wheelchairs', www.mobilityscooter.co.uk/electric-wheelchairs/ (accessed Nov 2010).

43 Corden et al, *The Impact of Disability Living Allowance and Attendance Allowance.*

44 Ibid.

45 Large, 'Paying for the additional costs of disability'.

46 M Hyman, quoted in *Large,* 'Paying for the additional costs of disability'.

47 UN General Assembly Resolution (48/96, 20 Dec 2010, 8.1) cited in *Indecon Indecon Report on the Cost of Disability, Dublin,* Indecon 2004.

48 Wood and Grant, *Destination Unknown.*

49 Smith et al, *Disabled People's Cost of Living.*

50 Smith et al's 'Consensual Budget Standards' method employed disabled people to identify needs of and costs incurred by various types of disabled households. For more information see Smith et al, *Disabled People's Cost of Living.*

51 Smith et al, *Disabled People's Cost of Living.*

52 Ibid.

53 Ibid.

54 Hyman, quoted in *Large,* 'Paying for the additional costs of disability'.

55 Corden et al, *The Impact of Disability Living Allowance and Attendance Allowance.*

56 D Campbell, 'Millions "lending" prescription drugs, research reveals', *Guardian,* 30 May 2010, www.guardian.co.uk/uk/2010/may/30/millions-lend-prescription-drugs-survey (accessed Nov 2010).

57 HM Treasury, *Spending Review 2010,* London: The Stationery Office, 2010.

58 A Begg, quoted in *I Macrae,* 'Begg hits out at government benefit cuts', Jul 2010, www.disabilitynow.org.uk/latest-news2/begg-hits-out-at-government-benefit-cuts (accessed Jul 2010).

59 D Stapleton, A Protik and C Stone, *Review of International Evidence on the Cost of Disability,* Research Report 542, London: Dept for Work and Pensions, 2008.

60 AL Chappell, 'Still out in the cold: people with learning difficulties and the social model of disability' in T Shakespeare (ed), *The Disability Reader: Social science perspectives,* London: Cassell, 1998.

61 Corden et al, *The Impact of Disability Living Allowance and Attendance Allowance.*

62 Ibid.

63 Ibid.

64 Ibid.

65 Ramesh and Butler, 'Budget 2010 losers: women, disabled and families bear the brunt'.

66 MS Society, *Claiming Disability Living Allowance,* July 2010, London: Multiple Sclerosis Society, 2010.

67 Ibid.

68 Ibid.

69 Ibid.

70 C Beatty, S Fothergill and D Platts-Fowler, *DLA Claimants—A New Assessment: The characteristics and aspirations of the Incapacity Benefit claimants who receive Disability Living Allowance,* Research Report 585, London: Dept for Work and Pensions, 2009.

71 Ibid.

72 Ramesh and Butler, 'Budget 2010 losers: women, disabled and families bear the brunt'.

73 HM Treasury, *Spending Review 2010.*

74 Dept for Work and Pensions, *Disability Living Allowance Reform.*

75 Ibid.

76 Dept for Work and Pensions, 'Disability Living Allowance—previous announcements', www.dwp.gov.uk/adviser/updates/spending-review-2010/#dla (accessed Nov 2010).

77 HM Treasury, *Budget 2010 Policy Costings.*

78 Dept for Work and Pensions, *Disability Living Allowance Reform.*

79 Ibid.

80 A Thomas and R Griffiths, *Disability Living Allowance and Work: Exploratory research and evidence review,* 2010, DWP Research Report 648, London: Dept for Work and Pensions, 2010.

81 A Corden et al, *The Impact of Disability Living Allowance and Attendance Allowance.*

82 DWP, *Carer's Allowance,* London: Dept for Work and Pensions, 2009.

83 In line with the median earned income (after tax and National Insurance have been deducted) for working families; see H Mulholland, 'George Osborne to cap welfare payments', *Guardian,* 4 Oct 2010, www.guardian.co.uk/politics/2010/oct/04/george-osborne-cap-welfare-payments (accessed Oct 2010).

84 H Cooper, 'Osborne axes child benefit and confirms welfare cap', *Community Care,* 4 Oct 2010, www.communitycare.co.uk/Articles/2010/10/04/115485/Osborne-axes-child-benefit-and-confirms-welfare-cap.htm (accessed Oct 2010).

85 A Zaidi and T Burchardt, *Comparing Incomes When Needs Differ: Equivalisation for the extra costs of disability in the UK,* Paper 64, London: Centre for Analysis of Social Exclusion, 2003.

86 Smith et al, *Disabled People's Cost of Living;* Tibble, *Review of Existing Research on the Extra Costs of Disability.*

87 Tibble, *Review of Existing Research on the Extra Costs of Disability.*

88 Ibid.

89 Tibble, *Review of Existing Research on the Extra Costs of Disability*.

90 Hyman, quoted in *Large,* 'Paying for the additional costs of disability'.

91 Ibid.

92 Smith et al, *Disabled People's Cost of Living*.

93 Ibid.

94 C Wood, *Personal Best,* London: Demos 2010.

95 Large, 'Paying for the additional costs of disability'.

96 Ibid.

97 Ibid.

98 Ibid; P Thompson with M Lavery and J Curtice, *Short Changed by Disability,* London: Disablement Income Group, 1990.

99 Thompson et al, *Short Changed by Disability*.

100 Hyman, quoted in Large, 'Paying for the additional costs of disability'; Thompson et al, *Short Changed by Disability*.

101 Hyman, quoted in Large, 'Paying for the additional costs of disability'.

102 Tibble, *Review of Existing Research on the Extra Costs of Disability*.

103 Smith et al, *Disabled People's Cost of Living*.

104 Ibid.

105 Tibble, *Review of Existing Research on the Extra Costs of Disability*.

106 Ibid.

107 Smith et al, *Disabled People's Cost of Living*.

108 Ibid.

109 Tibble, *Review of Existing Research on the Extra Costs of Disability*.

110 Ibid.

111 Ibid.

112 Ibid.

113 Ibid.

114 Ibid.

115 Ibid.

116 Parckar, *Disability Poverty in the UK;* A Matthews and P Truscott, *Disability, Household Income and Expenditure: A follow-up survey of disabled adults in the Family Expenditure Survey,* Dept of Social Security Research Report 2, London: HMSO, 1990.

117 See Parckar, *Disability Poverty in the UK*.

118 Ibid.

119 Ibid.

120 Ibid.

121 Ibid.

122 Tibble, *Review of Existing Research on the Extra Costs of Disability*.

123 Smith et al, *Disabled People's Cost of Living*.

124 Tibble, *Review of Existing Research on the Extra Costs of Disability*.

125 Smith et al, *Disabled People's Cost of Living*.

126 Indecon, *Indecon Report on the Cost of Disability*.

127 Smith et al, *Disabled People's Cost of Living*.

128 Parckar, *Disability Poverty in the UK*.

129 Tibble, *Review of Existing Research on the Extra Costs of Disability*.

130 Corden et al, *The Impact of Disability Living Allowance and Attendance Allowance*.

131 Parckar, *Disability Poverty in the UK*.

132 Corden et al, *The Impact of Disability Living Allowance and Attendance Allowance*.

133 N Watt, 'Frank Field to lead independent review into poverty in Britain', *Guardian,* 5 Jun 2010, www.guardian.co.uk/politics/2010/jun/05/frank-field-review-poverty-cameron (accessed Nov 2010).

134 Dept for Work and Pensions, *Disability Living Allowance Reform*.

135 Smith et al, *Disabled People's Cost of Living*.

136 House of Commons Work and Pensions Committee, 'Decision making and appeals in the benefits system', House of Commons, 9 Feb 2010, www.publications.parliament.uk/pa/cm200910/cmselect/cmworpen/313/31306.htm (accessed Nov 2010).

137 Dept for Work and Pensions, *Disability Living Allowance Reform*.

138 The survey used the following spending bands: £0–50, £50–100, £100–250, £250–500 and £500+. Each band was given a point from 1 to 5 and we were able to calculate total costs aggregated across all 19 cost categories by summing these points.

139 Dept for Work and Pensions, *Disability Living Allowance Reform*.

140 Gore and Parckar, *Disability and the Downturn;* L Kober, *In the Balance: Disabled people's experiences of debt,* London: Leonard Cheshire Disability, 2005.

141 Corden et al, *The Impact of Disability Living Allowance and Attendance Allowance*.

142 Dept for Work and Pensions, *Disability Living Allowance Reform*.

143 Ibid.

144 Ibid.

145 The inclusion of the presence or absence of aids or adaptations remains uncertain.

146 A Wollenberg, 'Disability allowance exists for a reason', *Guardian,* 23 Jun 2010, www.guardian.co.uk/commentisfree/2010/jun/23/disability-allowance-exists-reason (accessed Nov 2010).

147 Work and Pensions Select Committee, *Decision Making and Appeals in the Benefits System: Government Response to the Committee's Second Report of Session 2009–10,* London: The Stationery Office: 2010.

148 Wollenberg, 'Disability allowance exists for a reason'.

149 Ibid.

150 Dept for Work and Pensions, *Disability Living Allowance Reform.*

151 Ibid.

152 Furthermore, it may be worth considering the possibility that participating in social activities and building social capital may well help build networks of informal support, which, as our data show, many disabled people are dependent on regardless of whether they receive formal support.

153 Evans, *Disability, Skills and Work.*

154 Wood and Grant, *Destination Unknown.*

155 Ibid.

156 C Greenhalgh and E Gore, *Disability Review 2009,* London: Leonard Cheshire Disability, 2009.

157 Ibid; T Lithgow, 'Disabled "failed" by social housing', *Inside Housing,* 27 Jan 2005, www.insidehousing.co.uk/disabled-'failed-by-social-housing/1446237.article (accessed Sep 2010).

158 Lithgow, 'Disabled "failed" by social housing'.

159 'Summary of changes to the Code for Sustainable Homes, technical guidance, 2010', London: Dept for Communities and Local Government, 2010.

160 E Gore and G Parckar, *Rights and Reality: Disabled people's experience of accessing goods and services,* London: Leonard Cheshire Disability, 2010.

161 M Wind-Cowie, *Recapitalising the Poor: Why property is not theft,* London: Demos, 2009; Wood and Grant, *Destination Unknown.*

162 As per the Disability Discrimination Act 1995.

163 Greenhalgh and Gore, *Disability Review 2009;* Gore and Parckar, *Rights and Reality;* R McQuigg, *Mind the Gap,* London: Leonard Cheshire Disability, 2008.

164 Gore and Parckar, *Rights and Reality.*

165 Greenhalgh and Gore, *Disability Review 2009.*

166 Office for Disability Issues, 'Equality Act 2010 and the Disability Discrimination Act 1995', www.officefordisability.gov.uk/disabled-people-and-legislation/equality-act-2010-and-dda-1995.php (accessed December 2010).

167 In a recent Demos report we outlined how the government's strategy for incentivising work was flawed in that inadequate welfare to work support was provided. See Wood and Grant, *Destination Unknown.*

References

'Welfare budget faces further £7bn in cuts', *Independent,* 20 Oct 2010, www.independent.co.uk/news/uk/politics/welfare-budget-faces-further-7bn-in-cuts-2111788.html (accessed December 2010).

Beatty, C, Fothergill, S and Platts-Fowler, D, *DLA Claimants—A New Assessment: The characteristics and aspirations of the Incapacity Benefit claimants who receive Disability Living Allowance,* Research Report 585, London: Dept for Work and Pensions, 2009.

Begg, A, quoted in I Macrae, 'Begg hits out at government benefit cuts', Jul 2010, www.disabilitynow.org.uk/latest-news2/begg-hits-out-at-government-benefit-cuts (accessed Jul 2010).

Campbell, D, 'Millions "lending" prescription drugs, research reveals', *Guardian,* 30 May 2010, www.guardian.co.uk/uk/2010/may/30/millions-lend-prescription-drugs-survey (accessed Nov 2010).

Chappell, AL, 'Still out in the cold: people with learning difficulties and the social model of disability' in T Shakespeare (ed), *The Disability Reader: Social science perspectives,* London: Cassell, 1998.

Cooper, H, 'Osborne axes child benefit and confirms welfare cap', *Community Care,* 4 Oct 2010, www.communitycare.co.uk/Articles/2010/10/04/115485/Osborne-axes-child-benefit-and-confirms-welfare-cap.htm (accessed Oct 2010).

Corden, A et al, *The Impact of Disability Living Allowance and Attendance Allowance: Findings from exploratory qualitative research,* DWP Research Report 649, London: Dept for Work and Pensions, 2010.

Dept for Work and Pensions, *Disability Living Allowance Reform,* London: HM Government, 2010.

Evans, S, Disability, *Skills and Work: Raising our ambitions,* London: Social Market Foundation, 2007.

Field, F, *The Foundation Years: Preventing poor children becoming poor adults,* London: HM Government, 2010).

Gore, E and Parckar, G, *Disability and the Downturn,* London: Leonard Cheshire Disability, 2009.

Gore, E and Parckar, G, *Rights and Reality: Disabled people's experience of accessing goods and services,* London: Leonard Cheshire Disability, 2010.

Greenhalgh, C and Gore, E, *Disability Review 2009,* London: Leonard Cheshire Disability, 2009.

HM Treasury, *Budget 2010 Policy Costings,* London: HM Treasury and HM Revenue & Customs, 2010.

HM Treasury, *Spending Review 2010,* London: The Stationery Office, 2010.

Kuklys, W, *Amartya Sen's Capability Approach: Theoretical insights and empirical applications,* New York: Springer-Verlag, 2005.

Large, P, 'Paying for the additional costs of disability' in G Dalley (ed), *Disability and social policy,* London: Policy Studies Institute, 1991.

Lithgow, T, 'Disabled "failed" by social housing', *Inside Housing,* 27 Jan 2005, www.insidehousing.co.uk/disabled-'failed-by-social-housing/1446237.article (accessed Sep 2010).

Matthews, A and Truscott, P, Disability, *Household Income and Expenditure: A follow-up survey of disabled adults in the Family Expenditure Survey,* Dept of Social Security Research Report 2, London: HMSO, 1990.

McQuigg, R, *Mind the Gap,* London: Leonard Cheshire Disability, 2008.

Mobilityscooter.co.uk, 'Mobility scooters', www.mobilityscooter.co.uk/ (accessed Nov 2010); Mobilityscooter.co.uk, 'Electric wheelchairs', www.mobilityscooter.co.uk/electric-wheelchairs/ (accessed Nov 2010).

MS Society, *Claiming Disability Living Allowance,* July 2010, London: Multiple Sclerosis Society, 2010.

Mulholland, H, 'George Osborne to cap welfare payments', *Guardian,* 4 Oct 2010, www.guardian.co.uk/politics/2010/oct/04/george-osborne-cap-welfare-payments (accessed Oct 2010).

Office for Disability Issues, 'Equality Act 2010 and the Disability Discrimination Act 1995', www.officefordisability.gov.uk/disabled-people-and-legislation/equality-act-2010-and-dda-1995.php (accessed December 2010).

Parckar, G, *Disability Poverty in the UK,* London: Leonard Cheshire Disability, 2008.

Ramesh, R and Butler, P, 'Budget 2010 losers: women, disabled and families bear the brunt', *Guardian,* 23 Jun 2010, www.guardian.co.uk/politics/2010/jun/23/budget-2010-losers-women-disabled (accessed Aug 2010).

Sen, A, *The Idea of Justice,* London: Allen Lane, 2009.

Smith, N et al, *Disabled People's Cost of Living: more than you would think,* York: Joseph Rowntree Foundation, 2004).

Stapleton, D, Protik, A and Stone, C, *Review of International Evidence on the Cost of Disability,* Research Report 542, London: Dept for Work and Pensions, 2008.

Thomas, A and Griffiths, R, *Disability Living Allowance and Work: Exploratory research and evidence review,* 2010, DWP Research Report 648, London: Dept for Work and Pensions, 2010.

Thompson, P with Lavery, M and Curtice, J, *Short Changed by Disability,* London: Disablement Income Group, 1990.

Tibble, M, *Review of Existing Research on the Extra Costs of Disability,* London: Dept for Work and Pensions, 2005).

Watt, N, 'Frank Field to lead independent review into poverty in Britain', *Guardian,* 5 Jun 2010, www.guardian.co.uk/politics/2010/jun/05/frank-field-review-poverty-cameron (accessed Nov 2010).

Wind-Cowie, M, *Recapitalising the Poor: Why property is not theft,* London: Demos, 2009.

Wollenberg, A, 'Disability allowance exists for a reason', *Guardian,* 23 Jun 2010, www.guardian.co.uk/commentisfree/2010/jun/23/disability-allowance-exists-reason (accessed Nov 2010).

Wood, C, *Personal Best,* London: Demos 2010.

Wood, C and Grant, E, *Destination Unknown,* London: Demos, 2010.

Work and Pensions Select Committee, *Decision Making and Appeals in the Benefits System: Government Response to the Committee's Second Report of Session 2009–10,* London: The Stationery Office: 2010.

Zaidi, A and Burchardt, T, *Comparing Incomes When Needs Differ: Equivalisation for the extra costs of disability in the UK,* Paper 64, London: Centre for Analysis of Social Exclusion, 2003.

Demos — Licence to Publish

The work (as defined below) is provided under the terms of this licence ('licence'). The work is protected by copyright and/or other applicable law. Any use of the work other than as authorized under this licence is prohibited. By exercising any rights to the work provided here, you accept and agree to be bound by the terms of this licence. Demos grants you the rights contained here in consideration of your acceptance of such terms and conditions.

1 Definitions

A **'Collective Work'** means a work, such as a periodical issue, anthology or encyclopedia, in which the Work in its entirety in unmodified form, along with a number of other contributions, constituting separate and independent works in themselves, are assembled into a collective whole. A work that constitutes a Collective Work will not be considered a Derivative Work (as defined below) for the purposes of this Licence.

B **'Derivative Work'** means a work based upon the Work or upon the Work and other pre-existing works, such as a musical arrangement, dramatization, fictionalization, motion picture version, sound recording, art reproduction, abridgment, condensation, or any other form in which the Work may be recast, transformed, or adapted, except that a work that constitutes a Collective Work or a translation from English into another language will not be considered a Derivative Work for the purpose of this Licence.

C **'Licensor'** means the individual or entity that offers the Work under the terms of this Licence.

D **'Original Author'** means the individual or entity who created the Work.

E **'Work'** means the copyrightable work of authorship offered under the terms of this Licence.

F **'You'** means an individual or entity exercising rights under this Licence who has not previously violated the terms of this Licence with respect to the Work,or who has received express permission from Demos to exercise rights under this Licence despite a previous violation.

2 Fair Use Rights

Nothing in this licence is intended to reduce, limit, or restrict any rights arising from fair use, first sale or other limitations on the exclusive rights of the copyright owner under copyright law or other applicable laws.

3 Licence Grant

Subject to the terms and conditions of this Licence, Licensor hereby grants You a worldwide, royalty-free, non-exclusive,perpetual (for the duration of the applicable copyright) licence to exercise the rights in the Work as stated below:

A to reproduce the Work, to incorporate the Work into one or more Collective Works, and to reproduce the Work as incorporated in the Collective Works;

B to distribute copies or phonorecords of, display publicly,perform publicly, and perform publicly by means of a digital audio transmission the Work including as incorporated in Collective Works; The above rights may be exercised in all media and formats whether now known or hereafter devised.The above rights include the right to make such modifications as are technically necessary to exercise the rights in other media and formats. All rights not expressly granted by Licensor are hereby reserved.

4 Restrictions

The licence granted in Section 3 above is expressly made subject to and limited by the following restrictions:

A You may distribute,publicly display, publicly perform, or publicly digitally perform the Work only under the terms of this Licence, and You must include a copy of, or the Uniform Resource Identifier for, this Licence with every copy or phonorecord of the Work You distribute, publicly display,publicly perform, or publicly digitally perform.You may not offer or impose any terms on the Work that alter or restrict the terms of this Licence or the recipients' exercise of the rights granted hereunder.You may not sublicence the Work.You must keep intact all notices that refer to this Licence and to the disclaimer of warranties. You may not distribute, publicly display, publicly perform, or publicly digitally perform the Work with any technological measures that control access or use of the Work in a manner inconsistent with the terms of this Licence Agreement.The above applies to the Work as incorporated in a Collective Work, but this does not require the Collective Work apart from the Work itself to be made subject to the terms of this Licence. If You create a Collective Work, upon notice from any Licencor You must, to the extent practicable, remove from the Collective Work any reference to such Licensor or the Original Author, as requested.

B You may not exercise any of the rights granted to You in Section 3 above in any manner that is primarily intended for or directed toward commercial advantage or private monetary compensation.The exchange of the Work for other copyrighted works by means of digital filesharing or otherwise shall not be considered to be intended for or directed toward commercial advantage or private monetary compensation, provided there is no payment of any monetary compensation in connection with the exchange of copyrighted works.

C If you distribute, publicly display, publicly perform, or publicly digitally perform the Work or any Collective Works,You must keep intact all copyright notices for the Work and give the Original Author credit reasonable to the medium or means You are utilizing by conveying the name (or pseudonym if applicable) of the Original Author if supplied; the title of the Work if supplied. Such credit may be implemented in any reasonable manner; provided, however, that in the case of a Collective Work, at a minimum such credit will appear where any other comparable authorship credit appears and in a manner at least as prominent as such other comparable authorship credit.

5 Representations, Warranties and Disclaimer

A By offering the Work for public release under this Licence, Licensor represents and warrants that, to the best of Licensor's knowledge after reasonable inquiry:

i Licensor has secured all rights in the Work necessary to grant the licence rights hereunder and to permit the lawful exercise of the rights granted hereunder without You having any obligation to pay any royalties, compulsory licence fees, residuals or any other payments;

ii The Work does not infringe the copyright, trademark, publicity rights, common law rights or any other right of any third party or constitute defamation, invasion of privacy or other tortious injury to any third party.

B except as expressly stated in this licence or otherwise agreed in writing or required by applicable law,the work is licenced on an 'as is'basis,without warranties of any kind, either express or implied including,without limitation,any warranties regarding the contents or accuracy of the work.

6 Limitation on Liability

Except to the extent required by applicable law, and except for damages arising from liability to a third party resulting from breach of the warranties in section 5, in no event will licensor be liable to you on any legal theory for any special, incidental,consequential, punitive or exemplary damages arising out of this licence or the use of the work, even if licensor has been advised of the possibility of such damages.

7 Termination

A This Licence and the rights granted hereunder will terminate automatically upon any breach by You of the terms of this Licence. Individuals or entities who have received Collective Works from You under this Licence,however, will not have their licences terminated provided such individuals or entities remain in full compliance with those licences. Sections 1, 2, 5, 6, 7, and 8 will survive any termination of this Licence.

B Subject to the above terms and conditions, the licence granted here is perpetual (for the duration of the applicable copyright in the Work). Notwithstanding the above, Licensor reserves the right to release the Work under different licence terms or to stop distributing the Work at any time; provided, however that any such election will not serve to withdraw this Licence (or any other licence that has been, or is required to be, granted under the terms of this Licence), and this Licence will continue in full force and effect unless terminated as stated above.

8 Miscellaneous

A Each time You distribute or publicly digitally perform the Work or a Collective Work, Demos offers to the recipient a licence to the Work on the same terms and conditions as the licence granted to You under this Licence.

B If any provision of this Licence is invalid or unenforceable under applicable law, it shall not affect the validity or enforceability of the remainder of the terms of this Licence, and without further action by the parties to this agreement, such provision shall be reformed to the minimum extent necessary to make such provision valid and enforceable.

C No term or provision of this Licence shall be deemed waived and no breach consented to unless such waiver or consent shall be in writing and signed by the party to be charged with such waiver or consent.

D This Licence constitutes the entire agreement between the parties with respect to the Work licensed here.There are no understandings, agreements or representations with respect to the Work not specified here. Licensor shall not be bound by any additional provisions that may appear in any communication from You.This Licence may not be modified without the mutual written agreement of Demos and You.

This project was supported by:

scope

About cerebral palsy.
For disabled people achieving equality.

The link between disability and poverty is well established. High levels of unemployment and unstable and low paid employment means disabled people are more likely to live below the poverty threshold and be dependent on benefits as a proportion of their income. Increased unemployment and a range of welfare and public service cuts following the economic downturn has only exacerbated the situation, with disability benefit claimants set to lose £9 billion in benefits over the course of the next Parliament.

Yet disability poverty is a dual phenomenon, driven by lower incomes and higher costs. In what Amartya Sen called the 'conversion disadvantage', many disabled people need to spend more than non-disabled people to achieve the same standard of living.

Counting the Cost argues that the Government could reduce disability poverty more effectively, and for larger numbers of people, by reducing costs rather than increasing income. Disability costs are not solely generated by factors government cannot change such as impairment, condition or age. They are driven by a range of environmental factors which, with the right intervention, could reduce disability costs significantly.

Claudia Wood is head of the Public Services and Welfare Programme at Demos.

Eugene Grant is a junior associate at Demos.

ISBN 978-1-906693-59-6 £10