

The Tipping Point

The human and economic costs of cutting disabled people's support



A report from the Hardest Hit coalition bringing together over 90 disabled people's organisations and charities that are members of the UK Disabled People's Council and the Disability Benefits Consortium

Hardest Hit
Fight cuts to disability benefits

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Report structure

The introduction (Chapter 1) provides some context, explaining why 2012 was a year of notable highs but many terrible lows for disabled people. 'The hardest hit by the cuts' (Chapter 2) summarises the key events and trends that have affected disabled people since the Hardest Hit coalition campaigned for a fairer approach to welfare changes a year ago, in October 2011. In 'The human impact of the cuts' (Chapter 3) we give voice to disabled people's anger and fears. This is the main focus of 'The tipping point'. We feature a series of quotes from disabled people; on their views and experiences of the welfare and social care systems and their concerns about the future. We explain why a change of approach is so important. Later chapters ('The economic costs of the cuts' on page 42) and ('Getting it right for disabled people' on page 50') consider the hidden financial costs of cutting vital welfare support and the key decisions the Government needs to get right over the next year. We conclude by summarising the Hardest Hit's priorities for urgent action.

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Foreword



I was a corporal in the Royal Electrical and Mechanical Engineers during the Iraq War. One day in Basra six of my colleagues' vehicle broke down. I rescued them but as I withdrew, I was hit by sniper fire. After seventeen days of being in a coma I learnt I had lost my left eye and had only ten per cent peripheral vision in my right.

It was six years ago now. I had my face reconstructed and a prosthetic eye fitted but I have done a lot since then including gaining new qualifications and studying in my hometown of Morley in

West Yorkshire. I am living independently but this is mainly because of the support I receive.

I did not reach this stage through heroics or individual resilience alone. What has proven so crucial, and I feel strongly that this applies to the millions of disabled people living in similar situations, is the Disability Living Allowance (DLA) I get from the Department for Work and Pensions. Simply put I could not be who I am and I could not do what I do without higher rate mobility DLA.

There are extra costs involved with having an impairment. The best way to explain it is if you need an extra pound to overcome each obstacle that is a lot of extra pounds when you add them all up. I am blind but the personal testimony in this report suggests disabled people have far more in common than separates us; we all face obstacles, whether it is in the form of inaccessible transport; the need for help with communication; a need for extra help to carry out household tasks or assistance with personal care. None of it particularly stuff we feel great about; none of it especially glamorous but fundamental to living life with dignity and confidence.

It is not like there are many £100 outgoings at once but it is all the little things. I have to turn on a machine to read my post. I cannot see so I have to wash clothes more often which means more water, more electricity; more soap powder. I know people with other impairments. It is no different. Try hoovering when you have advanced Parkinson's. Imagine doing your shopping in a wheelchair. Ever considered what it might be like to carry out these key tasks if you have a learning disability, or a mental health condition? I have and I know the costs would stack up.

What worries me so much with the new criteria for Personal Independence Payment (PIP) is that it won't recognise that disabled people have good and bad days. We want to be independent but if we are constantly reassessed we will inevitably have a day where things are going ok. But these days are few and far between and not a reflection of real day to day life for disabled people. DLA was put in place to help us to pay for all the extra costs we face and put us on an equal footing. That is why I am anxious half a million fewer disabled people will receive PIP than those who receive DLA today.

I am pleased to be involved in the Hardest Hit campaign. This report covers many more issues besides a reform to DLA but all of it comes down to one simple proposition: how we can ensure disabled people have the same standard of acceptable living as everyone else in society. We do not want to be punished for having an impairment but badly executed reforms could lead disabled people into a downward spiral affecting both our mental and physical health. That will cost the Government more money. I hope the report gives cause for consideration when so many vital decisions on disabled people's future prospects are about to be made.

Simon Brown

Executive Summary

The Paralympics was an important moment for Britain's 11 million disabled people and indeed the whole nation. August saw column inches filled with the news of our Paralympians' heroics, but away from the Olympic Park, 2012 has in many respects been a dreadful year for disabled people. Continued cuts to benefits and services have left many disabled people feeling angrier and less in control of their lives than for perhaps a generation.

The Government made promises on its approach to tackling the deficit:

“Too often when countries undertake major consolidations... it is the poorest – those who had least to do with the cause of the economic misfortunes – who are hit hardest. Perhaps that has been a mistake that our country has made in the past. This Coalition Government will be different.”

**Rt Hon George Osborne MP,
Chancellor of the Exchequer,
Emergency Budget, June 22nd
2010**

Yet cuts and changes in crucial benefits and support for disabled people present a serious threat to this ambition of protecting the poorest. Cuts that are inconsistent with the goal of

independent living undermine the rights of disabled people enshrined in the UN Convention on the Rights of Persons with Disabilities (UNCRPD)¹. Moreover, they jeopardise the vision set out by the Prime Minister of an 'aspiration nation'² that unlocks the promise of all people. Disabled people want to work and contribute to their communities but too many hurdles are being put in their way.

“There are hidden costs [to being disabled]. Computing what those costs are is very difficult... but fundamentally they exist. Withdrawal of [that] additional funding to cover those additional costs, if that is being planned, will jeopardise the independence of disabled people.”

**David Clarke, Paralympian,
September 10th 2012³**

Our new research

This report reveals disabled people now find themselves at a "tipping point". Many disabled people feel that they are living on the edge, and that the loss of even a small amount of income could tip their already complex lives into greater dependence and insecurity.



During the summer of 2012 the Hardest Hit coalition surveyed over 4,500 disabled people on their views and experiences of the welfare and social care systems. We also conducted a series of fifty in-depth interviews with disabled people and a poll of over 350 independent welfare advisors.

The verdict is in: disabled people and their families are struggling to make ends meet and feel increasingly nervous about the future. Crucial decisions to come on the support disabled people receive can put this right. We call on the Government to act urgently to arrest disabled people's slide into entrenched isolation and poverty.

The hardest hit by the cuts

Disabled people have experienced a massive drop in income of £500million since the Emergency Budget of 2010⁴. Recent reports have shown that cuts range from £200 to £2,065 for typical disabled households just in the past year⁵. The latest estimates suggest disabled people will experience £9bn cuts over the lifetime of this Parliament; half the total cuts being taken from the welfare budget⁶.

The cumulative impact of cuts to date, not just to disability benefits, but across many vital areas of public expenditure, is already taking a huge toll:

- **Arbitrary cuts to support for people who are too ill or disabled to work**, as the 12-month time limit on contributory Employment and Support Allowance (ESA) takes effect for 400,000 people in the Work Related Activity Group (WRAG) by 2013/14⁷.
- **Thousands of very sick and disabled people are being wrongly labelled fit to work** and denied ESA through flawed benefits assessments, forcing them to face long, stressful and costly appeals⁸.

- **£2bn is being taken out of care budgets by local authorities** even though demand for care services continues to grow⁹.
- **Vast hikes in charges for essential services**, including a £77million rise in charges for care¹⁰, a 13 per cent increase in meals on wheels charges, and a 33 per cent increase in transport fees¹¹.
- **Cash value of benefits being reduced due to changes in the way benefits are uprated in line with inflation** meaning the squeeze on living standards hits disabled people struggling with rising costs.

Yet it doesn't stop there. 88 per cent of the benefit cuts required to achieve the Government's original plans for a reduction in borrowing are still to come¹²

- **Half a million people are expected to lose out on vital support as the Government scraps Disability Living Allowance (DLA)**, a benefit designed specifically to support disabled people with the extra costs of living with a disability, to replace it with the new benefit, Personal Independence Payment (PIP). This is designed to save the Government over £2bn¹³
- **450,000 disabled people could stand to lose out under Universal Credit¹⁴.** Many disabled people will get significantly less help under the new system.

In addition, the Chancellor's threat of slashing a further £10bn from the welfare system¹⁵ looms ominously, with disabled people fearing that they'll once again bear the brunt of the cuts.

The human impact of the cuts: our survey

Our survey¹⁶ reveals a series of shocking statistics - presented for the first time in this report. Key aspects of the welfare reform agenda already hitting disabled people hard include the Work Capability Assessment (WCA):

- **More than three quarters (78 per cent) of disabled people said their health had got worse as a result of the stress caused by their Work Capability Assessment (WCA) for Employment and Support Allowance (ESA).**
- **Two thirds (65 per cent) of disabled people felt that ESA assessors did not understand their condition.**
- **Nearly 9 in 10 (87 per cent) of welfare advisors said the frequency of reassessments for ESA is having a negative impact on disabled claimants' health.**

With half a million disabled people set to lose Disability Living Allowance by 2015/16 we can now report:

- **8 in 10** (84 per cent) **of disabled people believe that losing their Disability Living Allowance would drive them into isolation and struggling to manage their condition.**
- **9 in 10** (94 per cent) **of disabled people fear that losing their Disability Living Allowance would be detrimental to their health.**

Our research indicates that cutting the DLA/PIP budget won't only have a profound impact on individual disabled people's lives but will also result in significant longer-term financial costs to Government. Our new research found that:

- **65 per cent of respondents in work stated that without DLA they would not be able to work.**
- **Three in ten disabled people stated that without DLA their carer would not be able to work.**
- **Three quarters of disabled people said that losing DLA would mean they would need more social care support from their local council.**

"I know the government say they have to cut spending, but cutting DLA will simply mean they'll have to spend more on other things. It's a false economy."

Hardest Hit research, 2012

When you take into account the knock-on and implementation costs of replacing DLA with PIP **we conclude that the Government has overestimated the total amount of savings it will generate, by potentially up to £1.6bn¹⁷.**

The tipping point: getting it right for disabled people

We are at a political tipping point, with crucial decisions to be made for disabled people over the next twelve months. The Government needs to reduce the deficit but it faces political and economic choices about how it reduces public debt.

In the short term, final decisions are still being made by the Department of Work and Pensions on the detail of Personal Independence Payment and Universal Credit. These are decisions which could have a significant impact on the lives of hundreds of thousands of disabled people and must not be taken lightly.

Disabled people are calling on their representatives in Parliament to properly scrutinise the planned welfare reforms and ensure that the PIP and Universal Credit regulations being debated later this year are amended to make them as fair and proportionate as possible. It's also not too late to correct some of the mistakes of the past, such as the problems with the ESA

assessment and our crumbling social care system.

As a priority, the Hardest Hit coalition calls on the Government to:

- **Learn from the mistakes of the WCA and ensure the assessment for Personal Independence Payment (PIP) is as fair as possible** by: ensuring that the assessment criteria take proper account of the full range of barriers faced by people with disabilities and health conditions; making the assessment and reassessment processes as simple, transparent and proportionate as possible; and ensuring that robust evaluation and monitoring processes are in place.
- **Get the fundamentals of Universal Credit (UC) right**, ensuring disabled people do not lose out in cash terms as a result of the transition to UC from 2013. Key areas the Government must urgently reconsider include the abolition of the severe disability premium, the loss of financial assistance for disabled people in work and the loss in income for some families with disabled children.
- **Reform the Work Capability Assessment (WCA)** to ensure that it is working consistently and fairly to accurately recognise all individuals with limited capability for work or work-related activity, particularly

those with fluctuating conditions, mental health conditions and sensory impairments.

- **Provide a lasting solution to the crisis in social care**, which has endured years of chronic under-funding, by implementing the recommendations of the Dilnot Commission and urgently addressing the current funding gap.

In the longer term, the Government must not treat disabled people as an easy target for cuts in the budget and spending review.

Giving voice to disabled people

As a coalition comprised of disabled people and organisations working with disabled people we have been moved to write this report because of the personal stories we hear every day. We have heard from people living on the edge who feel the nation's economic misfortunes are their misfortunes. We have spoken to disabled people who strive for a better life but who feel the current approach to welfare reform condemns them to a life of unnecessary struggle. This report aims to give a voice to the many millions of disabled people who are looking to Government to make the right decisions over the next year¹⁸.

1. Introduction: the context



The mood of the nation

For twelve days during August 2012 Britain cheered on and celebrated the feats of its Paralympians. Johnnie Peacock, Ellie Simmonds and David Weir instantly became household names. Britain - however briefly - paused to give some thought to disability.

It was an exciting moment, for the country as a whole but particularly for Britain's eleven million disabled people.

Disabled people were being talked about in positive terms. As a coalition bringing together disabled people The Hardest Hit was delighted people with disabilities and long-term conditions were being praised, not pitied and for once it seemed like Britain truly understood what it meant to be disabled. Something more fundamental than spectator sport was taking place; it appeared the mood of the nation was changing.

“I do think the Paralympics have changed people’s perception of disability and hopefully that will remove some of the barriers disabled people face. It will be just a total shame if the Paralympics finished and that was it. It has got to be worked at.”

**Danielle Brown, Paralympian,
September 8th 2012¹⁹**

Yet around the same time we heard the number of **recorded incidents of disability hate crime in England and Wales was at its highest total since records began²⁰**. One week after the Games came to a close a **survey on public attitudes revealed plummeting levels of support backing benefits for disabled people who cannot work²¹**. The sense of inclusion the Paralympics helped bring about suddenly seemed quite fragile, fleeting.

August saw column inches filled with news of disabled people's heroics but in many respects 2012 has been a truly dreadful year for disabled people. Continued cuts to benefits and services have left many disabled people feeling angrier, more anxious and less in control of their lives than for perhaps a generation.

The UK dimension

Cuts at the Westminster level will affect the benefits received by people living across the country but the impact is of course felt differently in areas with

greater numbers of people living in relative poverty. In some parts of the UK the number of claimants on certain benefits is higher than the national average. The knock-on effects of welfare cuts will be felt unevenly.

- In Scotland, for example, there are approximately 300,000 Incapacity Benefit (IB) claimants. The employment rate varies considerably across local authority areas, with only one third of disabled people in Glasgow in work²².
- Wales has the highest proportion of disabled people in the UK, with one fifth (21 per cent) of working age people living with a disability²³. Wales also has the highest proportion of benefit recipients for all types of benefits (one fifth of working age)²⁴.
- Recent statistics show that just over 10 per cent of Northern Ireland's population are in receipt of DLA²⁵. Research would suggest that part of the explanation for higher numbers of DLA claimants in Northern Ireland lies in its greater levels of ill-health²⁶.

With each of the devolved administrations now engaged in consultation or implementing changes in passported benefits, the issues raised in 'The tipping point' have never been more relevant.

The human impact of cuts

Many disabled people live complex lives, having to deal with a wide range of barriers that non-disabled people do not have to meet on a daily basis. Despite their differences, one key theme emerged amongst the disabled people we interviewed and surveyed over the summer of 2012. The barriers disabled people have to overcome if they are to participate in society on equal terms will become steeper still if key benefits like Disability Living Allowance (DLA) are reduced or removed.

Our research highlights not only the impact that the cuts are already having on disabled people, but also the fear that the prospect of future cuts, is instilling. We have heard disabled people express dismay they are the target for cuts.

"I understand them [the Government] trying to save money but taking it from people who really need it is wrong".

Hardest Hit research, 2012

Myths and reality

We also hear from disabled people who feel the Government's rhetoric justifying disability benefit cuts is hardening public attitudes. Many disabled people feel the media portrayal of 'benefit scroungers' is behind disability hate crime being at an all time high. This is despite the fact that estimated overpayments of DLA due to fraud make up less than 0.5% of total spending²⁷.

"It's the government - all this talk about fraud and benefits cheats has made it so much worse. Suddenly everyone feels free to make a moral judgement about you."

Hardest Hit research, 2012

"It's scary, actually. The things you see in the papers and on TV that paint us as scroungers and layabouts. And you know that the government are at it behind the scenes."

Hardest Hit research, 2012

There are a lot of myths in the debate about welfare reform, and some are very damaging to disabled people. We wish to confront them head-on before we consider what we mean when we say disabled people are the hardest hit.

Disability benefit fraud levels

Official levels of fraud and error in disability and out-of-work benefits are far lower than public perceptions and polling on these issues might suggest. Office for National Statistics highlights that just 0.3 per cent of overpayments for Incapacity Benefits were due to fraud. Figures on fraud²⁸ (for both DLA and Incapacity Benefits) are outstripped by 'customer error' and worse still, 'official error', in other words mistakes on the part of the Department for Work and Pensions.

The "ballooning" welfare budget

Though it is true the welfare bill grew in ten years (by £60bn)²⁹ disability benefits were not the main cause for this expenditure³⁰. Nor in fact were out-of-work benefits - growth here has largely been concentrated over the period of the recession. Payments to the retired, to families with children and to low-income workers were responsible for the large part of this growth, partly because of demographic change and partly due to government policies that command a large degree of public support and consensus (so for example tackling child poverty)³¹. In 2008/9, 60 per cent of the DWP's social security spending was accounted for by payments made to people of state pension age, primarily pensions³².

UK spending on disability benefits imperils the recovery

OECD aggregated data for 2007 (the last date statistics are available) shows that the UK's incapacity-related social expenditure represented 2.4 per cent of GDP, a figure that had remained fairly constant since 1990 and was lower than that recorded in Denmark, Finland, Norway, Sweden and Switzerland, all relatively competitive economies³³.

Getting it right for disabled people

There are conflicting reports about what the Government needs to do in order to meet its chief fiscal target of reducing the debt to GDP ratio by 2015/16. At his 2012 Budget George Osborne warned that unless welfare bills were "curbed" even further the full weight of the spending restraint would need to fall on other Whitehall budgets. The Chancellor will provide further indication of his plans when he delivers his Autumn Statement in December but we are extremely concerned disabled people could be targeted again when the impact of being the hardest hit to date is already taking its toll.

2. The hardest hit by cuts

Disabled people are twice as likely to live in poverty as other citizens³⁴.

Even a small loss of income can tip disabled people into greater dependence. When the additional costs disabled people face as a result of their impairment are factored in, figures suggest that well over half of disabled people in the UK could be living in poverty³⁵.

A helpful way of understanding why disabled people are uniquely affected by austerity is to see disability poverty as a "dual phenomenon", driven by lower incomes and higher costs³⁶.

- **Nearly 9 in 10 (87 per cent) of disabled people say their everyday living costs are significantly higher because of their condition.**

Benefits like Disability Living Allowance (DLA) are intended to contribute to the general extra cost of living faced over the long haul by disabled people and their families - higher fuel bills to pay for extra lighting and heating, the costs of hospital visits and so on. For a more detailed description of DLA and the rates it is paid out at please go to **Annexe A (on page 59)**.

The statistics below serve to highlight the ongoing financial difficulties of disabled people:

- **13 per cent of households with a disabled member experience “great difficulty” in “usually making ends meet”, nearly double the number compared with the general population.³⁷**
- **Disabled adults are twice as likely to live in persistent poverty as non-disabled adults.³⁸**

Disabled people face the perfect storm of benefits cuts and cuts in local care and support. The cumulative impact of all these cuts is easily underestimated so it is important not to think of these welfare changes in isolation; or indeed to think of all disabled people as individuals with a single health condition or impairment.

Key measures and trends causing disabled people to be the hardest hit include:

A massive drop in income of £500million

Disabled people and their carers' have experienced a drop in income of £500million since the Emergency

Budget of 2010³⁹. One estimate is that Britain's 3.6 million people claiming disability benefits will be £9bn worse off from 2010 to the end of this Parliament meaning on average a loss of two to three thousand pounds for each household affected⁴⁰.

Arbitrary cut to support for 400,000 too ill or disabled to work:

In April 2012 40,000 disabled people who had paid national insurance contributions in good times but had fallen out of work in bad, lost more than £90 a week as contributory Employment and Support Allowance was capped to just a twelve month payment⁴¹. By April 2013 ten times that number, 400,000 disabled people, will have lost some or all of their ESA meaning they face a future of unemployment and on average a £52 a week drop in income⁴².

£77million rise in charges for essential support

The Association of Directors of Adult Social Services (ADASS) reports that savings in care and support have been achieved through a combination of efficiencies, reduced service provision and increased charges. **Increased charges of £77million are likely to affect access to basic care services.** Data from 93 out of 153 councils in England showed **disabled and older people who have to pay charges for meals on wheels have seen fees go**

up by 13 per cent over the last two years, while transport fees rose by 33 per cent⁴³. Moreover, ADASS reports that 85 per cent of councils now restrict care to people with 'substantial' and 'critical' needs, which are thresholds proving ever more difficult to reach in terms of proving eligibility⁴⁴.

£2bn being taken out of care budgets

Directors of adult social services in England are in the process of taking £890million out of the nation's total social care budget between April this year and March 2013⁴⁵. When combined with last year's figures, the cumulative reduction in adult social care budgets is £1.89bn - at a time when growing pressures from rising numbers of older and disabled adults continues to grow at three per cent per year⁴⁶. Furthermore, Age UK and Carers UK estimate £4bn is now being lost as a result of people leaving work to look after elderly or disabled relatives, with the Treasury losing £1bn of taxes they would otherwise have paid. The charities have warned that the missing £5bn is equivalent to more than 0.3 per cent of Britain's gross domestic product (GDP) and the status quo would get worse if we see continuing cuts to care budgets⁴⁷.

Cash value of benefits reduced as living costs rise

The decision in the Emergency Budget 2010 to switch to the Consumer Price Index (CPI) for the price indexation of all benefits and tax credits has affected disabled claimants across the board. The change in the indexation from the higher RPI to the lower CPI from April 2011 is already starting to have a profound effect on the cash value of vital benefits like Disability Living Allowance (DLA). The index switch represents a total loss of £360 per year for higher DLA care claimants, yet the Government says its DLA reforms are intended to help disabled people “with the greatest needs”.

Even if modest growth returns in the coming years low and middle income households that receive support from the state will see their living standards fall steadily further behind⁴⁸. The Office for National Statistics is consulting on amending the way RPI is measured, perhaps to bring it more in line with CPI but this will come as scarce consolation to disabled people, who will be among those households to feel the full effects of the squeeze on living standards.

Yet it doesn't stop there. 88 per cent of the benefit cuts required to achieve the Government's original plans for a reduction in borrowing are still to come⁴⁹.

Half a million people are expected to lose out on vital support as the Government scraps Disability Living Allowance (DLA), a benefit designed specifically to support disabled people with the extra costs of living with a disability, to replace it with the new benefit, Personal Independence Payment (PIP). This is designed to save the Government over £2bn⁵⁰, and an estimated 500,000 disabled people are expected to lose out on this vital support as a result.

450,000 disabled people could stand to lose out under Universal Credit.

Many disabled people will get significantly less help under the new system. **Up to 100,000 families with a disabled child could receive only £28 a week under Universal Credit compared with £57 a week under the disability element of child tax credit today.** This is equivalent to the loss of around £1,500 per year for most families with a disabled child⁵¹. The plans for Universal Credit involve a shift in resources to better target disabled people with the greatest needs, for example those in the support group for ESA. However, the abolition of the severe disability premium (SDP) means even those with the most serious health conditions or the greatest level of impairment will receive £28 less a week if they live on their own⁵². For more information on the strengths and weaknesses of the proposed design of Universal Credit read **Annexe C**.

Taken together the reforms to welfare support risk intensifying disability poverty. The Institute for Fiscal Studies has shown that the largest average losses as a fraction of net income from the modelled tax and benefit reforms to be introduced in 2012–13 (such as the twelve-month time limit to contributory ESA) are among those in the bottom half of the income distribution⁵³. Research suggests a reduction in disabled people's cash incomes leads to an increase in deprivation⁵⁴ but the first working age people undergoing reassessments for Personal Independence Payment (PIP) risk losing some or all of their extra costs benefits as soon as October 2013.

All in this together

The commitment in the Emergency Budget was that the poorest in society should pay less as a proportion of their income than the richest. We would “all be in this together”. In our view disabled people are being hit by a wave of new policies that have stretched this promise to its breaking point. Unless Government takes firm and urgent action to remedy the situation, a number of welfare changes look set to adversely affect disabled people, defining their future levels of income and independence for many years.



3. The human impact of cuts

Our research reveals that:

- **More than three quarters** (78 per cent) of disabled people are worried that they won't qualify for the new extra costs benefit, Personal Independence Payment (PIP).
- **Eight in ten** (84 per cent) disabled people said that without DLA they would be isolated, and would struggle to manage their condition.
- **More than nine out of ten** (94 per cent of) disabled people felt that losing DLA would have a negative impact on their health.

The Welfare Reform Act 2012 ushered in a series of radical reforms; to Disability Living Allowance (DLA), to tax credits and working age income-based benefits; to contributory benefits such as contributory Employment and Support Allowance and many other benefits besides. By the end of the spending review period £18bn welfare cuts will have taken place as part of the national effort to tighten the public finances⁵⁵, many of which will take their toll on disabled people and their families. For background information on the Act read **Annexe B**.

Even before the Welfare Reform Act came into effect, disabled people and their organisations had major worries

about the fairness and effectiveness of the benefits system. For example a large number of organisations have expressed grave concern about the Work Capability Assessment (WCA), which regularly judges seriously ill and disabled individuals "Fit for Work", and therefore not eligible for Employment and Support Allowance (ESA). For more detailed information on the WCA please look at **Annexe D**.

The sheer levels of anxiety disabled people feel, especially now WCA-style face-to-face assessments are to be extended to also include future tests for Personal Independence Payment (PIP), cannot be underestimated. **A strong theme that emerged from the Hardest Hit research - both our interviews and our survey - were the high levels of fear and frustration so many disabled people now feel.**

"All this stress and worry is just paralysing me. Sometimes I can't sleep for nights on end. I get very depressed and don't go out much at all. I just sit at home and fret. If I lost my DLA, I wouldn't be able to live – it's as simple as that."

Hardest Hit Research, 2012

Tragically we hear from people who feel distressed or even suicidal:

"My ESA medical in 2010 made me suicidal... [my] benefit stopped. [I spent] many months fighting...to have my benefit reinstated. I eventually received an apology...I have received an appointment for another medical this month, but there has been no change since my last assessment - my mental health is worse than eleven months ago. I can't do this anymore."

Hardest Hit research, 2012

Many disabled people are conscious changes in welfare and other types of support are likely to cost the Government more in the long-run.

"It's ridiculous. All the cuts in the health service means that they can't provide me with what I know I need, so I pay for it myself – and then they start cutting my money so I can't afford it. It's like they're not actually interested in helping people at all. I know that if I didn't keep myself as healthy as possible, I'd be in and out of hospital and that would cost a whole lot more."

Hardest Hit research, 2012

A sometimes hidden, but very damaging effect of cuts is increased isolation. Eight in ten respondents to our survey said that without DLA they would be isolated. Some disabled people are already finding they are spending more time staying at home.

"I used to have a social worker who'd come shopping with me and help me find the best buys and make better choices, but I was told that I could do my shopping on the internet and have it delivered. Now I'm paying even more for my shopping because I don't get the special offers as much. It also means I don't get out as much and talk to other people. I used to look forward to going shopping, it was like a day out for me, but now I'm stuck in front of a screen".

Hardest Hit research, 2012

The Hardest Hit coalition also hears from people who tell us they have "put into the system" and after many years of work are shocked that they now have to go it alone.

"I still meet with discrimination in the jobs market and have still not gained employment after almost two and a half years. Moreover, I've come to accept that, at 55, I might not get another job. ESA is vital to our standard of living and, as my husband is still working, I may lose this benefit altogether. I wouldn't be eligible for ESA using a means test. Taking away contributory ESA after

12 months would be grossly unfair to people like us, who have paid into the system but can no longer do the work they used to and, perhaps most importantly, find work they can do now. I despair."

Hardest Hit research, 2012

The cumulative impact

Quantifying the overall effect of the cuts and changes in benefits and support for disabled people is difficult. All sorts of variables need to be considered.

However, that doesn't mean the Government is right not to try. The rest of this chapter seeks to plug some of the gap by taking a comprehensive look at areas already causing disabled people huge concern. These are: work, health and wellbeing; paying for care and mobility; daily living and housing costs and public attitudes.

Work, health and wellbeing

"When I'm asked to go [for a Work Capability Assessment] again, it just makes me angry and depressed. It's just so wrong. Then there are more forms, and my money is then reduced while I appeal...it's just a nightmare the whole system is meant to trip you up, and deceive you."

Hardest Hit research, 2012

Our new research highlights that:

- In our survey **three-quarters (77 per cent of) disabled people who responded told us they were not currently in paid work. Of these, almost half (47 per cent) stated that they want a paid job**, but the same number believed that their impairment or health condition meant that they cannot work at all.
- **More than seven in ten (72 per cent) people who responded to our survey and were out of work said employers' attitudes towards their impairment meant it was difficult to find a job.**
- **81 per cent of the people who responded to our survey and were in work said their condition or disability limited the range of jobs that they could do.** This figure rises to 88 per cent for those respondents who were not in work.

Substantial recommendations for improving the WCA assessment have been made by Professor Malcolm Harrington. Although the Hardest Hit coalition is clear that some of these will take time to be implemented, progress is still tragically too slow. The evidence from our survey of disabled people showed that the assessments remain highly flawed:

- **Two thirds** of people we surveyed felt that ESA assessors did not understand their condition.
- **Six in ten** did not feel that the assessor had asked about all the symptoms/aspects of their impairment or health condition that affect their ability to work.
- **Almost seven in ten** (68 per cent) stated that the assessor did not take into account how their symptoms/aspects of their impairment or health condition change/fluctuate.
- **Fewer than one in five** (16 per cent) agreed that the assessment took account of how their symptoms are affected by repeated activity (e.g. fatigue, pain or worsening of condition).

Despite the work underway to act on Professor Harrington and stakeholder groups' concerns our survey of 350 welfare advisors highlights that the WCA is still highly problematic:

- **Nearly nine in ten** (87 per cent of) advisors disagree that the accuracy of Atos assessors⁵⁶ has improved over the past eighteen months.
- **Around the same number** - 85 per cent - of advisors disagree that Atos assessors have paid more attention to any additional evidence available to them over the past eighteen months.

- **Nearly nine in ten** (86 per cent) of advisors disagree with the statement that more applicants are getting the right decision in their assessment for ESA eligibility.

Some of the respondents to our survey commented on the bewildering level of bureaucracy and the irrational outcomes that follow the WCA.

"How can the same company doctor write a report to my employer in November 2011, saying my condition will deteriorate, will never get better, which led to my dismissal due to poor attendance management, and in May 2012 they [DWP] say I should be put into the work related group, as I will get better? I am no doctor, but common sense does not prevail with ATOS."

Hardest Hit research, 2012

We have heard from people who find it difficult to comprehend why they are the focus of so many reassessments when their illness or disability can only get worse. It is clear that many seriously ill and disabled people, some with progressively deteriorating conditions are being told they can go back to work.

"I fear what going through all this [repeat assessments] will do to me... Going through the whole of this again is terrifying to me, which by proxy will not do me any good regarding the state of my health... For people who have degenerative illnesses, I think it

is unfair since the stress of all these assessments can actually exacerbate the disease. Seriously, do they think we like being ill?"

Hardest Hit research, 2012

Following reports from claimants that they were being reassessed more frequently for ESA, we asked advisers about reassessments.

- More than three quarters (over 75 per cent) thought claimants were being reassessed more frequently.

Respondents to the survey particularly drew our attention to the indignity they sometimes feel.

"...It was like he [the assessor] was trying to catch me out with things."

Hardest Hit research, 2012

"I suffer from bowel problems, migraines, depression, anxiety and extreme pain. Each of these caused me problems on the day of the assessment. Overall it was an experience I would not like to repeat though no doubt I will have to. I'm dreading the next one."

Hardest Hit research, 2012

"It [the WCA] is humiliating. Down right disgusting. At least they did have some paper hankies. I am a grown man of sixty-two years of age."

Hardest Hit research, 2012

Just over half of disabled people we surveyed (51 per cent) disagreed that the person who carried out their WCA assessment had treated them as an individual.

"My first assessment was very stressful. I felt as though I was just a number and not an individual...On the second assessment I felt more at ease, but on reading the report they sent back to me the answers were very different to how I thought she [the assessor] had understood my movement and pain."

Hardest Hit research, 2012

"It [the WCA] was a totally dreadful process. I left in tears and a shaking wreck. Most of the questions asked were not appropriate to my condition. I felt it was "20 questions fits all". I was told to go on anti-depression medication on leaving."

Hardest Hit research, 2012

Disabled people undergoing the WCA express shock about the way they have been treated by assessors.

"I felt as if I was there asking for something I was not entitled to. The building and all office space was full of people who looked at me as if to say, 'she looks alright'. I felt embarrassed and uncomfortable and desperately wanted to cry, but fought not to. I was not well for a few days afterwards."

Hardest Hit research, 2012

"I was surprised to be called for this assessment so quickly after claiming benefits for the first time in my life. Before my recent health problems I had an excellent work record."

Hardest Hit research, 2012

Many of the individuals we interviewed recognised the positive effects of being in work, both in terms of self-esteem and in interacting with other people. The principle of ESA - offering people who are able the right support to move back towards the workplace - is laudable. Looking for and obtaining work can be difficult, however, and our research showed that the necessary support is often sadly lacking. Large numbers of people in the Work Related Activity Group, who are expected to engage in activities 'to prepare for work', stated that they had received little or no useful support to return to work:

"At my interview at my local Jobcentre my advisor told me that she had no jobs or courses for someone with my degree of disability. She then told me due to me being placed in the ESA work-related activity group I would lose my benefit (ESA) in 2013. Our joint income would not entitle us – yet my husband is my carer and is still having to work full time on a low wage."

Hardest Hit research, 2012

"None [I have received no support] - the building [where the assessment is] is not wheelchair accessible so never had to attend and was told it was pointless to appeal by job centre staff. The staff told me they thought the decision was wrong as I obviously was in no state to work through illness."

Hardest Hit research, 2012

For those who are in the Work-Related Activity Group of ESA, attending work-related activities and interviews is mandatory and they can lose their benefits if they fail to attend. However, this can be a problem if the venue is inaccessible or unfamiliar. One young man with a visual impairment was asked to attend a training module in a nearby town:

"They said 'you can get a bus, it's only a short ride', but they didn't seem to understand that it's not that easy if you can't see the bus properly or don't know where to get off. So I always try and keep some [Disability Living Allowance] money aside just in case [I need to get a taxi]. It's ironic that I have to save some of my DLA so that I can meet the conditions of ESA."

Hardest Hit research, 2012

Many of the people we interviewed recognised the important role that DLA plays in keeping them engaged with the world of work and all expressed concerns about what they would do if they lost their benefit.

“I want to be a journalist, and the volunteering gives me valuable experience, but they can’t afford to pay my travel expenses. This means that I have to use taxis a lot to get to appointments, and that’s how I use my DLA...If I didn’t have DLA, I wouldn’t be able to carry on, and I’d be less employable as a result”.

Hardest Hit interview with disabled person, 2012

Losing DLA and then finding it harder to search for or take up work and volunteering opportunities would not only impact on the wellbeing of those losing out, but could have a significant economic impact, which we explore later on in Chapter 4.



Personal care and mobility

“I don’t know what I’d do without it [Higher rate DLA mobility and the Motability scheme]. It’s been an absolute godsend and has meant that I don’t have to rely on anyone else to get out and about. Before I got the car, I’d be stuck at home for days on end and have to rely on someone taking me in their car. I don’t want to go back to being like that.”

Hardest Hit research, 2012

Our new research highlights that:

- **Eight in ten** (84 per cent) respondents living with disability, impairments or long term conditions said that without DLA they would struggle to manage their conditions.
- **More than nine out of ten** disabled people felt that losing DLA would have a negative impact on their health.
- **A staggering 85 per cent of disabled people who responded in our benefits survey** told us that they did not receive any social care from their council.
- **Three quarters** of disabled people said that losing DLA would mean they would need more social care support from their local council

The Government states that spending on Personal Independence Payment (PIP) will simply return us to 2009/10 levels of expenditure⁵⁷ but it is hard to reconcile the economic imperatives with the stories of debt, poverty, ill health and inequality that our research indicates may result from the loss of DLA.

"I always seem to have the heating on, even in summer, because I find that the cold gets into my joints and makes it painful. If I didn't have the heating on full blast, I wouldn't be able to do the housework or cooking. If I didn't have DLA, I wouldn't be able to do that, because the cost is so high."

Hardest Hit research, 2012

"It gets very tiring and my own health isn't very good, so every three months or so, I pay for someone to come in and provide me with respite care. It's expensive and takes most of my DLA, but without it, she [my wife] would probably have to go into a home, and I can't let that happen."

Hardest Hit research, 2012

Many disabled people live complex lives, having to deal with barriers that non-disabled people do not have to meet on a daily basis. Disability Living Allowance (DLA) in particular plays a key role in enabling people to overcome these barriers and lead more independent and more fulfilling lives.

Personal care was one of the main areas of expenditure for people we interviewed. Forty of the fifty respondents identified it as a cost. Care ranges from almost total help, where someone needs assistance in all aspects of daily life, such as washing and dressing, to a few hours a week in helping around the home, such as cleaning or helping to prepare meals.

"My illness means I am chronically tired all the time. I sleep most of the daytime as I have disturbed sleep from severe pain. I have psoriatic arthritis in the majority of my joints, damaged tendons, ligaments and soft tissue damage...my joints limit my physical capability to do every day things and I take several strong medications including codeine and morphine to cope with the pain which in itself causes side effects of sickness. Without my DLA I wouldn't be able to afford a car to attend my hospital, doctors or physio appointments and would have to rely on my husband taking time off work to take me which might eventually end up in him leaving work and becoming my full time carer."

Hardest Hit research, 2012

Of the forty interview respondents (out of fifty) who identified care as expenditure, only fifteen had a care package from their local authority that met their needs. A further twelve had a package that they had to supplement, and the remaining thirteen had no statutory provision of care whatsoever. Many people relied to some degree on informal care from family and friends.

“What is social care? I have never been offered it and don’t know what it is.”

Hardest Hit research, 2012

Many stated that their DLA is vital to pay for small amounts of care and support to help them to stay independent.

“I used to get a few hours [social care] a week, just helping me with general stuff around the home, making sure that things were safe and clean and helping with cooking meals that I could put in the freezer. Then last year they said that I didn’t need the help anymore because I wasn’t disabled enough. Thing is that without the help, I get really anxious and that makes my condition worse, so I’ve had to use nearly all my DLA to pay for someone to come in once a week. I don’t know what I’d do if that (DLA) stopped.”

Hardest Hit research, 2012



The greatest fear of losing support was actually amongst those people who relied wholly or partially on sources of informal care, as opposed to those in receipt of statutory help. They were more likely to feel that the loss of DLA would mean that they could no longer pay for family and friends to help, as the cost of other expenses in their lives would have to be met first. It is the case that these people were often those with barriers that were deemed insufficient to qualify for statutory care, and also those most likely to be in receipt of Lower Rate Care in DLA.

"I get Lower Rate Care [DLA] and it isn't enough to pay for someone to come in, so I use it to pay for my sister's petrol when she comes over. She goes through my cupboards and checks that food hasn't gone out of date and that everything's clean and tidy. I couldn't pay without the DLA and she's got her own family to look after."

Hardest Hit research, 2012

It would seem therefore that those people who are less disabled in terms of qualifying for DLA could be those for whom the impact of losing it would be most severe.

Case Study 1

Terri, Lancashire

Terri, a blind mother of three, says she relies on her benefits to survive. She said, *"I get £105.90 a week from DLA to run my house but more than half of that goes on paid assistance where a carer comes round for 12 hours a week. Once they discovered a jam jar full of fly eggs where my daughters, two of whom have sight loss, hadn't resealed it properly. I would never have noticed. Can you imagine what it would have been like if I'd eaten them. I don't go out, I don't drink, I don't have money for treats. Am I supposed to not eat now if my benefits are cut?"*

Another obvious theme that emerged from our interviews was the extent to which people use their DLA on improving their health and well-being, both on a short-term and long-term basis. This is one area where DLA acts as a true personal budget; with recipients being able to make decisions about treatments and support that really helps them. The loss of DLA, however, could affect people's ability to look after themselves and take control of their health, potentially meaning greater health and social care provision would be required.

Case Study 2

Stuart

Stuart has been living with the effects of AIDS for many years and has been receiving DLA (Higher Rate Care and Mobility) since 1993.

He lives with a companion who provides his daily care. The local authority provides Stuart's companion with nine hours vital respite care per week, which is topped up from Stuart's benefit income.

Stuart is determined to remain as independent as possible, but is increasingly aware of his reliance on others. He admits that there is no aspect of his life where he does not need support of some kind, as his symptoms are unpredictable. He acknowledges that without the help that

DLA affords him, he would lose any pretence of his independence, and his life would "rapidly start to unravel".

DLA also qualifies Stuart for the Motability scheme, and his car is a vital lifeline for him, because of his illness he cannot use public transport safely. Without DLA he would end up housebound, reliant only on the goodwill of friends.

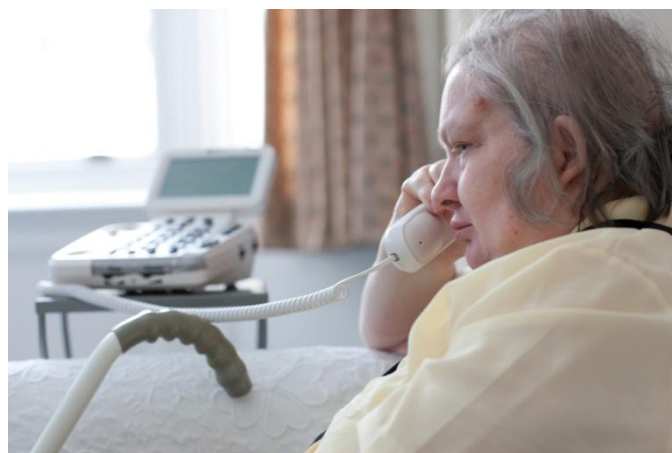
Safety is a major concern for Stuart, as is maintaining his health as best he can. He has been diagnosed as a pre-diabetic and keeps to healthy and highly nutritious food, especially fresh fruit and vegetables.

Another major expense has only recently just appeared as some of the medications that he had been prescribed for his condition were made unavailable in early 2012. Stuart now has to purchase them himself over the internet which is a massive drain on his limited resources. He also has to import special clothing which reduces pressure on his legs when sitting.

Being at home a lot means he has to keep the heating on constantly, but has the thermostat set very low because he is worried about spiralling fuel costs, and wears lots of layers of clothing. Without DLA, he worries that his health would deteriorate as he would have to buy cheaper food and ration the central heating even more, perhaps by living in one room.

Social Care reforms

Disabled people and their organisations are clear that the social care system is broken. It cannot cope with a rapidly ageing population and people living longer with illness and disability. Urgent reform and additional funding are essential.



"I'm cared for by my partner of 44 years. He will reach retirement age in October and will consequently lose his Carers Allowance. When he is no longer able to lift me which is now a minimum ten times a day or help with the intimate matters such as toileting and showering, what then? Do I reach for the tablets?"

Hardest Hit research, 2012

To introduce an assessment for Personal Independence Payment (PIP) that compounds the situation by removing support from disabled people so they can meet their additional care and mobility costs would be a massive mistake.

“My arthritis is so bad I can’t prepare food and it is difficult to hold cutlery to eat food and most household tasks are a significant challenge. I was not granted any care component. No social care help from my local council. I only recently managed to get any DLA despite having multiple medical conditions resulting from cancer treatment for significantly longer”.

Hardest Hit research, 2012

Some of our interviews focused on informal care, which props up the health and social care system.

“Until recently, I was always able to care for my husband, but since I had my stroke, I haven’t been able to manage as well, so we use the money to pay for someone to look after him, which has made a massive dent in our savings – thank God for DLA which helps, otherwise I don’t know how we’d cope.”

Hardest Hit research, 2012

DLA income can prove extremely helpful in meeting disabled people's mobility needs.

“I want to be independent, and travel on my own, but I can’t afford to do it as often as I’d like. The train fare [to visit friends] is £20, and I can’t book online to get cheaper fares, so I can only do it once a month. Without the DLA, I couldn’t even manage that.”

Hardest Hit research, 2012

For people with the most profound and complex barriers to independent living DLA can even prove the difference between living in your own home and having to consider residential care.

Case Study 3

Tom, East Anglia (interview with Tom's father, James)

Tom lives independently in East Anglia and receives DLA Middle Rate Care and Lower Rate Mobility. He currently receives six hours care per week through the local authority - though this has recently been reduced from 15 hours due to financial pressures. Tom needs help with several household activities, including cooking, cleaning, repairing things, finances and travel. He cannot use the cooker well, and eats a lot of micro-waved and pre-prepared food that is often much more expensive.

He is very wary of strangers and does not always remember the rules of social engagement - as a result he has to avoid busy areas. He is also very reliant on routine - and any disruption can cause him problems. As a result he pays for a monthly mobile phone contract in case he gets into difficulties.

Tom's major expense is transport - although he has a bus pass, he finds it difficult to use public transport, especially for travel on unfamiliar routes. This was exacerbated when a driver

refused to let him on a bus because he did not believe that Tom was disabled. This means that Tom relies a lot on taxis, particularly when going shopping. Sometimes his carer will drive him, but Tom has to pay for the petrol.

Tom's father, James, has seen his son make great strides since living independently, far exceeding expectations of what he could achieve. DLA has been a crucial element in this - especially in increasing confidence and self esteem.

Tom has also made contact with a local charity and does some voluntary work for them every week. James fears that the loss of DLA will disable Tom more, and force him out of his more independent lifestyle and back to the more institutionalised setting he has managed to leave behind.

Daily living and housing costs

Our new research highlights that:

- **Nine in ten (87 per cent of people) surveyed told us their everyday living costs are significantly higher because of their illness or disability.**

“I’ve got a pre-pay meter in my flat, and it’s really expensive. I always wear lots of layers at home – sometimes I even sit and watch television with my coat on – just to avoid having to put the central heating on.”

Hardest Hit research, 2012



Disabled people often find that everyday costs in and around the home are greater than for non-disabled people, and **those who receive DLA often use their money to meet these hidden extra costs.** For example, there was a consensus among respondents that they did often spend more on heating their homes, especially in the winter. People were well aware of the help that DLA gives them in being able to meet

their energy bills. Household equipment was identified as an extra cost for many; and washing machines in particular were identified as being in almost constant use by several people.

“I try and keep a little money aside for when things go wrong. Being disabled means that I can’t fix things around the home – so if a light bulb needs changing or the sink gets blocked, I have to call someone in to fix it, and it really makes a massive dent in my income”.

Hardest Hit research, 2012

“I don’t know what I’d do [if I were to lose DLA]. At the moment, I can just about make ends meet...without the DLA, I’d worry that I couldn’t pay for food and heating. I don’t want to have to go back to living with my parents, but I may end up with no choice.”

Hardest Hit research, 2012

“Well, I’d have to cut down on heating [if I lose DLA] and I’d have to eat whatever’s on special offer this week. I do most of my shopping at charity shops anyway now, and I’ve got some warm clothes so I won’t have to have the heating on so much over the winter.”

Hardest Hit research, 2012

Almost half of those we interviewed said that they had problems with preparing and cooking food. While some had help in the kitchen, others had to rely on buying pre-prepared microwaveable meals which proved expensive.

I’ve got diabetes as well as arthritis, and I need to watch what I eat, so it’s lot of fresh food and nothing processed, but it’s getting really expensive. Also, I can only make it to the supermarket once a week and the food goes off, so I have to buy locally, which is even more pricy”.

Hardest Hit research, 2012

“I know it’s not good for me, but I find it difficult in the kitchen, preparing a meal from scratch. I’ve ended up cutting my thumb, and pouring scalding water all over me at times. So I end up eating a lot of processed food and that can add £20 to a weekly shop. When you’re on a limited income, that’s a lot of money”.

Hardest Hit research, 2012

The precariousness of many disabled people's financial situation means even apparently minor changes in support can tip them over from "just about coping" into a state of ill health, isolation or worse.

Case Study 4

Christopher Blake, North West

Christopher lives on his own in the north west of England. He receives help three or four times every week from a close friend. His friend provides him with his main source of transport. Because of his condition, Christopher doesn't feel safe going out on his own. Using public transport is virtually impossible for him as it increases his anxiety. Christopher's illness, where symptoms can often last for months at a time, often means he needs prompting to remember to do daily activities such as cooking, cleaning and even eating.

When he doesn't have someone to take him where he needs to go, Christopher uses his DLA to pay for taxis. Without taxis, he thinks he would find it difficult to make hospital visits, especially when he has to attend an emergency appointment. This worries Christopher because he knows that non-attendance at some appointments could result in him being hospitalised.

There have been times when he hasn't eaten for days, and he has forgotten to put the heating on when cold. Christopher fears that even a small loss of DLA would affect his ability to meet his fuel costs meaning he wouldn't be able to heat his home properly. He also worries that with no savings on which to draw on when things go wrong, paying for repairs and replacements would be a

problem. Currently he has to rely on friends and family to repair things or even to buy replacements for him and he uses his benefits to pay them by instalments.

Public attitudes

Not long before the Paralympics Scope and polling company ComRes released the results from their survey of disabled people, their parents and carers. Almost half (46 per cent) of the five hundred people surveyed said they felt attitudes towards them had got worse in the past year with only 13 per cent saying they had improved⁵⁸. The survey also found over four fifths (83 per cent) said media coverage about benefits scroungers is fuelling public hostility towards disabled people in general⁵⁹.

"It has got worse actually. The last couple of years, I've had people accuse me of being a scrounger, a fraud. Just people in shops or on the street. It's like they've suddenly got a license to interrogate me and ask personal questions. It's humiliating when that happens."

Hardest Hit research, 2012

"It's happened twice now - I've been by myself in town and someone has made a comment - one man kept following me and asking me why he should pay for me 'lazing around all day' from his taxes. He implied that if I was really disabled, I should be in a home. I don't go into town on my own now unless I really have to."

Hardest Hit research, 2012

Other research commissioned this year by Inclusion London⁶⁰ found that articles focusing on disability benefit and fraud more than doubled from 2.8 per cent in 2004/5 to 6.1 per cent in 2010/11. When focus groups were asked to describe a typical story in the newspapers on disability benefit fraud was the most popular theme mentioned.

"It's the government - all this talk about fraud and benefits cheats has made it so much worse. Suddenly everyone feels free to make a moral judgement about you."

Hardest Hit research, 2012

"It's scary, actually. The things you see in the papers and on TV that paint us as scroungers and layabouts. And you know that the government are behind the scenes."

Hardest Hit research, 2012



A number of newspaper articles have appeared to misconstrue Department for Work and Pensions statistics on Incapacity Benefit reassessment. These include the now infamous headline, "Sick benefits: 75% are faking". More recently we have seen a headline – again on the subject of fraud and disabled people "faking" benefit claims – that suggests "The Paralympics show up a corrupt benefits system".

Clearly the Department for Work and Pensions cannot dictate what stories appear in the newspapers but with attitudes towards disabled people hardening and the economic climate set to get tougher still the Government must do more to ensure that DWP statistical releases do not encourage misunderstanding of the levels of fraud, and that misleading media articles are addressed and corrected.

The cumulative impact

Disabled people have shared their fears and concerns on a wide range of topics. Tens of thousands of disabled people have signed petitions and engaged online calling on the Government to undertake a cumulative impact assessment of its welfare measures and cuts in public expenditure⁶¹.

Equality concerns

Disabled people's fears over the lack of adequate assessment are shared by the Joint Committee on Human Rights (JCHR)⁶². The JCHR reported that its inquiry into disabled people's right to independent living:

“Received evidence that impact assessments of current reforms were not adequately carried out, and did not take into account the likely cumulative impact of reforms on disabled people. We therefore argue that the Government should publish a unified assessment of the likely cumulative impact of the proposals on independent living.”

The crucial point the Committee considered was the implementation of the Right of Disabled People to Independent Living. The Government has legal obligations under Article 19 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Article 19 requires states to take effective and appropriate measures that

will facilitate full enjoyment by disabled people of key rights to independent living and their full inclusion and participation in the community.

A comprehensive impact assessment would help the Government get a better overview of the many different factors combining to threaten disabled people's incomes and independence. Ultimately it would help the Government to mitigate the impacts of austerity on disabled people and fully realise its obligations under Article 19. This chapter has gone only a tiny way towards describing the cumulative impacts of cuts and changes in support. What is now required is a full, realistic appraisal of what disabled people are going through - with accountability obvious across Whitehall Departments.



4. The economic costs of the cuts

"I know the government say they have to cut spending, but cutting DLA will simply mean they'll have to spend more on other things. It's a false economy."

Hardest Hit interview, 2012

Clearly the Government faces tough choices. It needs to reduce the deficit at the same time it wishes to "protect the poorest". The Emergency Budget of 2010 placed great emphasis on the shared national effort to do the "heavy lifting" of tackling the deficit. No matter how tough the choices, it is incumbent on Government to steer the country on the fairest route out of austerity.

We have already considered the steep human cost of cutting disabled people's benefits and services. This section suggests there are potentially larger financial costs to reforming welfare and cutting benefits than might initially appear obvious.

Firstly, we share our observations on key elements of the Government's welfare reform programme, highlighting where we believe that welfare reforms not only undermine the Government's efforts to support disabled people into employment, but are resulting in huge sums being spent on appeals against wrong decisions.

Later on in this chapter we go on to consider the main policy disabled people told us was causing them concern - the decision to abolish Disability Living Allowance and replace it with Personal Independence Payment from April 2013, meaning half a million fewer disabled people will receive support to meet their extra costs. We highlight that the Government has failed to take into account the longer term impacts of removing this vital support. Furthermore we estimate that as a result the Government will save far less money than it anticipates through cuts to the DLA/PIP budget. Cutting DLA will have profound knock-on effects for disabled people but the wider economy too.

In fact when you take into account the knock-on and implementation costs of replacing DLA with PIP **we conclude that the Government has overestimated the total amount of savings it will generate, by potentially up to £1.6bn.**

Disabled people are not opposed to reforming welfare. There is much to reform. Benefit take up is problematically low. DWP and HMRC estimates from 2007/8 highlight more than £16bn in means-tested benefits and tax credits that go unclaimed each year⁶³. The complex interaction between different benefit rules means disabled people are often left unsure of the financial effects of moving into work or taking on more hours. Application forms for disability and out-of-work benefits often prove confusing and inaccessible: almost 8 in 10 (79 per cent) of respondents to our survey found the ESA application form 'hard' or 'very hard' to complete, and large numbers of people (more than a quarter) found that assessment centres were inaccessible. What we are opposed to is ill conceived or rushed reforms.

Welfare to work

Encouraging disabled people to move off benefits and into work is sometimes talked about as a policy panacea but **disabled people often face substantial barriers to work**⁶⁴. Nearly a fifth (19 per cent) of adults with

impairments cited "anxiety and lack of confidence" as a barrier to employment whereas this drops to only four per cent for adults without impairments⁶⁵.

The announcement of an additional £15million to help expand the numbers of disabled people receiving help from the Access to Work scheme is welcome. However, this will largely help disabled people who are already in work or have a secure job offer. DLA supports a large number of disabled people and their carers to remain in work, and the loss of this support could mean many of these people leave employment (see further analysis below).

In order for the welfare to work system to truly support disabled people into work, it is vital that disabled people get the support they need, and that conditionality and sanctions for claimants going through the Work Programme are proportionate. Many people found ineligible for Employment and Support Allowance nevertheless have health conditions or disabilities that mean they need individually tailored help. We are concerned to note that the Employment Related Services Association (ERSA) has commented on a lack of certainty about the interaction of the Work Capability Assessment and the Work Programme⁶⁶.

ERSA has said it is aware of instances where individual customers are referred to Work Programme providers when unable to work. This will clearly have an effect on welfare to work providers' ability to meet Work Programme outcome-based targets. More fundamental still, it suggests real problems with the delivery of expensive welfare-to-work contracts where sick and disabled people are wrongly found 'Fit for Work'. This is an area of policy that could, unchecked, create waste in the system as welfare to work companies are delivered customers who are too disabled to participate in active job search.

Errors in the system are not only jeopardising disabled people's ability to access the right support. They are also resulting in vast sums being spent on appeals:

- The cost to the Tribunals Service of ESA appeals in 2010-11 was approximately £42.2 million (for 176,600 ESA appeals decided in 2010-11).⁶⁷
- To date, 41 per cent of all Fit For Work decisions have been appealed against⁶⁸. Almost four in ten ESA and DLA appeals are currently successful, resulting in the DWP's decision being overturned⁶⁹.

If the Work Capability Assessment is not reformed, and steps are not taken to ensure that the assessment for PIP is as fair and accurate as possible, we could see these appeal costs rise dramatically. This would cost the Government vast sums of unnecessary expenditure. It would also cost individuals in terms of their health and wellbeing as they experience the stress of the lengthy appeals process.

Universal Credit

The new system of Universal Credit has two key aims. Firstly, to improve work incentives for families who can currently find it difficult to make work pay and secondly, to "radically simplify the complex welfare system, by combining a number of key means tested benefits" (Citizens Advice, The Children's Society and Disability Rights UK, 2012). It is laudable the Government seeks to end the risks and fears associated with moving in and out of work but we fear UC will fail to provide a decent income for all disabled people. For more information on our concerns regarding UC please read **Annexe C**.

Whatever the longer term effects of Universal Credit by 2020-21, the Institute for Fiscal Studies warns that the net direct effect of the Government's other tax and benefit changes is to increase both absolute and relative poverty. This is because other (more immediate) changes, such as the switch

from RPI- to CPI- indexation of means-tested benefits, more than offset the impact on poverty of Universal Credit⁷⁰.

As households with a disabled member lose the additional financial support of benefits like the severe disability premium or the disability element of child tax credit, which can often help to fund care and support in the home, more and more people may turn to health and social care services as their needs increase. With the Resolution Foundation warning that Universal Credit indexation (to CPI) could deepen the squeeze on living standards⁷¹ we urge the Government to get the fundamental design of UC right so it achieves its core policy objectives.

The hidden costs of cutting DLA

By cutting the DLA/PIP budget, the Government aims to save just over £2.2bn by 2015/16. That is the same year the Government hopes to achieve its second fiscal target, "public sector net debt as a percentage of GDP to be falling at a fixed date". But our **analysis indicates that the knock on costs of cuts to DLA** could have an important effect on the Treasury's ability to meet its fiscal target.

The worrying lack of detailed economic analysis by the DWP on the impact of cutting DLA mean that none of the figures presented in the following section of the report are definitive. However, we aim to give an idea of the sorts of knock on costs that could be generated, to highlight the impact of this failure to assess the economic impact.

Work impacts

Our research found that 65 per cent of respondents in work stated that without DLA they would not be able to work.

This mirrors similar findings from a Disability Alliance survey in 2010-11 that found that 56 per cent said a loss of DLA support meant they would have to stop or reduce work⁷². If we draw on the DWP estimate that about nine per cent of the people receiving DLA are in work⁷³, even taking Disability Alliance's more conservative findings, we estimate up to 25,200 disabled people may be unable to retain employment. This could amount to £146.7million in lost revenue to the Exchequer each year⁷⁴.

Disability Rights UK reminds us that many disabled people will not earn the national average and the Treasury is also likely to recoup savings from non-payment of tax credits to disabled people no longer in work. Although this research cannot present conclusive figures, the DWP have provided no better figures to use at this stage for analysing government plans. The

research is therefore useful for highlighting the potential failures and risks of the government's own lack of assessments.

As shown above, our 25,200 figure for disabled people possibly leaving work is also potentially a very conservative estimate. The total number of disabled people possibly losing work could be as high as 50,400, which could result in Treasury losses (based on average income) up to £293.3million per year in NI and income tax payments.

It is also important to observe that lost Treasury revenue is not the only cost if disabled people lose work under diminishing eligibility for DLA/PIP support. A further cost of disabled people being prevented from retaining employment is out of work benefits, which could increase costs significantly. We have opted to focus on lost revenue to the Exchequer because we are dealing with so many uncertain variables, not least the impact Universal Credit will have, if any, to offset a loss of DLA income.

Health and care impacts

One area that the DWP has failed to consider at all are knock-on costs for council-funded social care should 500,000 people lose DLA. **Three-quarters of disabled people who responded to the Hardest Hit survey in the summer of 2012 agreed that losing DLA would mean they would**

need to rely more on their local council for social care support. This could mean vast extra costs for local authorities.

While we cannot present a definitive figure, as those who lose DLA may not qualify for council funded care, we aim to provide some estimates of the costs that could be involved in terms of a greater need for care resulting from the DLA cuts.

To exercise caution we have chosen the more conservative estimate provided by the Disability Alliance, who found that 14 per cent of survey respondents said cuts to DLA would likely result in a need for more local council services⁷⁵. If half a million individuals are to lose DLA, this would represent 70,000 people in total needing more council help.

"If I lost [my DLA] I'd have to give up my therapy, which is the one thing that enables me to live a near-normal life. That would mean I'd probably have more stays in hospital, and that would end up costing more in the long run, wouldn't it?"

Hardest Hit research, 2012

The average cost of council support in the home is £204 a week (£10,608 a year). Based on this average, these 70,000 people could represent around £742.6million a year in unmet need for care that councils may need to meet.

There will be some within this 70,000 who may not qualify for council funded care for example due to means tests and tighter restrictions on eligibility. However in the Disability Alliance survey, many families reported that their relatives would need residential care placements if they lost the financial means to be looked after at home. Disabled people also suggested moving to care homes to avoid being 'burdens' on families. One person needing a council funded care home placement would cost £32,396 per year – so just a handful of people moving into residential care as a result of losing DLA would rack up enormous costs to local authorities.

Total costs

The costs of reducing the numbers of people claiming DLA/PIP by 500,000 include the costs to individuals in terms of increased isolation and ill health and also knock on costs to the wider economy. The DWP has neglected to assess the impact on social care costs and a loss in income tax revenue. We have shown that these costs could be as high as:

- £742 million for those disabled people needing social care
- £146million in lost income tax revenue

Added to the DWP's own estimate of £710 million implementation costs, this is an astonishing £1.6bn (over the three

years of implementation to 2015/16)⁷⁶. It would clearly be inaccurate to claim that this provides concrete proof of the real amounts that the Government will lose in implementing its key welfare reforms. However, we attempt to quantify some of the knock-on effects of cutting DLA and other vital benefits that disabled people have warned of and fear: to disabled people's health, independence and well-being, and the wider economy.

This calculation also highlights the risks of the government's failure to do its own modelling on these impacts. A proper cumulative impact assessment would at least consider the risks of such knock-on costs. To date no such cumulative impact assessment has been carried out so we would urge the Government to consider the direct and indirect impacts of reducing the numbers receiving DLA/PIP by 500,000 and ensure the assessment for PIP is as fair as possible.

A fair assessment would take proper account of the full range of barriers faced by people with disabilities and health conditions, including those with multiple impairments, and those whose needs fluctuate or are unpredictable.

5. Getting it right for disabled people

The Hardest Hit coalition calls on the Government to make sure that its welfare reforms are as fair as they can be to avoid undermining disabled people's stake in and contribution to society.

In making this call we appeal not simply to the Department for Work and Pensions, or indeed the Treasury but to the Prime Minister. The Prime Minister set his Government a very simple fairness test when he promised:

"People who are sick, who are vulnerable, the elderly - I want you to know we will always look after you"
(Rt Hon David Cameron MP, 6 October 2010, Party Conference speech by the Prime Minister).

Our survey findings and interviews with disabled people suggest that people who are ill and disabled feel that they are being attacked, rather than protected. In short: that the Government is failing this test.

We believe that the Government has a chance to fix the mistakes of the past

and to make the right decisions for disabled people. The human costs of the cuts, but also the potential hidden costs to the public purse mean that in many instances, the cuts are a false economy. Here we outline what we feel the Government **could** do to get it right for disabled people. These swingeing cuts are not the only option.

(a) Getting PIP right

Disability Living Allowance provides vital support to millions of disabled people. Disabled people are extremely concerned that Personal Independence Payment (PIP) is designed simply to make dramatic cuts to the DLA budget. But it could be a vehicle for empowering disabled people to overcome the barriers they face on a daily basis, supporting their involvement in their communities and in employment. It could have a preventative function, acting as the ultimate personal budget, so disabled people with relatively less severe care and mobility needs can use the little income available to meet their needs flexibly. And the assessment process, got right, could offer the opportunity to signpost people to a range of other areas of support

available, and even tackle the wider barriers that disabled people face.

All of this will only be possible if the assessment process is as fair as possible. **The regulations governing entitlement criteria for PIP can still be changed.** Key asks include:

- **Fair assessment criteria that take proper account of the full range of barriers faced by people with disabilities** and health conditions, including those with multiple impairments, and those whose needs fluctuate or are unpredictable.
- **The Department for Work and Pensions committing to carrying out a full, public consultation on the guidance** that assessors will need to follow.
- **An assessment and reassessment process that is simple, transparent and proportionate**, rather than wasting precious resources on unnecessary face-to-face assessments where sufficient evidence is already available.
- **Ensuring that people with long-term conditions and impairments that are unlikely to change (or only likely to degenerate) over time are not reassessed** unnecessarily or too frequently.
- **Robust evaluation and monitoring processes for checking the assessment is fit for purpose** and

applying proper sanctions on assessment providers when they do not perform.

(b) Getting Universal Credit (UC) right

The Government must ensure disabled people do not lose out in cash terms as a result of the transition to UC from 2013. Key areas the Government must urgently consider include the abolition of the severe disability premium and the loss in income for some families with disabled children. For more information on our concerns regarding UC read **Annexe C.**

Building on Baroness Tanni Grey-Thompson's inquiry on Disability and Universal Credit⁷⁷ we believe there are a number of ways that the aims of Universal Credit can be achieved more effectively without dramatically reducing disabled people's support. Whilst there would still be people who lose out, these recommendations would better support the most disadvantaged than the current proposals. The regulations governing the fundamental design of UC can still be changed. Key asks include:

- **Protect children on the mid rate care component of DLA.** If it is not possible to protect the additional levels of financial support for all disabled children, then this particular group should be protected. The government should provide for this group by introducing a third rate of disability addition for disabled children under Universal Credit⁷⁸.

- **Additional support should be provided for the costs of childcare for families with disabled children.** The Government should consider increasing the rate of support they provide for families with disabled children to cover 80 per cent of their childcare costs under UC⁷⁹.
- **Introduce a self-care addition to Universal Credit.** We recommend that the Severe Disability Premium (SDP) be retained in full. If this is not possible, we recommend the introduction of a self-care addition to be paid to any disabled adult who does not have someone caring for them.
- **Disability support in Universal Credit should be provided to working disabled people who are found to be fully 'fit for work' but are at significant disadvantage in the workplace as a result of an impairment of health condition.** Loss of in work financial support for many disabled people could severely affect their ability to move into and retain a job.

(c) Getting the Work Capability Assessment (WCA) right

It is clear that radical reform is needed to ensure that the WCA is working consistently and fairly for all individuals with limited capability for work or work-related activity, particularly for those with fluctuating conditions, mental health conditions and sensory



impairments. There is too much tinkering around the edges when what is really required is a fundamental rethink on some of the assessment criteria. Incremental improvements to guidance for assessors will only take us so far. Faster, deeper reform means acting as swiftly as possible to implement recommendations set out in the independent annual reviews of WCA. Key asks include:

- **Changing the WCA descriptors to better reflect the impact of complex and fluctuating conditions,** including particular mental health conditions and sensory impairments.

- **Giving claimants better information** on their right to request a home visit if necessary; plus better information on the ESA decision; reasons for the decision; and what it means for claimants.
- **Improving the ESA50 claim form.**
- **A greater use of additional evidence from professionals who know the claimant best** - at all stages of the assessment process, and a duty on decision makers to consider proactively gathering evidence where it is not provided.
- **Claimants should be assessed wherever possible by assessors with an understanding of their condition**, and training and guidance should be improved for all assessors.
- **Better monitoring by the DWP**, again with the focus on evaluating whether providers are performing.

(d) Getting the social care system right

The Government must provide a lasting solution to the crisis in social care which has endured years of chronic under-funding. It needs to implement the recommendations of the Dilnot Commission and urgently address the current funding gap in the social care system. The Dilnot recommendations are a practical and fair way forward. They more fairly share the costs of care between individuals and the state, protecting everyone from

catastrophic care costs and ensuring that low-income families and younger people are supported. Key asks include:

- **Bring forward a comprehensive Care and Support Bill at the 2013 Queen's Speech.** The Bill should address the long-term funding aspects of a new framework for care and support in England.
- **Introduce the £35,000 cap on care costs** and a £7,000 cap on 'hotel' costs.
- **Raise the means-test to £100,000 as recommended by the Dilnot Commission.**
- **Introduce a clear national system of eligibility and assessment** which includes a national minimum eligibility threshold oriented towards encouraging independent living and preventing long-term dependency.
- **A new strategy for awareness, advice, information and advocacy** around care and support.
- **Measures to relieve the short-term crisis in social care funding**, and sustainably increase funding for care and support in the long-term.

New thinking

There are a number of perspectives on the fairest approach to tackling the deficit. In a recent paper for the Joseph Rowntree Foundation (JRF) Jenny Morris said if disabled people are to make progress, we need to engage with debates other than social security and the finer details of benefits reform; for example we need to engage in debates on economic growth and our shared values in society. The Hardest Hit coalition welcomes new thinking because we are living in incredibly tough economic times. The scale of the challenge is such that no one group has a monopoly on finding solutions. There is an increasing focus in political and economic debate towards raising our productive potential, but there doesn't yet appear to be enough recognition of the role disabled people can play as part of this new agenda.

Disabled people want to be part of the UK's recovery; to work; contribute to their communities; volunteer and care for friends, family and loved ones. Disabled people are committed to playing their part but the plan for economic recovery should be built on inclusive recruitment and retention practices and a much broader, richer understanding of the value of supporting disabled people to live independently. **The vision for economic recovery cannot just focus on moving people off benefits.**

In one simple sense that would be of limited economic value because basic economics tells us low to middle income groups spend more of their income on essentials, which in turn has a useful multiplier effect on household consumption and therefore growth.

However there is another dimension to this debate which doesn't always get an airing. There is a social or public value to supporting disabled people with their additional costs. Disabled people need the kind of welfare state which invests in tackling disabling barriers and in providing resources to meet the additional costs related to impairment⁸⁰.

Tough choices

The Hardest Hit coalition urges the Government to rule out targeting disabled people as part of the next Spending Review. Disabled people have already taken a disproportionate amount of the pain. By the end of this Parliament disabled people and families of disabled people will be £9bn worse off. The human costs are clear to see. The hidden costs of cutting disabled people's benefits and support are not insignificant. Disabled people feel that they have been deliberately targeted, when it is clear that **there are alternatives**. Whilst it is not for us to prescribe where the Government should find its savings, we seek to make clear that cutting disabled people's support is

a choice. We do not feel that it is the right choice.

To illustrate this, the potential savings from cuts to DLA (particularly when bearing in mind the hidden costs outlined earlier in this report) pale in comparison to some of the figures floated in debates on other areas in which the Government could make savings:

- Tax evasion and avoidance cost the Government £9bn each year⁸¹.
- A "mansion tax" - on expensive properties above a threshold of £2million. It is estimated a mansion tax would affect an estimated 74,000 people and, at face value, raise £1.7bn, less the administration⁸².
- A Financial Transaction Tax (FTT), which is a tax of about 0.05 per cent on transactions like stocks, bonds, foreign currency and derivatives. The Bank Levy introduced in January 2011 raises £2.5bn annually but an FTT could raise up to ten times that amount, £20bn a year.

The Hardest Hit coalition represents a wide range of organisations and individuals who will all have differing personal views on where the government should find its savings to tackle the deficit. As a group, therefore, we do not take a view on this. But we are united in the agreement that targeting disabled people for cuts is not the right decision.

Not on the backs of the poor

Whatever one's view of the trade-offs, one thing politicians seem united on is the need to protect the poorest. The Prime Minister delivered his promise to always look after the sick, the vulnerable and elderly in October 2010. More recently the Deputy Prime Minister insisted the coalition will not make future spending cuts "on the backs of the poor"⁸³. Centre-right thinker Ferdinand Mount in the 'The New Few' warns of the dangers of letting society polarise further still between the 'haves' and the 'have nots'⁸⁴. Clearly everyone has a stake in the debate about returning to growth and finding the fairest way out of austerity.

The next twelve months

There are a number of practical things the Government can do over the next year. Here are our four key calls:

- **Learn from the mistakes of the WCA and ensure the assessment for Personal Independence Payment (PIP) is as fair as possible.** Our research shows the potential costs of getting it wrong - greater levels of ill health, unnecessary and costly tribunals and greater numbers of disabled people and their carers dropping out of work.

- **Review the Work Capability Assessment (WCA)** starting with the WCA "descriptors" to ensure that it is working consistently and fairly for all individuals with limited capability for work or work-related activity.
- **Get the fundamentals of Universal Credit (UC) right**, ensuring disabled people do not lose out in cash terms as a result of the transition to UC

from 2013. Key areas the Government must urgently consider include the abolition of the severe disability premium and the loss in income for some families with disabled children.

- **Provide a lasting solution to the crisis in social care** which has endured years of chronic under-funding.



Conclusion

The Government must not treat disabled people as an easy target for cuts in the budget and spending review. Disabled people already feel their basic rights under the UN Convention on the Rights of Persons with Disabilities (UNCRPD) have come under attack. This report has set out the human and financial costs to date and warns that unless disabled people's fundamental rights are upheld all of us will end up in a bad place: disabled people, but the country too as we search for the fairest route out of austerity.

We are at a tipping point, in terms of disabled people's role in society but politically speaking too. We have featured stories like Stuart's, who faces the choice of using his limited income to

heat his home or buy medications and food. We have heard from Christopher who faces unenviable choices on whether to spend his limited DLA income on taxis or face the prospect of missing vital health appointments. In fact we have heard from disabled people and carers from across the country battling in very tough economic circumstances. The Government now faces its own set of tough choices. It can put things right for disabled people, starting with the regulations on Personal Independence Payment and Universal Credit. If it fails to make the right choice the Hardest Hit coalition believes disabled people's incomes and independence will be adversely affected for many years.



Annexes

Annexe A: Background to Disability Living Allowance (DLA) and Personal Independence Payment (PIP)

Disability Living Allowance (DLA) was introduced in 1992 to help people meet the extra costs of being disabled, and is paid irrespective of whether someone is in paid work, and with no restrictions on the basis of income or savings.

DLA consists of two components - Care (which has three rates of payment) and mobility (which has two). To qualify for DLA a person has to need assistance from another person in daily life, though it has long been recognised that the two components act as a proxy for general disability-related expenditure⁸⁵.

The current weekly rates of payment for DLA are as follow;

Lower rate care	£20.55
Middle rate care	£51.85
Higher rate care	£73.60
Lower rate mobility	£20.55
Higher rate mobility	£54.05

The maximum amount of DLA that a person can receive is therefore £127.65, and that is for those people with the most profound barriers to social participation and therefore the greatest extra costs to meet. The vast majority of people receive far less than this⁸⁶.

These are not vast sums of money, but as our research shows, DLA can make a massive difference to people's lives, enabling them to remain independent, look after their health and remain in work.

The latest draft regulations for Personal Independence Payment (PIP) set out plans to create a benefit based on two components, a daily living component and a mobility component. Both components will consist of two rates: an enhanced rate and a standard rate. The actual monetary rates these will be set at are likely to be revealed around the time of the Chancellor's Autumn Statement. The second draft assessment criteria were opened to consultation between January and April 2012 so we still await the final details on the design of PIP.

As things stand, the assessment will ask claimants a series of questions designed to assess their ability to carry

out tasks across eleven activities ranging from 'Preparing food and drink' to 'Moving around'. Claimants will be scored against each of these activities with different 'descriptors' attracting different points based on an individual's experience. Again, we await final details once the final set of regulations are published later in the autumn but a claimant would need to score eight points across relevant activities to be entitled to the standard rate of the daily living and/or the mobility component. Alternatively, they would need to score at least twelve points to be entitled to the enhanced rate of the daily living and/or the mobility component.

Annexe B: The Welfare Reform Act 2012

The Welfare Reform Act abolished **Disability Living Allowance (DLA)**, which is to be replaced by the new benefit, PIP. This means not only stricter new criteria, new face to face assessments, the ending of indefinite awards, and more regular reviews of all awards. Most importantly, it means **half a million fewer disabled people are expected to receive the new Personal Independence Payment (PIP)** as a result of the Act.

The Welfare Reform Bill passed through the House of Commons fairly easily but received a far tougher time in the House of Lords with several amendments

being proposed. The Government was defeated seven times, with seven amendments passed, but following the defeats in the Lords, the Government invoked 'financial privilege'. By invoking the privilege, the Government was able to overturn all seven amendments.

Lots of the impact felt by disabled people will be as a result of changes to 'generic' non-disability specific benefits, such as Housing Benefit but three key measures will have a unique affect on disabled people.

- Replacing DLA for working age claimants with a new payment, the Personal Independence Payment.
- Time limiting contributory Employment and Support Allowance to twelve months for those in the Work Related Activity Group (WRAG).
- Bringing a range of income-based benefits and tax credits into the new Universal Credit.

Annexe C: Universal Credit

From October 2013 the Government will begin the process of bringing together of working age income-based benefits, including income-based Employment and Support Allowance, in a new **Universal Credit (UC)**. This process will mean big changes in the structure of financial support for lower income

families, both in and out of work. Transitional protection will mean existing claimants' benefits remain the same in cash terms but the real terms value of the benefits will reduce over time. Current claimants will have their level of benefit frozen with no increases to take account of rising prices. In addition they may see their support cut immediately if their household circumstances change.

The reforms are designed to improve work incentives, simplify the benefits system and redirect support to those who need it most. It is laudable the Government seeks to end the risks and fears associated with moving in and out of work but we fear UC will fail to provide a decent income for all disabled people.

Unless the Government urgently decides otherwise, Universal Credit will mean 230,000 severely disabled people who do not have another adult to assist them could receive between **£28 and £58 a week less than currently, or up to £3,000 less a year**⁸⁷.

In her inquiry on the impacts of Universal Credit⁸⁸ Baroness Tanni Grey-Thompson has said whilst some disabled people will gain from the new system (for example some working age households without children) many disabled people will get very significantly less help because some of

the additional support in the current system will not be provided to the same degree in Universal Credit.

Key changes include:

- the reduced disabled child additions which will cost families with a child born with a disability up to £24,000 by the time the child reaches 16 years old and
- abolition of the severe disability premium (SDP) which gives additional support to disabled adults who receive the middle rate or higher rate of the care component of DLA and live on their own (or just with children) and no one is paid carer's allowance for assisting them.
- the disability element of working tax credit not being carried through to UC.

At present, families with a disabled child may be entitled to receive support through the disability element of child tax credit, currently worth £57 a week. Under Universal Credit, this support is to be provided through 'disability additions' within household benefit entitlements but the proposal is to cut the help in half to just £28 a week. This change will affect all families with a disabled child unless the child is receiving the higher rate of the care component of Disability Living Allowance (DLA) or is registered blind. The Government estimates that this

change will affect around 100,000 disabled children. Citizens Advice, The Children's Society and Disability Rights UK have shown that many families with disabled children will, in fact, lose more than £28 a week as high childcare costs could mean that the more paid work they do, the more they will lose⁸⁹.

The Government is abolishing the severe disability premium (SDP) with the introduction of Universal Credit. This will cost disabled adults with no one to care for them, or with only a young carer, about £58 per week (over £3,000 per year). Around 230,000 people on income support or jobseeker's allowance receive the SDP (with the numbers on ESA in receipt of the premium not centrally collated). The DWP reports that 25,000 lone parents are currently in receipt of the severe disability premium.

The Government has stated it intends to use the savings from the abolition of the SDP, as well as other cuts to support for disabled people, to increase support to those disabled people with the greatest level of impairment. However, abolition of the SDP means that the group who are likely to be most disadvantaged - those with the most severe level of impairment and who live without an adult to assist them - will still lose at least £28 a week.

Disabled people who have a low earning power but who would be likely

to be found fit for work will lose significantly overall with the introduction of Universal Credit. Unlike the current system, they will receive no more financial assistance from Universal Credit than someone who is not disabled yet may well face significantly greater costs. There is a real risk that it will mean that some disabled people will not be able to afford to stay in work. Baroness Grey-Thompson's Inquiry found that up to 116,000 disabled people who work could be at risk of losing £40 per week⁹⁰. Moving to a model of online claims ('digital by default') presents further risks in terms of financial and digital exclusion.

Annexe D: Work Capability Assessment (WCA)

The Work Capability Assessment (WCA) is used to decide who is eligible for Employment and Support Allowance (ESA), which replaced new out-of-work claims for ill and disabled people from October 2008. The Government is also reassessing 41,000 Incapacity Benefit (IB) claimants per month to determine their entitlement to ESA from April 2011 up to 2014.

Although the WCA has been in place for a number of years this year's Welfare Reform Act limited the amount of time claimants could receive **contributory ESA** if they are judged capable of work related activity. Claimants will no longer

be able to receive contributory ESA after twelve months of payments, even though DWP statistics suggest nine in ten (94 per cent of) disabled people in the Work Related Activity Group take longer than a year to obtain work⁹¹ and many of the people put in this group have conditions which will progressively get worse, not better. This is a benefit which we pay into when working should we become too ill or disabled to work. By time limiting this benefit, the government is not only reneging on this principle of a national insurance against illness or disability, but it also places those who have a working partner or who have built up savings at a serious disadvantage. These are people who will not qualify for the means tested benefit even though their partner's earnings or savings may be modest.

Annexe E: List of Hardest Hit organisations

This report has been produced on behalf of the Hardest Hit coalition but it is not in any way intended to reflect the **specific views of an individual member organisation**. Rather, it represents a coalition effort to contribute new research and policy analysis into the ongoing debate on the future of disability benefits.

The Hardest Hit coalition brings together disabled people, their organisations and charities. It is a coalition of the UK

Disabled People's Council (UKDPC) and the Disability Benefits Consortium (DBC).

The UK Disabled People's Council is the national umbrella organisation of disabled people, run and controlled by, and representing the voices of disabled people in the UK. It represents more than 40 organisations. The Disability Benefits Consortium (DBC) comprises more than 50 national organisations that represent the needs of people who rely on disability benefits. Organisations involved in the DBC are listed at <http://disabilitybenefitsconsortium.wordpress.com/>

To keep our language consistent throughout, we often refer to "disabled people" which inevitably distances us, as authors, from the claims we are making. However, we would like to stress the Hardest Hit coalition is a coalition of, not just for disabled people. Disabled people's concerns are our concerns, hence our use of so many quotes. This report is about giving a voice to disabled people.

Policy recommendations in Chapter 5 ('Getting it right for disabled people') have been taken from the following sources: for PIP and WCA - the Disability Benefits Consortium; for social care reform - the Care and Support Alliance; and for Universal Credit, Baroness Tanni Grey Thompson's Universal Credit and Disability Inquiry.

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⁴ Destination Unknown report - Summer 2012, Wood, C, Demos (June 2012).

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¹⁴ Disability and Universal Credit inquiry conducted by Baroness Tanni Grey-Thompson, 'Holes in the safety net: The impact of Universal Credit on disabled people and their families' report published on October 17th 2012.

¹⁵ See Chancellor of the Exchequer's speech to the Conservative Party Conference (8/10/12).

¹⁶ There were 4,506 responses in total. The survey was publicised through the member organisations of the Disability Benefits Consortium meaning we heard from a diverse cross-section of disabled people from across the UK. Statistics breaking down respondents' answers by region of the UK and impairment or condition are available on request.

¹⁷ We discuss these estimates in greater detail in Chapter 4 on the economic costs of the cuts.

¹⁸ The Hardest Hit coalition brings together disabled people, disabled people's organisations and a number of charities. Throughout the report we have taken the deliberate decision to refer to disabled people in general terms but we are grounded in the social model of disability and believe it is unhelpful to place too much focus on individual impairments and medical diagnoses. Although the Hardest Hit coalition has managed to interview people willing to share their personal details, due to the sensitive nature of the topics being discussed and most respondents' preference not to disclose their details, we have taken the decision to anonymise the majority of quotes. These quotes have simply been listed, 'Hardest Hit research, 2012'. They are mainly derived from our interviews with 50 disabled people but some of the quotes have

been taken from free text boxes in our survey of over 4,500 disabled people. To keep our language consistent throughout, we often refer to "disabled people" which inevitably distances us, as authors, from the claims we are making. However, we would like to stress the Hardest Hit coalition is a coalition of, not just for disabled people. Disabled people's concerns are our concerns, hence our use of so many quotes. This report is about giving a voice to disabled people.

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³⁵ Disability and the downturn, Gore E and Parckar G, Leonard Cheshire Disability, 2010.

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³⁷ (ODI, Life Opportunities Survey 2012).

³⁸ Before Housing Costs figures from 2005-08 show that 12 per cent of disabled adults were living in persistent poverty, compared to 6 per cent of non-disabled adults. This includes Disability Living Allowance (DLA) income and of course relates to figures before the recession, Office for Disability Issues 'Disability Equality Indicators'.

³⁹ Demos, Destination Unknown, Summer 2012 Report (June 2012).

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<http://www.demos.co.uk/projects/disabilityausterity>

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⁴⁴ ADASS Budget Survey (April/May 2012).

⁴⁵ Ibid.

⁴⁶ Ibid.

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⁴⁸ Who Gains from Growth? Living standards in 2020, Institute for Employment Research, Institute for Fiscal Studies and Resolution Foundation, 2012

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⁵⁵ For more information please look at the Treasury documents for the Comprehensive Spending Review published in October 2010.

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⁷⁶ The £710million costs detailed in the DWP Impact Assessment look as though they cover the three year-period; from the moment first new claims and reassessments take place in 2013 through to the target date of reducing expenditure by £2.2bn by 2015/16. So the estimated costs of implementing PIP for one

year, for example in 2015/16, would total nearer £237million.

⁷⁷ Published on October 17th 2012.

⁷⁸ This would be between the low rate and the high rate that would be equivalent to the current disability element of Child Tax Credit, protecting them from the cut without increasing their level of support.

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⁸⁹ Ibid.

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