

“For disabled people,
the worst is yet
to come...”

**DESTINATION UNKNOWN:
SUMMER 2012**

Claudia Wood

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Claudia Wood
June 2012

Foreword

Shortly after the formation of the Coalition Government in May 2010, the Secretary of State for Work and Pensions, Iain Duncan Smith, laid the foundations for one of the most radical programmes of reform to the welfare benefits system since its creation. But his speech – ‘Welfare for the 21st Century’ – included a note of caution: the Government would have to ‘constantly remind themselves that we are here to help the poorest and most vulnerable in our society’.

Since this time, the Government has initiated £18 billion worth of cuts to the benefits system. At the same time, it has reduced funding settlements for local authorities across the country. The fallout of these cuts is becoming more evident as councils look to raise eligibility criteria for social care, increase charges for services and in many cases even close them down. As the Coalition’s programme of spending cuts and welfare reforms have become clearer and more defined; so too has the impact on disabled people and their families.

It was evident from the early days that the Coalition’s deficit reduction programme would have severe – if unintended – consequences for disabled people. Fuelled by our joint belief that these consequences and effects needed to be documented and scrutinised, Demos and Scope set out to map the impact on disabled people with the launch of the first *Destination Unknown* report in October 2010.

For a two-year period we have been following six disabled families and through their experiences we have seen the policy landscape undergo a seismic shift – culminating in the Welfare Reform Act 2012. The stories of our families reveal – with startling clarity – the depth and breadth of the impact cuts to state support and services are having on their lives. Their stories are not unusual; many families like them up and

down the country are increasingly coming under huge stress and pressure.

We have seen evidence of declining mental health, exacerbated by fear for the future, of physical and emotional strain, as informal carers bear the brunt of losing the support and services they once relied on. And most of all, we are seeing it become increasingly difficult for disabled people to participate in everyday family and civic life. This has all taken place against a backdrop of growing hostility towards those who claim disability and welfare support.

By exposing the real life consequences – both intended and not – of the Government’s reforms, the *Destination Unknown* series has helped demonstrate how the impact of its reforms run directly counter to its own vision for stronger communities that support families and has highlighted the real and urgent need for a rethink.

This report should be a wakeup call to the Government and we urge it to take action now, to reassess its reforms, or risk sending a clear message to disabled people, that it may not stand by its own commitment to ‘help the poorest and most vulnerable in our society’ after all.

Richard Hawkes
Chief Executive
Scope

Executive summary

Since October 2010, Demos has been exploring the impact of the Coalition Government's welfare reform agenda on disabled people. With the support of the disability charity Scope, in our first report *Destination Unknown* we modelled the impact of several welfare changes (as announced in the emergency budget of June 2010 and the comprehensive spending review) on the incomes of four disabled households that could be considered 'typical' among the disabled population, according to the packages of benefits they each received, and one additional household, which was in a particularly difficult situation.¹

However, we realised that the real impact of the Government's cuts would not be fully captured by one snapshot report. This is because we primarily focused on changes to welfare benefits in *Destination Unknown*, as it was too early to predict how changes to local authority spending and central government cuts would affect public service delivery. Thus we were only able to see one side of what disabled people were experiencing and might be facing in the coming months and years. It was also clear that further welfare reforms would be announced, and we would need further research to investigate how these might affect disabled people and their families.

We decided to revisit each of the five households every six months to see how the impact of welfare and local service cuts were affecting their quality of life. The combination of reduced benefits income and reduced availability and affordability of services paint a bleak picture for disabled people, which is not static. As the Coalition Government's policies evolve, are implemented and 'bed down', so the fortunes of disabled people change from month to month and indeed from week to week.

To capture the shifting policy landscape, we published two update reports in the spring and autumn of 2011. We revisited

the five households from the original work reported in *Destination Unknown* in October 2010 to see how they had fared over the subsequent six months, and added a sixth household, a social care user. They reported the changes they were seeing to their benefits income, wellbeing and quality of life more broadly, as a result of cuts to public services and local budgets.²

These updates challenged the predictive methodology we employed in our original 2010 report. We found that although we could calculate and predict the financial impact of a shift in the uprating of benefits from the retail price index (RPI) to the lower consumer price index (CPI) inflation rate, for example, several other reforms were affecting the households in our study, which we had not taken account of. These included pensions and mortgage repayments, social care funding policy, closure of local services, increases in fuel prices, and so on. We were able to paint a far richer picture of the circumstances in which these disabled households found themselves, and were struck by their financial vulnerability in their daily lives, and the oppressive sense of uncertainty that they had to live with, which clearly jeopardised their emotional wellbeing. Although nearly everyone faces tough times in this current economic climate, disabled people are hit particularly hard as a result of lower income, higher costs, fewer support services and unpredictable health conditions.

We had planned on revisiting our households six months after our October 2011 report, in April 2012. However, the first quarter of 2012 was extremely eventful. The Welfare Reform Act – which enshrined the most radical changes to state benefits – passed through the Commons and the Lords before becoming an act at the beginning of March. The hitherto shifting policy landscape that we have been tracking in the Disability in Austerity study has now been set in stone. Scope and Demos decided, therefore, to bring the Disability in Austerity study to its conclusion, ‘wrapping up’ the study in June 2012 to coincide with the two-year anniversary of the emergency budget, when the first disability benefit cuts were announced.

This report is therefore the third and final in a series of follow-up publications following the original *Destination Unknown*, tracking the same households as the cuts to services

and changes to welfare benefits begin to take full effect. Our case studies report on:

- a young disabled child (Aisha) cared for by her mother and father
- a disabled man (Albert) and his wife, who cares for him and has moderate disabilities herself
- a single disabled man (Philip)
- a single disabled woman (Carla)
- a middle-aged, disabled man (Steve) who is a social care service user
- a disabled mother (Helen) caring for her disabled child

Our findings cover:

- the predictable impact of the Government's welfare reform – including but not exclusively the transfer to CPI uprating, reassessment of Incapacity Benefit, etc
- the less predictable impact of the Government's budgetary cuts and the wider economic climate on local services
- the events that demonstrate the precarious financial situation disabled households face, including administrative errors
- how well the household is coping and the sources of alternative – but unsustainable – support being used
- an overview of their experiences over the past two years, and a look ahead at what they might expect as key reforms enshrined in the WRA take effect over the next two to three years

The predictable impact of welfare reform

We have calculated how much income the six households have lost over the eight-month period between this report and our previous update report:

- Aisha and her parents lost £211.09
- Albert and his wife lost £1,285.12
- Steve lost £663.70
- Philip lost £70.98

- Carla lost £129.35
- Helen and her son lost £319.41

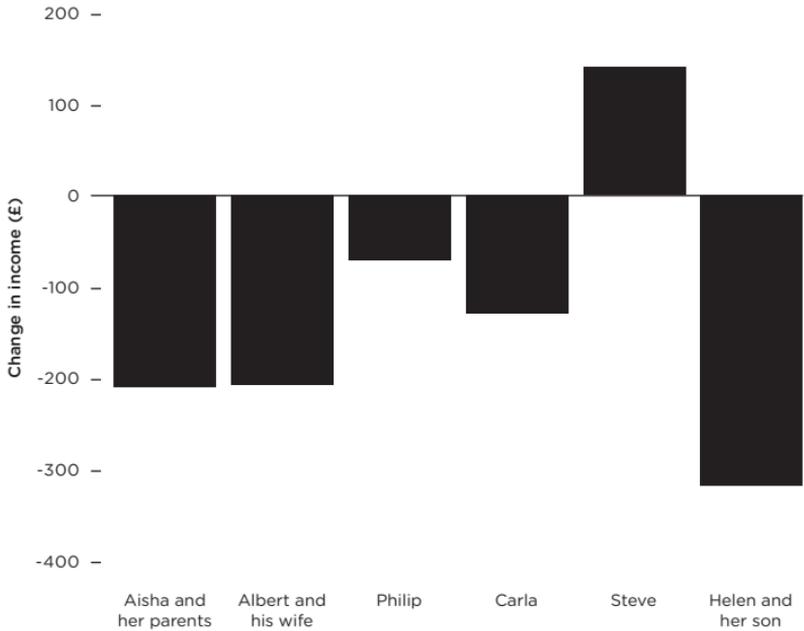
These losses arise from a combination of lower than expected benefit increases (linked to the Government policy of uprating benefits by CPI instead of RPI from April 2011) and other more significant reforms – Albert and his wife Lucy have lost benefits as a result of Lucy’s new pension income, leaving them worse off overall. Steve’s large loss results from him having now to contribute over £25 per week towards his care.

Figure 1 shows the change in income from benefits in the last eight months for the six households we have covered, and figure 2 shows the total loss in income for these households during this period.

In the following report, we review some of the key policy developments that have taken place in 2012 before describing how each of the six households have fared since October 2011. We then reflect on some of the key themes from this latest evidence, which we describe as the ‘legacy’ of welfare reform – issues which we believe will become worse in the coming months and years:

- An ever-diminishing level of civic and social engagement – our households are becoming socially more isolated, and reducing the amount of activities they engage in – from essentials such as work and medical appointments to ‘luxuries’ such as volunteering and training. This is at odds with the Government’s vision of stronger and active communities.
- Retrenchment of services – both statutory services and third sector services are being cut, leaving disabled people with nowhere else to turn. The concept of the safety net no longer resonates with people experiencing serious crises before help is provided.
- Declining mental health – our households are increasingly experiencing anxiety, depression and fear for the future, with some relying on increased medication. Even Philip, a stoic supporter of the Government’s deficit reduction plans, is now worried about his potential loss of benefits and work capability assessment.

Figure 1 **Change in benefits income for the six families over the past eight months**

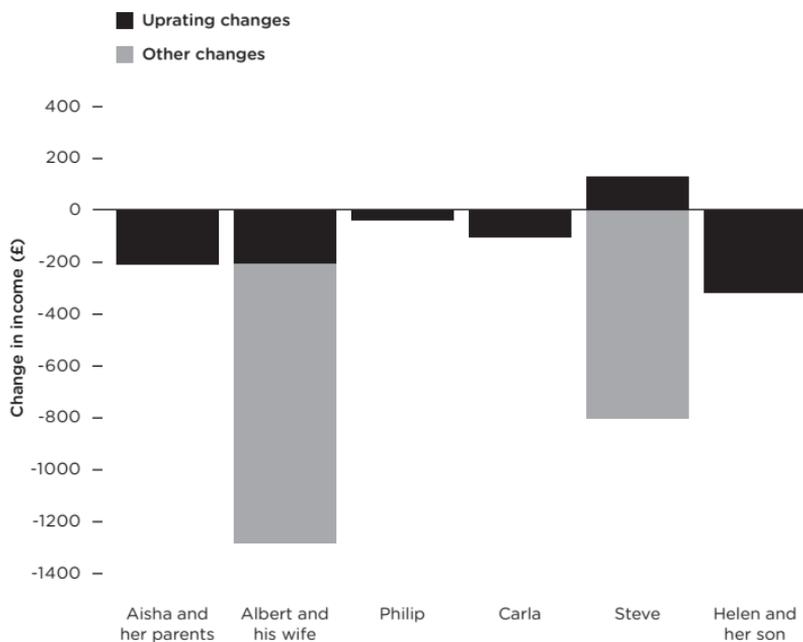


- The burden of care – informal carers are taking the strain as the disabled people in our study are losing the financial support and services they once relied on. There is a clear physical and emotional toll on them.

Finally, we reflect on what we – and what the Government – should learn from the insights in our study over the past two years.

First, if the Government is serious in its commitment to supporting disabled people to achieve greater independence in their community and through employment, they must adopt a more constructive media narrative as a matter of urgency. The current approach, which garners public support for welfare cuts by alienating disabled people and encouraging paranoia and

Figure 2 **The total loss in income for the six families over the past eight months**



hostility towards benefits claimants, will only serve to encourage disablism and undermine community cohesion and trust in the longer term.

Second, the Government must recognise that disabled people are often financially vulnerable, and many have to cope with significant instability in their lives simply in managing their condition or impairment. Changes as vitally important as replacing or reducing benefits must be communicated and explained in a way that allows disabled people and their families time to prepare and adapt. Financial stability, clarity and certainty are vital for those with unexpected health crises and related expenses. Putting content to one side, we believe the way in which welfare reform has been communicated to those likely to be affected leaves much to be desired and has done nothing to

counter the uncertainty and distress felt in millions of households across the country.

Third, disabled people do not live their lives within the boundaries of departmental responsibility. The disabled people in our study certainly did not define themselves by the benefits they claimed, but rather saw them as the vehicle and facilitator through which they were able to live a normal life. The Department for Work and Pensions (DWP) should oversee the framework through which disabled people access employment, education, and other public services, and the Government should have a level of overview to ensure one does not detract from the other. And yet we see this has happened – financial hardship brought about through reductions in benefits income has negatively affected those in our households’ health and access to health services, their ability to lead a community life, to stay in employment, to care for their children. It is vital that the Government takes a step back to ensure their drive to reduce welfare spending does not generate costs elsewhere (such as in the health or care system).

Remembering that people are not defined by their benefits income is also important when considering the cumulative impact of the reduction in benefits and service spending, and local authority budgets. While the DWP is seeking to meet its cost reduction targets, the departments of Health and Education, Ministry of Justice and every local authority in the country is trying to do the same. Disabled households are not benefits recipients – they are parents, employees, students, home owners, older people and citizens. They rely on the same diverse range of services as everyone else, but the Government’s failure to grasp the whole picture beyond the welfare reform agenda can lead to an underestimation of the cumulative impact these hundreds of individual cuts can have on each multi-service-using household. Disabled people are most vulnerable to this accumulation of cuts simply because they are more likely to rely on several benefits and several public services.

So, our final lesson that ought to be learnt is that the Government’s impact assessments should not just consider the *aggregate* impact of *one* cut – but also should look at the

individual impact of *several* cuts with typical households being used as case studies to model the interaction of several different reforms. It is clear the traditional impact assessment is only fit for purpose when one reform is being implemented at a time. It is wholly inappropriate when applied to a comprehensive agenda of reforms spanning welfare and local services.

At the moment, we know that 500,000 people will lose their Disability Living Allowance (DLA) in 2013. And we know that 36 per cent of people will lose their Incapacity Benefit by 2014. We know, too, that the number of councils funding support for people with ‘substantial and critical’ needs only has risen from 78 per cent to 81 per cent from 2010/11 to 2011/12, and that only three local authorities no longer take income from DLA into account when assessing how much a person has to pay towards their care. But do we know – do we have even the faintest idea – how many people will suffer from all four of these budget-driven changes, and what this will do to their household income and quality of life?

Until the Government is able to answer such questions, and start thinking about the cumulative household impact of reform, rather than each in isolation, the human cost of the austerity measures will remain overlooked and policy will be all the worse for it.

1 Introduction

Destination unknown

In 2010, the Coalition Government announced several radical reforms to the welfare system. This was motivated by a need to end what the Government saw as unacceptable welfare dependency and a system that disincentivised work. Nowhere was this more focused than in the world of sickness benefits, the steep rises in which over the last two decades were seen to typify the trend of long-term and multi-generational worklessness among people who were, in fact, fit to work. The concept of ‘festering’ on welfare was introduced, and a less generous ‘scrounger’ rhetoric became all too common.

Within this context, disabled people have expressed concerns that the Government’s cuts are excessive, and do not take proper account of the impact they will have on households’ incomes and quality of life, in particular, the cumulative impact of cuts to multiple benefits for disabled people relying on benefits for most of their income, which had not been properly taken into account. Critics also point out that willingness to work is not an issue for most disabled people. Rather, in the current economic climate, disabled people are often at the back of a very long queue for jobs – and the availability of suitable jobs and employers willing to employ disabled people is the crux of the problem. And despite payment by results schemes being built into the Work Programme, recent statistics suggest the Government’s system of helping people back into work is not reaching anywhere near as many disabled people as had been expected.

Demos set out to explore what, exactly, the impact of benefit cuts would be for disabled people. Our first report, *Destination Unknown*, was produced in October 2010 and modelled the impact of the Government’s welfare changes (as

outlined in the June 2010 emergency budget and October 2010 comprehensive spending review) on the incomes of four disabled households, which could be considered ‘typical’ households among the disabled population according to the packages of benefits they each received. We also added a fifth household whose members were in a more extreme situation to understand just how bad things could get when benefits income was radically reduced.

We contacted these households through the disability charity Scope and mapped exactly what benefits each received, and how much they were worth. We then changed the benefits package of each household according to the proposed reforms, and were able to estimate the loss of income for each household over the course of this parliament – up to 2015. Using further modelling, we calculated an aggregate figure, based on the number of people receiving the same package of benefits as our households across the UK. We concluded that the 3.6 million people claiming disability benefits in Britain today would be £9 billion worse off from 2010 to the end of the current parliament.

However, we realised that the real impact of the Government’s cuts would not be fully captured by this work, because we primarily focused on changes to welfare benefits – it was simply too early to predict how changes to local authority spending and central government cuts would affect public service delivery. We were only able to see one half of the coin when it came to the situation among disabled people.

Disability in austerity

To capture the shifting policy landscape we decided to embark on a six-monthly update series to *Destination Unknown*, following the lives of six disabled households in different situations, in different parts of the country. In April 2011, we published our first update, after revisiting the five households from our original research plus one new household (a social care user), to see how they had fared over the subsequent six months. They reported the changes they were seeing to their benefits income and quality

of life more broadly, as a result of cuts to public services and local budgets. The report, *Destination Unknown: Spring 2011*, challenged the predictive methodology we employed in the original *Destination Unknown* (published in October 2010).³ We found that while we could calculate and predict the financial impact of a shift in the uprating of benefits from RPI to the lower CPI inflation rate, for example, several other reforms were affecting the households in our study, which we had not taken account of, including pensions and mortgage repayments, social care funding policy, closure of local services, increases in fuel prices, and so on. We were able to paint a far richer picture of the circumstances in which disabled people found themselves as a result of lower income, higher costs, fewer support services and unpredictable health conditions. We were struck by the financial vulnerability of the households, the way they lived from day to day, and the oppressive sense of uncertainty that they had to live with, which clearly jeopardised their emotional wellbeing. As the mother of Aisha, one of the participants in this study, told us last year: 'I shouldn't have been pushed so hard. It really pushed me beyond what I can cope with.'

In October 2011, we revisited the households and saw them pushed to increasingly more desperate financial situations. We witnessed local budget cuts taking effect: people were struggling to get equipment, being refused community health services, and having to contribute a proportion of their benefits to services which had hitherto been free. Moreover – and unlike in our April report where we could only predict losses over 2011 – we now had concrete figures on how much worse off the households in our study were in the six months since benefit reforms had started to be implemented in April. These losses ranged from £74.70 to a staggering £781.55 between April and October 2011, and some of the people we spoke to reported having to choose between fuel and food, to cancel hospital appointments as they were unable to afford transport costs, and to let their houses fall into disrepair. It was clear that with each passing month the financial resilience of the households in our study was declining – savings were being wiped out, debts accumulating, and opportunities for one-off emergency grants were exhausted.⁴

We had planned on revisiting our households six months after our October 2011 report, in April 2012, to see what impact an additional six months under this new welfare and local cuts regime had on our households. However, the first quarter of 2012 was extremely eventful. The Welfare Reform Act – which enshrined the most radical changes to state benefits – passed through the Commons and the Lords before becoming an act at the beginning of March. The controversies surrounding this process are described in more detail in the following section, but suffice to say the bulk of the changes have been passed into law unamended. The hitherto shifting policy landscape that we have been tracking in the Disability in Austerity study has now been set in stone. Scope and Demos decided, therefore, to bring the Disability in Austerity study to its conclusion, ‘wrapping up’ the study in June 2012 to coincide with the two-year anniversary of the emergency budget, when the first disability benefit cuts were announced. In the following section, we summarise briefly this two-year process, and the situation disabled people now find themselves facing at the Welfare Reform Act takes effect, before describing how our six households have fared since October 2011.

Two years of radical reform

As we approach the two-year anniversary of the emergency budget, issued by the new Coalition Government just a month after they were elected, it is difficult to enumerate the plethora of reforms that have been ushered in. Not a single benefit or tax credit remains unchanged in some way as the budget announced £11 billion of welfare cuts. The Government’s ambition regarding the scale of reform, and the pace at which it has been achieved, is impressive to say the least. The downside to such rapid change is that corners have sometimes been cut – impact assessments have not always been fully thought through, consultations are less thorough and responses hastily reviewed, and the reforms themselves are seen – at least in some quarters – as slapdash in the way they have been developed.

Given the sheer scale of welfare reform over the past two years, we will not review everything that has occurred here.

Destination Unknown, Destination Unknown: Spring 2011 and *Destination Unknown: Autumn 2011* provide ample detail on the latest developments throughout this period. In this section, we will only discuss the key developing issues which have the biggest impact on disabled people, and focus primarily on the dramatic developments that occurred in February and March 2012 when the Welfare Reform Act, which enshrined most of the key reforms, became law.

The Welfare Reform Act

The Welfare Reform Bill was introduced to the House in February 2012 and was given royal assent in March 2012. It is a substantial piece of legislation, bringing together the reforms proposed in the emergency budget and comprehensive spending review of 2010, as well as the other major reforms announced in December 2010 – the replacement of DLA with a new Personal Independence Payment (PIP), and the introduction of a Universal Credit to replace six individual benefits from 2013.

The key elements of the WRA most likely to affect disabled people are:

- a new PIP to replace the current DLA from April 2013, built within it a target to reduce DLA spending by 20 per cent
- Housing Benefit being reduced for social housing tenants whose accommodation is larger than needed – the ‘under occupation’ penalty will affect 14 per cent of social renters⁵
- Local Housing Allowance rates (set at the bottom 30 per cent of rental prices instead of the average local rental rate, from April 2011) being uprated by the CPI rather than changes in rental prices
- payment of contributory Employment and Support Allowance (ESA) for those in the Work Related Activity Group (WRAG) being limited to a 12-month period
- the total amount of benefit that can be claimed being capped at £26,000 per year; the DWP estimates that about 67,000 households will be affected by the measure in 2013/14 rising to 75,000 in 2014/15

- Universal Credit being introduced to replace six means-tested benefits and tax credits for people of working age from April 2013

The Welfare Reform Bill passed through the Commons fairly easily but received a far tougher time in the Lords with several amendments being proposed. The Government was defeated seven times, with seven amendments passed, in what was described as a humiliation unprecedented in modern times.⁶

Box 1 **Amendments to the Welfare Reform Bill passed by the Lords**

- *amendment 1: protecting disabled children on lower rates of DLA from the reduction in their 'Disability Addition', paid to them if their parents are on low incomes or out of work*
- *amendment 12: protecting housing benefit for social tenants deemed to have un-needed spare rooms*
- *amendment 36a: protecting young disabled people's eligibility for contributory Employment Support Allowance (ESA)*
- *amendment 38: raising to 24 months the proposed 12-month limit on claiming contributory ESA*
- *amendment 38a: exempting cancer patients from the contributory ESA time limits*
- *amendment 59: excluding child benefit from the £26,000 household benefit cap*
- *amendment 62c: dropping the proposal to charge single parents for using the Child Support Agency (CSA)*

In addition to these amendments, the Government also conceded a number of other changes in the face of Lords opposition.

Government concessions to the Welfare Reform Bill

- *The qualifying period for receiving DLA – the length of time recipients have to show they will be eligible – has been cut from six to three months.*
- *The mobility component of DLA – which pays for transport and travel costs – will be retained for those in residential care homes.*
- *Housing benefit caps have been delayed for existing claimants from April 2011 to January 2012.*
- *A discretionary fund will be established for local authorities to use in ‘difficult cases’ – such as ensuring a family is not forced to move when a child is at a critical stage in its schooling.*
- *There will be ‘transitional arrangements’ to ease the impact of the overall benefit cap – including a nine-month ‘grace period’ for those who had been in work for the previous 12 months and additional short-term payments to families who cannot move immediately for reasons such as child protection and education.*
- *‘Assessments, weightings and entitlement criteria’ are agreed by the Commons before PIP goes ahead, that PIP assessments will be tested on ‘real people’, and that disabled people will be involved in the ‘design and implementation’ of PIP.*
- *The lowest income single parents seeking support from the CSA will not be charged a fee. Other parents will be charged £20 upfront fee, and then ongoing charges of 7–12 per cent to the CSA for collecting their maintenance.*

However, following the defeats in the Lords, the Government invoked ‘financial privilege’ – an archaic resolution from 1671, which states that the Lords cannot rule on bills of ‘aids and supplies’ – raising tax and spending it. By invoking the privilege, the Government was able to overturn all seven amendments, with critics commenting that the move made clear what everyone already knew – the bill was designed to reduce spending, not reform welfare per se.

The bill became an act with the concessions outlined above, but with none of the more substantial amendments put forward by the Lords.

DLA reform – scope, select committees and Spartacus

In December 2010 the Government announced that instead of simply reducing DLA spending as previously suggested it would replace the benefit with PIP. Following a consultation phase, in April 2011, the Government published the initial draft of assessment regulations for PIP, and between May and August 2011, asked for comments (rather than carrying out a formal consultation) on these draft assessment criteria. It also (controversially) piloted them before comments were received between May and September among a group of volunteers already in receipt of DLA.

In October 2011, the Work and Pensions Select Committee began to take evidence on ‘Government support towards the additional living costs of working-age disabled people’, exploring the Government’s policy objectives in replacing DLA, the PIP draft eligibility criteria and similarities to the Work Capability Assessment.

In the same month, a coalition of 24 organisations signed a report authored by Scope, responding to the first PIP proposals. The report, *The Future of PIP: A social model-based approach*, was described in detail in *Destination Unknown: October 2011*.⁷ It put forward an alternative assessment model, which ‘genuinely seeks to capture the barriers that a disabled person faces in their everyday life, and what affect these have on their capability for choice and control, participation and independence’. Partly drawing on research by Demos exploring disability-related costs, Scope proposed an assessment which took into account other variables likely to drive up disability costs and stay true to the ‘social model’ of disability, rather than focus on what it viewed to be an unacceptably narrow, medical approach put forward by the Government.

Unfortunately, this was not taken on board, and the newly drafted criteria, issued for a second consultation phase on 16

January 2012, remained founded on a points-based PIP assessment, which many compared to the much-criticised work capability assessment because of its focus on physical and functional limitations. Critics pointed out that this test, focusing on medical issues, physical and functional limitations, clearly showed that the Government had reneged on its commitment to adopting the social model of disability, which focuses on the social barriers which make life harder (and in the context of DLA, more expensive) and how to overcome them.

The Government's support for the social model was expressed on several occasions – not least in the first DLA consultation document in 2010, which stated 'we remain committed to the social model of disability'.⁸ Before the consultation, the Minister for Disabled People, Maria Miller, insisted that the Government was 'absolutely committed to a social model for [the reform of DLA], not a medical model'⁹ and was quoted making similar claims as late as January 2011. Yet within less than a year, this commitment had been entirely undermined, with the Minister for Welfare Reform, Lord Freud, commenting on the DLA reforms in the Lords: 'I do accept that it is not a full social model assessment; it is not intended to be.'¹⁰ Scope expressed particular concern at this shift in narrative, pointing out that DLA was 'designed to contribute to disabled people's additional costs, which themselves arise from the same social barriers that lie at the heart of the social model of disability'. In its response to the DWP's latest consultation on the PIP assessment criteria, Scope went on to comment:

*The new criteria fixate on assessing an individual's ability as determined by their impairment – be this 'physical, sensory, mental, intellectual or cognitive; or any combination of these'. Clearly, this is another medical model test – the type that the minister had previously insisted would be avoided.*¹¹

Shortly after the consultation on the second version of the assessment criteria had ended, and just as the Welfare Reform Bill started being debated in the Lords, the report *Responsible Reform* (also known as the Spartacus Report) was published.¹²

Written by a group of disabled people, it analysed over 500 responses to the first PIP consultation issued in December 2010. It found that, overall:

- 74 per cent of respondents were against the proposals for PIP.
- 19 per cent had mixed views.
- Only 7 per cent supported it fully.

The report concluded that the consultation response had underplayed the extent of the opposition to the plans, and, more damagingly, found that the consultation process did not meet the Government's code of practice on consultation:

It was two weeks shorter than recommended and took place over the Christmas holidays. Crucially, the Welfare Reform Bill was presented to Parliament two days before the consultation ended, meaning that responses could not be taken into account when drafting legislation for PIP¹³

It also debunked the Government's claim that there had been a 30 per cent rise in DLA claims relevant to PIP, and suggested that this figure was actually 13 per cent:

These figures were not made clear to parliamentarians as they debated the bill, despite a Government report being signed off in May 2010. Government are still using the 30% figure despite admitting that it gives a 'distorted view'.¹⁴

The report found that the vast majority of disabled people did not agree there was a need for an entirely new benefit to replace DLA, and that as it cost £675 million to implement, it was a 'costly irrelevance' in a time of austerity.

The Spartacus report generated significant media and social media interest, and was credited with spurring the Lords to vote against the Government on a series of amendments just two days later.¹⁵

The following month, the Work and Pensions Committee published its findings, concluding:

The PIP assessment criteria, as drafted, tend towards the ‘medical model’ of disability. Significant improvements have been made in the second draft but the criteria will still assess people’s impairments rather than the barriers to full participation in society which they face.¹⁶

It published 54 written submissions following its call for evidence in September. Most of the feedback received was highly unfavourable. The Disability Benefits Consortium, a national coalition of over 50 charities and other organisations, was particularly critical of the fact that the PIP reform is designed to achieve a 20 per cent reduction in DLA expenditure, an arbitrary reduction put in place without consideration of the implications this would have on disabled people.

Alongside this, the Disability Alliance,¹⁷ a coalition of 250 disability charities, pointed out that there are currently 652,000 working-age low rate care DLA recipients, and as PIP only has two rates of payment and abolishes the ‘low rate’, it is possible that all of these people will lose their financial support.

On 26 March 2012, the third consultation on the PIP assessment was published, and is running until the end of June. In May, the DWP issued an impact assessment confirming that around 500,000 working age disabled people would lose their financial support by 2015/16.¹⁸

In an interview with the *Telegraph* Iain Duncan Smith referred to the 30 per cent figure (already demonstrated to be false) as a reason for reform, and explicitly linked PIP to the need for care and support. This confirms concerns, aired at the Select Committee evidence sessions, that the Government is linking PIP to care and duplicating social care support for those with the greatest need, rather than those with the highest disability related living costs (which, as previous Demos research demonstrates, do not always go hand in hand).¹⁹

In May 2012 Iain Duncan Smith said:

We are creating a new benefit, because the last benefit grew by something like 30 per cent in the past few years. It’s been rising well ahead of any other gauge you might make about illness, sickness, disability or, for that matter, general trends in society.

*It's not like incapacity benefit; it's not a statement of sickness. It is a gauge of your capability. In other words, 'Do you need care, do you need support to get around?' Those are the two things that are measured. Not, 'You have lost a limb.'*²⁰

These comments not only suggest the Government has begun aligning PIP to social care needs (and eligibility), but also confirms the medical model approach being taken – looking at a person's functional limitations to get around rather than the social barriers and costs that might be associated with it.

ESA – time limitations and fitness to work

The time limitation of eligibility for contributory ESA (WRAG) to one year, which was announced in the October 2010 spending review, has proven highly controversial because of the arbitrary nature of the one-year limit, the fact that it is particularly harsh (the Government's equality impact assessment estimates that 90 per cent of contributory ESA claimants in the WRAG will be affected by the one-year time limitation) and because it undermines the contributory principle of welfare. Chris Grayling admitted in the Commons in May 2011 that in fact he expected 94 per cent of WRAG claimants to take longer than 12 months to find employment,²¹ and also confirmed that the decision to set the limit at 12 months 'certainly has a strong financial dimension to it'.²²

Another controversial point is that those claiming contributory ESA have made adequate national insurance contributions to claim it, and the time limitation is imposed regardless of the amount of contribution a person has made. The Disability Benefits Consortium states that 85 per cent of contributory ESA claimants had been in employment for most of their working lives, and only 26 per cent return to work within 18 months.²³ Many see this undermining of the contributory principle in welfare deeply unfair.

As outlined above, the Lords challenged this proposal and amendments were passed to extend the limit to two years and

exempt cancer patients from this, but both were subsequently overturned in the Commons.

In a related development, Paul Farmer, the chief executive of Mind, resigned from the Work Capability Assessment scrutiny panel, which monitors its use in assessing people for ESA. Farmer stated that he resigned from this panel because of the reluctance of the Government to improve the tests, despite very high appeal rates:

*The DWP seems absolutely committed to pushing 11,000 people a week through a flawed system. That's the real problem for us... That doesn't feel fair. I've moved from being puzzled about the reluctance to change, to being increasingly frustrated. I genuinely don't understand why the government doesn't just pause the process and reflect on why it's not working... tens of thousands of people are being reassessed using a test that is still not fit for purpose. Approximately 50 per cent of people are appealing against the decision, and a remarkable half of those appeals are being upheld, meaning that as many as one in four tests are wrong. The cost to the taxpayer of the tribunal system alone is £50m, about half the £100m a year being spent on reassessment. We've heard about jobcentres being shocked when someone who is clearly unwell turns up having been told that they are fit for work.*²⁴

There is now an increasing trickle of media stories of cases people dying of their conditions shortly after receiving their 'fit to work' judgements,²⁵ and people with terminal illness or complex disabilities requiring 24-hour care being judged fit to work.²⁶ Indeed, a recent FOI request carried out by the *Mirror* newspaper discovered that 1,100 people died between January and August 2011 while in the WRAG group, and a further 1,600 died before their assessment had been completed.²⁷

Remploy closures

Remploy, offering sheltered employment to disabled people in factories making school and library furniture, car parts and so on, lost its government subsidy in March 2012 following the June 2011 Sayce Review.²⁸ Around 1,700 people were made redundant as a result.

The Sayce Review recommended an end to segregated employment like that provided by Remploy factories, where subsidised placements are created for disabled people. Instead, the funds diverted from Remploy should be ploughed into the promotion of access to mainstream employment for disabled people. It asserted that disabled people, in having the same career aspirations and desire to use their talents as everyone else, should be able to access the same broad range of career opportunities through personalised support, rather than being given limited options – like subsidised employment in a narrow range of sectors. To achieve this, the review recommended doubling the numbers of disabled people using Access to Work, a scheme which provides adaptations, equipment and other support to ensure disabled people can access the workplaces (and therefore job opportunities) in the mainstream job market.

While it costs around £25,000 a year to keep a Remploy employee in work, it costs £2,700 per person for the Access to Work scheme – so potentially far greater numbers of disabled people could be helped into work by redeploying the Remploy funding. On announcing the closure of some of the Remploy factories, Maria Miller MP duly promised an extra £15 million for Access to Work, on top of the current budget of £100 million, and stated that up to 8,000 more disabled people could be supported into mainstream employment with the freeing up of Remploy funds.

However, this additional funding aside, there have been concerns expressed from all sides that there is inadequate support on offer for Remploy's former employees, who need considerable help with the transition to finding employment in the mainstream job market.

The Sayce Review recommended that those made redundant by the closure of Remploy businesses should have:

individual resources for a guaranteed place in Work Choice, Remploy Employment Services or alternative employment support of their choice. Remploy should ensure that practical support for wider family and community life is on offer. There should be support and life planning actively offered at least six months prior to any business change and the

*package should recognise people's long-standing work with Remploy. The Department and Remploy should actively pursue links with employers to provide alternative employment opportunities.*²⁹

And yet, the Government has promised just £8 million to help the redundant Remploy workers find another job, representing around £4,700 each. This £4,700 does not even cover a Work Programme provider's placement fee (which is awarded to them when they find employment for a disabled person) – let alone the costs of the actual welfare to work support.³⁰ It is certainly a fraction of what would be required to implement Sayce's recommendation.

Of course, once redundant, Remploy workers are likely to claim ESA, which at around £5,000 per year is still less costly than subsidised employment. Most will fall into the contributory ESA group (thanks to their employment histories), which, as we mention above, is now limited to one year before means testing takes effect which may see some of these workers lose their benefit, with Jobseeker's Allowance (JSA) the only option. This will considerably reduce the costs for government, but will leave those Remploy workers unfortunate enough not to find another job within a year of redundancy with very little financial and welfare to work support.

Given the insufficient support on offer for the newly redundant employees, unions and disability charities alike have warned that many of these workers will face prolonged unemployment and benefits dependency – with some suggesting the workers will never find another job and will spend a lifetime on benefits.³¹

In this context, Iain Duncan Smith's most recent comments regarding this group provoked calls for his resignation. He stated: 'Is it a kindness to stick people in some factory where they are not doing any work at all? Just making cups of coffee?'³²

This added insult to injury for the workers, many of whom now face a very real likelihood of a lifetime of benefits dependency, because the Government has not followed the Sayce Review's recommendations to provide intensive and ongoing welfare to work support for those made redundant.

Work experience for disabled people

In recent months, there has been controversy about the Government's work experience offer as part of its Work Programme. In February 2012 there was increased scrutiny on the voluntary eight-week work placements offered as part of the Work Programme, as people claiming JSA reported feeling compelled to take part or risk losing their benefits and it emerged that benefits would be stopped if a person wanted to leave the placement after the one-week cooling-off period. The Government was accused of offering 'free labour' to large retailers such as Tesco. However, there was less debate regarding a less well-known clause (54) in the Welfare Reform Act, which will allow Jobcentre Plus staff to place those in the WRAG group of ESA onto work experience placements for an unlimited time, rather than the eight-week period for JSA claimants. There is provision also to compel disabled people to carry out these placements or face the withholding of their benefits.³³ Several disability experts voiced their concerns that Jobcentre Plus staff were not properly qualified to mandate work for those with complex physical and/or mental conditions, and that particularly for those with fluctuating and mental health conditions, such activities would require regular review to ensure not more harm than good was coming from such placements.³⁴

In a related development, it was reported at the end of May 2012 that Work Programme providers have been unable to secure employment for as many disabled people as had been expected. It was originally envisaged that around 30 per cent of referrals to the Work Programme would be Incapacity Benefit or ESA claimants, but this figure is actually 7 per cent, so some specialist disability Work Programme sub-contractors cannot survive. Poor IT systems, Jobcentre Plus staff failing to refer disabled people to the Work Programme and the high level of appeals against ESA decisions have all been blamed for this poor take-up.³⁵

Looking ahead

Although it is true most of the reforms have now passed into law and many already implemented, there are still a number of milestones on the horizon. As this is the final report in this series,

we will not be tracking further changes to the welfare regime, and so briefly outline what the future holds here.³⁶

In January 2013:

- Child Benefit will be withdrawn from households where an individual earns more than £50,000.

In April 2013:

- Council Tax Benefit will be replaced by localised support for Council Tax – schemes set up by local authorities within a 10 per cent reduced budget.
- DLA will begin to be replaced with PIP in trial form.
- Size criteria will be extended from the private rented sector to the social rented sector. People living in houses larger than they need (under-occupiers) will have their Housing Benefit cut. There will be a 14 per cent cut for under-occupying by one bedroom and a 25 per cent cut for under-occupying by two or more bedrooms. This will affect 670,000 working-age social sector tenants.
- Local Housing Allowance rates will be increased in line with CPI inflation instead of the market rents in each area.
- Crisis loans when waiting for benefit claims to be processed and budgeting loans are to be replaced by a ‘payment on account’ system.
- Other crisis loans and community care grants are to be abolished with the budget being passed to local authorities, who may or may not introduce their own system of assistance.
- Any rise in income of £5,000 or more during the award year will be taken into account when finalising a tax credit award. Previously, only income rises of £10,000 or more were taken into account.
- The £26,000 benefit cap will come into force.

In October 2013:

- The transfer of existing benefits claimants onto Universal Credit will begin and should be completed by October 2017.

- All working-age claimants will be reassessed with 500,000 losing their benefit between 2013 and 2014/15, with new claimants going straight onto PIP.

In March 2014:

- The migration of Incapacity Benefit claimants onto ESA will be completed, having started in 2008. All Incapacity Benefit claimants will have been reassessed regarding their fitness to work with the Work Capability Assessment.

Coping with the cuts - how local services are affected

In the wake of so many radical new changes to welfare benefits, it can be easy to lose sight of the other side of the coin. However, the Government's plans to reduce the budgetary deficit also include unprecedented cuts to many public services and local authority budgets. Therefore disabled people, who are disproportionately more likely than others to be dependent on benefits for a large proportion of their income and more reliant on public services (relating to not just health and social care, but also housing) and third sector organisations whose grants have also been cut, are essentially facing a double setback of reduced income and reduced access to support services. In the October 2010 spending review, annual budget reductions of 7.1 per cent for local authorities were announced, with the first of these new local authority budgets coming into effect in April 2011. To throw some light on this issue, in September 2011 Demos and Scope published *Coping with the Cuts*, which collated data from a series of freedom of information requests sent to local authorities across England and Wales to explore how budget cuts were impacting front line disability services.³⁷ We summarised them in *Destination Unknown: Autumn 2011*,³⁸ but to recap:

- The number of councils setting their care eligibility criteria at 'substantial and critical' needs only has risen from 78 per cent to 81 per cent from 2010/11 to 2011/12.

- Over half of the local authorities surveyed had closed some kind of disability support service.
- Only seven councils had decreased the charges people pay for services such as meals on wheels this year; 22 councils had kept charges frozen, while the remaining 123 had increased their charges by up to 400 per cent.
- Only three local authorities no longer take income from DLA into account when assessing how much a person has to pay towards their care.

Such changes do not include cuts to other services such as Supporting People (cut by 12 per cent³⁹) and the Independent Living Fund (closed to new applicants), and cuts to charitable grants (77 per cent of charities expected public sector funding of their organisation to decrease in 2011/12 with those giving a figure expecting a median 31–40 per cent cut).⁴⁰

2 Revisiting disabled households – the lived experience of welfare reform and local cuts

This report is the last in a series of follow-up publications succeeding the original *Destination Unknown*, which aim to describe the lived experiences of disabled people as the cuts to services and the changes to welfare benefits take effect.

Our case studies are:

- a young disabled child (Aisha), who is cared for by her mother and father
- a disabled man (Albert) and his wife who cares for him and also has moderate disabilities
- a single disabled man (Philip)
- a single disabled woman (Carla)
- a middle-aged, disabled man (Steve), who is a social care service user
- a disabled mother (Helen) caring for her disabled child

Many of the welfare reforms announced in the emergency budget, spending review and subsequent months have had clear and predictable effects on the disabled households we are following. In particular, the change in uprating benefits according to the CPI means that, each April, the benefits increase is based on the previous September's (lower) CPI inflation rate instead of the RPI or Rossi rates. As a result of this change, in our first update in May 2011, the benefits of the disabled people in our study increased by 3.1 per cent instead of 4.6 per cent, or 4.8 per cent for Rossi-linked benefits such as Incapacity Benefit – a loss of 1.5 to 1.7 percentage points from each benefit. Then, in April 2012, benefits increased by 5.2 per

cent instead of 5.6 per cent or 6.8 per cent for Rossi-linked benefits, a loss of an additional 0.4 percentage points or 1.6 percentage points. These losses were easily calculated and while these reductions will seem small when considered weekly, over time they can accumulate into hundreds of pounds.

By speaking to disabled people regularly since our October 2011 update report, we have also been able to gain an insight into the variety of ways in which budgetary cuts have impacted on the lives of those in our households which are more difficult to calculate or predict – including the closure of services and changes to non-disability benefits.

In our previous reports, we were struck by several things. The first was that disabled households are extremely vulnerable to financial shocks, and most were managing some level of debt in order to get by. The second was the precarious nature of their impairments or conditions. Most of the households reported frequent changes and often deteriorations to their health over the course of the project. The third was the constant need to ‘battle’ and ‘fight’ for access to services and benefits to which they were entitled. Administrative complexity, frequent delays and being given conflicting advice exacerbated the situation, leaving households with no financial safety net in sometimes desperate situations.

Finally, we saw how these households were trying to cope with their increasingly difficult financial situations. They were sourcing alternative support – from charities, families, grants and so on – as state support was being wound down. However, it was immediately clear that all of these options were used as one-off emergency measures, rather than sustainable solutions. In the light of reduced funding for voluntary organisations in the face of increased demands for help, it is unsurprising that disabled people are finding it difficult now to secure any alternative means of support.

These themes have all reoccurred in this, the final Destination Unknown update report. Two of the households have had the financial shock of an unexpectedly high utility bill, and two are still battling for their children’s disability-related entitlements from their local authorities. Four reported

deteriorating health, and three told us of how they had sourced support from alternative (often charitable) means but said that this had come to an end. However, further additional themes have emerged – ones that we might describe as the ‘legacy’ of welfare reform – such as a clearly increased burden on informal carers and deteriorating mental health across most of our households. We go into these additional themes in more detail at the end of this section where we also sum up our findings. We will first describe each household in turn.

Aisha: a disabled child, cared for by her parents

The situation is getting better but that’s because we’ve got better at fighting for her needs. The situation actually got worse.

It’s because of this financial uncertainty; families are under pressure all the time. You can’t afford for anything to go wrong.

- Aisha was born with cerebral palsy and has quadriplegia and epilepsy.
- Her primary carer is her mother; her father works.
- Her father is now taking regular unpaid leave to help care for Aisha and the couple’s five other children.
- They have a £120,000 mortgage and £20,000 in debts.
- Aisha’s family receives:
 - DLA for Aisha (high mobility; high care)
 - Child Benefit
 - Carer’s Allowance

What were we expecting?

The primary impact on this family is the lower than expected increases to a range of benefits in April 2011 and April 2012, as a result of increasing benefits by the CPI in September 2010 and September 2011 (3.1 per cent and 5.2 per cent respectively) instead of RPI (4.6 per cent and 5.6 per cent respectively). However, as Aisha’s parents also receive Child Benefit for their

Table 1 **The amount by which Aisha's family's income has been reduced since we last saw them**

Family benefits	Reforms to benefits from April 2011	Worse off in 2011? to June 2012?
DLA – high mobility	Benefit increased by CPI instead of RPI – from £49.85 to £51.40 per week (CPI), instead of £52.14 (RPI) in FY 2011 then to £54.05 (CPI) instead of £54.27 (RPI) in FY 2012	74p per week, £14.80 worse off over five months to April 2012, then 23p per week, £2.74 over 3 months from April to June 2012
DLA – high care	Benefit increased by CPI instead of RPI – from £71.40 to £73.60 per week (CPI), instead of £74.68 (RPI) in FY 2011 then to £77.45 (CPI) instead of £77.72 (RPI) in FY 2012	1.08p per week, £21.60 worse off over five months to April 2012, then 27p, £3.26 worse off over 3 months from April to June 2012
Child Benefit	Benefit frozen – so no increase from £87.30 per week in 2010; would have increased to £91.31 with RPI in FY 2011 and to £95.40 in FY 2012	£4.01 per week, £80.20 worse off over five months to April 2012, then £5.11, £61.36 worse off over 3 months from April to June 2012
Carer's Allowance	Benefit increased by CPI instead of RPI – from £53.90 to £55.57 per week (CPI), instead of £56.37 (RPI) in FY 2011 then to £58.45 (CPI) instead of £58.66 (RPI) in FY 2012	82p per week, £24.60 worse off over five months to April 2012, and 21p, £2.53 worse off over 3 months from April to June 2012

Aisha's family has lost £211.09 in the last eight months

other children – which the Government has now frozen at 2010 rates for the next three years – their overall reduction in benefits income is more substantial than that of other households in our study.

What didn't we account for?

A lack of statutory support and charity cuts

In May last year, Aisha had a fitting for a standing frame, provided by the NHS. When we last spoke to the family, five months after the assessment, it still had not arrived. Finally, in February 2012, nine months after the assessment, the frame arrived. However, Aisha's mother now reports that the local authority refuses to provide the family with more than four mornings of support for Aisha, because she has two parents who are married. Supposedly, they should provide each other with support and not rely on external help, and when Aisha's mother tried to get support from a social worker, they were told that there were families in worse situations.

When we last spoke to the family in autumn 2011 they were receiving support from a children's charity instead for an additional morning, so for five mornings a week, a support worker would come and help get Aisha up, washed, dressed and fed, while her mother got the rest of the children ready for school. In April 2012, however, one of the support workers left and the charity – hit by budget cuts – has not been able to afford a replacement. As a result the family has gone back to receiving help on four days a week only. To help relieve the strain on Aisha's father, Aisha's eldest sister Marie, who is 10, now helps look after her and takes her out. For Aisha's mother, having Marie's input is a huge help, but, she is uncomfortable with putting such burdens on another child – 'only ten years old and is already working before school'.

As we described in previous updates, Aisha's condition requires her to see a physiotherapist regularly and the family used to have appointments every month. However, they report that over the past 18 months, the increasing demands on and reduced availability of specialists means the family can only get three appointments a year. 'Now we have to phone them all the time,' Aisha's mother says.

Carers' health

In our spring and autumn 2011 updates we described how Aisha's room had been renovated to the wrong specifications by the local authority occupational therapist. While the care team

admitted liability for this, they said they did not have the money to fix the problem, leaving Aisha unable to use her room as her hoist could not fit in there with her bed. The good news in October 2011 was that after several months of fighting, the local authority agreed to pay part of the cost to have the room fixed, while Aisha's father's employer – who runs a grant scheme for employees in financial distress – agreed to pay the rest. However, Aisha's mother had told us that the strain of winning the fight to make Aisha's bedroom accessible had taken its toll on the family; and she acknowledged that the struggle had left her less in control over her anxiety and depression.

On revisiting the family this spring we were told that in April 2012 Aisha's father had collapsed. He was off work for a month. Despite his employer being 'very understanding', and having good support from his union rep, Aisha's father still has 52 days of work to make up before the end of the year – he already takes four week's unpaid leave each year to help with Aisha's care.

This has had a big impact on the family. They now refuse hospital appointments unless they are scheduled at certain times, so that Aisha's father can go to work for at least half a day to make up the lost days: 'We do get a bit of resistance [from hospital staff] [but] I just can't risk his health anymore. We've been trying to do too much, for too long.' Aisha's father is now on medication, which they purchase at the current prescription rate of £7.65, to help him relax and balance his moods.

According to Aisha's mother, her husband's health 'has suffered quite badly'. Each morning, he leaves for work at 5am. As he is the family's sole earner, and has such an early start, he is unable to help care for Aisha during the night – the 'night shift', as they call it. Aisha's mother and her husband sleep in different rooms throughout the week so that one is on duty while the other can sleep. During the week, when her husband works, he sleeps downstairs; at weekends, they switch so that she can get some respite. 'It puts a strain on family and married life', says Aisha's mother. 'Time together [between her and her husband] is just gone.'

The extent of Aisha's care needs have had a significant impact on her mother's health, too. Over a year ago, Aisha – who

can at times throw herself backwards violently – injured her mother’s shoulder. Because Aisha needs constant care – in addition to the attention required by her siblings, including her younger brother – her mother was unable to see a nurse or doctor about the injury. Instead, she continued with her daily routine and caring duties, despite suffering a lot of pain and her shoulder joint being inflamed. ‘There was no way I could rest it at all,’ she said. It is only now, almost a year later, that she has been able to put the time aside to make an appointment with a nurse to see if she needs proper treatment.

As documented in past reports in this series, Aisha’s mother suffers from anxiety and depression, which at times has been compounded by ongoing problems with social services. Now, she says she is ‘more in control’ than when we last spoke to her. Nevertheless she will have to remain on medication, which she buys through a pre-paid certificate at £100 a year, for some six to eight months. The turmoil over the past year ‘has [had] such a profound effect, symptoms could still re-establish... and still do, in some respects’.

Adult education

Because her caring responsibilities have left her unable to work for the past three years, Aisha’s mother enrolled on an Open University degree course, which she started a year before our first report, *Destination Unknown*, was produced in October 2010. Now halfway through her six-year course, Aisha’s mother reports that since the current government has come to power, the grants she – and others – receive for her studies have been cut significantly. This year, she has had to pay £150 for her course; for the last two years she received a full grant and had to pay nothing. She is currently waiting to see how high the fees for her fourth year will be. If she is unable to afford it, she will stop her course, which she thinks will have a big impact on her wellbeing. Study, she says, ‘is a little way to get a bit of self-esteem for carers who are at home’; ‘it allows me to be an adult’. A lot of carers study, she remarks, but now ‘the Government has even robbed us of that’.

Good news

Aisha's family has recently learnt that they are entitled to a 12 per cent discount on their Council Tax bill, which has been backdated for four years. They were paying a little more than a £1,000 per year, but will now save between £12 and £15 per month – money they will use to help offset their fuel bills. As we know, Aisha's family spends a considerable amount on diesel, as they need to drive their daughter to different medical appointments a fair distance from the family home. They estimated for us back in spring 2011 that they spend £150 per month on fuel, but then reported in autumn 2011 that the rising cost of diesel at the pumps meant they had started skipping hospital appointments. The high price of fuel – in the first quarter of 2012 diesel prices reached £143.05 per litre – will certainly have hit the family hard.

Aisha's own education is going well. When we last spoke to the family in late 2011, they were struggling to get the local authority to update Aisha's special educational needs statement so that the council would be obliged to provide the lunchtime supervision she needs – she is at risk of choking if left to eat alone. Since then, the school requested that the educational officer came out to the school to meet Aisha, which, up until then, had not happened. 'They [the named officer] just have pieces of paper to read; they don't ever meet the child.' However, on meeting Aisha, the educational officer apologised to the family and has since updated Aisha's statement. The school also provided Aisha with a toilet chair and a motorised hoist so that one person is able to lift her and help her going to the toilet (before, by the time it took to find two members of staff to help, Aisha would often soil herself).

How is Aisha's family coping?

In our last update, we noted that after the local authority's refusal to provide an electric outdoor wheelchair for Aisha, Aisha's parents engaged in a big fundraising effort in their local community from June 2011 and managed to raise enough, by October 2011, to afford Aisha's chair themselves. They were grateful for the support but Aisha's mother told us that having to

‘beg’ was very hard for her husband. Now, Aisha needs an accessible wardrobe, one which she can approach in her wheelchair. The family has managed to save £200 towards it, but cannot find the remaining funds; so once again, the family has turned to the community around them for help. Aisha’s father is doing an abseil for charity: half the funds he raises will go to Aisha’s school; the other half will go towards paying for her wardrobe. Twenty-five parents of disabled children are taking part in the abseil. Aisha’s mother tells us that it is good for fathers of disabled children – who are frequently not the primary carers – to do something like this for their children.

Summary

The last year or so has been a difficult battle for Aisha’s family. Her father’s recent collapse and her mother’s return to medication and anti-depressants show the strain the family are under. Now that Aisha has moved into her newly redesigned room and is having lessons at school to use her power chair, we asked her mother whether things were looking up for the family. ‘The situation is getting better; but that’s because we’ve got better at fighting for her needs,’ her mother said. ‘The situation actually got worse.’

Box 3

How many people are in Aisha’s family’s situation?

We know that 323,140 claim Carer’s Allowance and no other benefit, like Aisha’s mother. Unfortunately, the DWP does not collect data on how many of this group also claim Child Benefit (and therefore probably care for a disabled child.) However, we do know there are 123,490 children like Aisha, aged under 16, who claim DLA (higher rate care). As it is likely that most children claiming DLA have a parent as a carer, who claims Carer’s Allowance, the most reasonable figure for this family is 123,490.

Aisha’s family is somewhat unusual in that her parents have a larger number of children than average, making their loss from the freeze in Child Benefit also larger than average.

However, if we assume that these 123,490 claimants are in average-size families, so therefore an only child or perhaps with one sibling, then the loss to child benefits income would be more in the region of £1.88 per week rather than £4.01.

Families like Aisha's – with an average number of children – are £123.18 worse off in the last eight months, or £15.2 million worse off as a group, and £30.3 million worse off since the emergency budget of 2010.

What does the future hold for Aisha's family?

The introduction of PIP to replace DLA, due in 2013, will apply to working age disabled people only, so Aisha will not go through this assessment. However, it is possible PIP will be extended to children and older people in the future.

As Aisha claims DLA, her family's benefits income will not be capped when PIP is introduced in April 2013. In October 2013, however, the transfer to Universal Credit will begin. After some discussion about this reform, Aisha's mother's Carer's Allowance will not be included in this credit. In April 2014, Child Benefit will be 'unfrozen', which will be a boon to Aisha's family, but it will be uprated by CPI from the 2010 base, so will be lower in real terms than before.

Albert: disabled man, cared for by his wife Lucy, who has moderate disabilities herself

It's a worry – all the time – not having enough money to survive.

- A former self-employed businessman, in 2006 Albert suffered a stroke, which left him with a weakness in his left hand; his left leg is often prone to locking. He also has two heart defects, which required him to have surgery. He experiences regular memory loss.
- His wife and carer, Lucy, was made redundant four years ago. She has arthritis.

- The couple has a £137,000 mortgage. Until recently, they were in mortgage arrears of £13,000; they are £67,000 in debt.
- They receive:
 - DLA for Albert (high mob; middle care);
 - DLA for Lucy (low care)
 - Incapacity Benefit
 - Support for Mortgage Interest (SMI) pension and carer's premium for Lucy

What were we expecting?

As with our other case study participants, Albert and his wife received lower than expected increases to their benefits in April 2011 and 2012 after the switch from rating them according to CPI rather than RPI. A bigger loss is Albert's Incapacity Benefit 'age addition' of £15 (given to him as he became disabled before he turned 45), which was cut to £13.80 in 2011 and just £11.70 per week in 2012, creating a larger than expected drop in income. Over the last eight months, Albert and his wife have £63.60 less in income because of this one reform.

However, the biggest impact has been Lucy reaching retirement age. As we described in our last update report, because Lucy received a pension and carer's premium she lost her entitlement to Income Support and Carer's Allowance. Yet the amount she now receives is significantly lower than before – overall she is over £1,200 worse off as a result in the last eight months. This is in addition to the reduced income Lucy and Albert receive from SMI. Since October 2010, SMI has been paid at the level of the Bank of England's average mortgage rate (3.63 per cent), which is significantly lower than the previous SMI rate of 6.08 per cent, set in December 2008. This reduction led to a shortfall in Albert and Lucy's mortgage payments, and they were £13,000 in arrears by the time we spoke to them for our autumn 2011 report.

Table 2 **The amount by which Albert and Lucy's income has been reduced since we last saw them**

Household benefits	Reforms to benefits from April 2011	Worse off in 2011? to June 2012?
DLA - high mobility	Benefit increased by CPI instead of RPI - from £49.85 to £51.40 per week (CPI), instead of £52.14 (RPI) in FY 2011 then to £54.05 (CPI) instead of £54.27 (RPI) in FY 2012	74p per week, £14.80 worse off over five months to April 2012, then 23p per week, £2.74 over 3 months from April to June 2012
DLA - middle care	Benefit increased by CPI instead of RPI - from £47.80 to £49.30 per week (CPI), instead of £49.99 (RPI) in FY 2011 then to £51.85 (CPI) instead of £52.06 (RPI) in FY 2012	69p per week, £13.80 worse off over five months to April 2012, then 21p, £2.53 worse off over 3 months from April to June 2012
DLA - low care for Albert's wife	Benefit increased by CPI instead of RPI - from £18.95 to £19.55 per week (CPI), instead of £19.82 (RPI) in FY 2011 then to £20.55 (CPI) instead of £20.64 (RPI) in FY 2012	27p per week, £5.40 worse off over five months to April 2012, then 9p, £1.14 worse off over 3 months from April to June 2012
Incapacity Benefit + age addition	Benefit increased by CPI instead of Rossi - from £91.40 to £94.25 per week (CPI), instead of £95.70 (Rossi) in FY 2011 then to £99.15 (CPI) instead of £100.65 (Rossi) in FY 2012	£1.45 per week, £29 worse off over five months to April 2012, and £1.51 or £18.11 worse off over 3 months from April to June 2012
	Age addition of £15 reduced to £13.80 in 2011 and £11.70 in 2012	£1.20 per week, £54.60 worse off over five months to April 2012, and £3.30 or £66 worse off over 3 months from April to June 2012

Table 2 **The amount by which Albert and Lucy's income has been reduced since we last saw them – *continued***

Family benefits	Reforms to benefits from April 2011	Worse off in 2011? to June 2012?
Income Support (couple, higher rate)	Lost this benefit when Lucy received her pension.	A loss of £110.60 per week between October 2011 and April 2012 and £116.40 per week between April and June 2012; £2,212 and £1,396.80
Carer's Allowance for Albert's wife	Lost this benefit when Lucy received her pension; a loss of £55.55 per week between October 2011 and April 2012 and £58.40 per week between April and June 2012	£1,111 and £700.80
Albert's wife's pension	Receives £102.15 per week +£31 carer's premium from October 2011 to April 2012, then £107.45 from April + £32.60 carer's premium	Total pension income from October 2011 to June 2012 is £4,343.60; total loss of Income Support and Carer's Allowance is £5,420.06 over same period

Albert and his wife have lost £208.12 in income between October 2011 and June 2012 as a result of lower benefits, plus a loss of £1,077 in lost benefits as a result of Lucy gaining a pension.

Total loss in eight-month period = £1,285.12

What didn't we account for?

A last minute reprieve

When we last spoke to Albert, he and his wife were in significant arrears (£13,000) on their mortgage. Their ability to pay had been badly affected by a reduction to their benefits income and, in particular, cuts to the SMI payments they received. Between our spring and autumn 2011 updates, their arrears had increased by £6,000.

After a barrage of letters and phone calls from their mortgage lender, during which time Albert was told to ‘get a job’, despite having had a stroke; sell the car, which is specially adapted to his needs; ask his neighbours for money; and use his pension, which Albert was, by law, incapable of doing, the couple was told they would be evicted from their home of ten years in February 2012.

When we spoke to Albert again in May 2012, he filled us in on what had occurred. He had offered to pay off part of the arrears, but this was dismissed and the lender demanded full payment. ‘They wanted all or nothing’, he said. It was ‘a very stressful time’. But just as the repossession notice was about to be processed (‘the clock was ticking’) Lucy’s son stepped in to pay off the mortgage arrears, and Albert and Lucy have been able to stay in their home.

However, the debts have not been written off – Albert is now indebted to his stepson to the tune of £13,000. ‘We’ve always got that on our mind,’ Albert said. ‘We’ve always got that anchor around our necks.’ Albert and Lucy are now trying to sell the house, before they start accumulating arrears again, and move to cheaper accommodation. But things are moving slowly: despite putting the property on the market nine months ago, they have had just three viewings.

Fuel bills

The house is in better condition than when we last spoke to Albert, who because of his financial difficulties had lived with broken windows for about a year (something that would have had a profound effect not only on their heating bills but also the way the couple manage their health conditions; Albert goes into a type of shock if he gets too cold). The windows have since been fixed; but their heating and fuel bills have ‘shot up through the roof’. Because of their conditions, the couple has to have the heating on for significant periods of time, costing them more.

The couple receive help with their electricity bill, via the Government’s Warm Home Discount scheme, and are on top of utility payments. But, they have been told they use ‘too much’ heating to be on a low tariff gas scheme and owe around £135 for

their gas bills. Albert estimates that the couple pays around £83 per month for gas and £70 for electricity. Furthermore, their boiler broke down on three different occasions over the course of last winter; for a couple of days Albert and his wife were left without heating or hot water. Fortunately, they pay their gas provider an insurance-style cover charge of £44 per month, which entitled them to access an emergency boiler mechanic – free of charge – who managed to fix their boiler (at the third attempt) in February.

Statutory services and charity support

The local services Albert and his wife rely on have also been affected by the cuts. In March 2012, Lucy's doctor's surgery shut down. He believes it was forced to close because of budget reductions: 'It was a cost-cutting exercise.' The new surgery they use (they both see a doctor at least once a month) is a mile and a half away, further than the previous one, which was just half a mile from their house.

When we last spoke to Albert, he mentioned he had recently asked for help from a community psychiatrist nurse but had been informed by his primary care trust that because of budget cuts they no longer had such staff available; instead, they suggested he applied for help to a charity. Albert is now seeing a nurse, provided by a mental health charity free of charge, once a week, despite the health centre being five miles away, on the other side of town.

Summary

The last two years have brought significant turbulence to Albert and Lucy's lives – not least because had Lucy's son not bailed them out the couple would have been evicted from their home. Since the project began, the couple's debts have rocketed and they have increasingly struggled to pay the bills and make essential household repairs. A year ago, Albert and his wife expressed concerns that they were living from hand to mouth, just making ends meet. Looking at the months ahead, this concern remains at the forefront of Albert's mind: 'It's a worry – all the time – not having enough money to survive.'

Box 4

How many people are in Albert and Lucy's situation?

We know there are 433,590 people who, like Albert, claim DLA, Incapacity Benefit and Income Support. We also know where there are 121,510 people who, like Lucy, claim Carer's Allowance and Pension Credit or Income Support, but we do not know how many people have lost out because of the combination of benefits and pensions income. So, just looking at Albert's situation as an individual, we can see that people like Albert are £201 worse off, or £87 million worse off as a group in just eight months, and £149.7 million worse off since the emergency budget of 2010.

What does the future hold for Albert and Lucy?

In 2013, the Government will start reassessing DLA claimants and 500,000 people will lose this benefit over the course of a year. As there will be two rates paid for PIP (mobility and daily living) and three for DLA care and two for DLA mobility, it is difficult to establish what risk Albert faces in losing his support when reassessed. We do know, however, that around 290,000 are currently in Albert's situation of receiving high rate mobility and middle rate care – under PIP, the equivalent category would be Enhanced Mobility and Standard Care. Only 190,000 people will qualify for this benefit, so Albert may be at risk of losing his DLA.

Lucy receives DLA (low rate care). There is no 'low rate' – only 'standard' in the new PIP model but, again, 100,000 people who receive no mobility rate of DLA (like Lucy) across all three care groups will lose their DLA between 2013 and 2014. As Lucy receives the lowest rate, she is likely to be most at risk of losing her benefit.

Albert will also be reassessed for his Incapacity Benefit claim, and migrated onto either ESA or found fit to work. Latest statistics from the DWP suggest just over 36 per cent of Incapacity Benefit claimants will be judged fit to work, while 35 per cent are placed in the WRAG group. The reassessment phase is due to finish in 2014.

Philip: a single disabled man

I have no idea what will happen over the next six months – not a clue.

- Philip is in his late 40s and lives alone.
- He has life-long epilepsy, which deteriorated in 2008 and left him unable to work and separated from his wife.
- He has a mortgage of £73,000, credit card debts that float between £4,500 and £5,500, a £1,500–2,500 overdraft, and owes his brother £6,500.
- He receives:
 - DLA: low mobility; middle care
 - ESA
 - Council Tax Benefit.

What were we expecting?

Like other disabled people, Philip received a smaller increase in his DLA than he would have done if it had continued to be uprated by the CPI rather than the RPI, but the most significant development for Philip will be the new time limit for claiming the contributory WRAG rate of ESA. As he had been claiming this for longer than a year when the policy was applied in April 2011, he only had 12 months left to claim ESA from that point. When we spoke to Philip about this in October 2011, he was not aware of this change – he told us he had seen his benefits adviser in June, who told him that he could expect to remain in the WRAG unless he heard otherwise.

In April 2012, Philip was one of the 60 per cent of contributory ESA claimants who were transferred to income-based ESA after 12 months. He was eligible for this as he lives alone and has no income. Were he to have a partner who worked, he would have been ineligible for this benefit. Income-based and contributory ESA are paid at the same rate, and so Philip has seen no change in his ESA income.

Table 3 **The amount by which Philip's income has been reduced since we last saw him**

Philip's benefits	Reforms to benefits from April 2011	Worse off in 2011? to June 2012?
DLA – low mobility	Benefit increased by CPI instead of RPI – from £18.95 in 2010 to £19.55 per week (CPI), instead of £19.82 (RPI) in FY 2011 then to £20.55 (CPI) instead of £20.64 (RPI) in FY 2012	27p per week, £5.40 worse off over five months to April 2012, and 9p, £1.14 worse off over 3 months from April to June 2012
DLA – middle care	Benefit increased by CPI instead of RPI – from £47.80 to £49.30 per week (CPI), instead of £49.99 (RPI) in FY 2011, then to £51.85 (CPI) instead of £52.06 (RPI) in FY 2012	69p per week, £13.80 worse off over five months to April 2012, then 21p, £2.53 worse off over 3 months from April to June 2012
ESA WRAG rate	Benefit increased by CPI instead of Rossi – from £91.40 to £94.25 per week (CPI), instead of £95.78 (Rossi) in FY 2011, then to £99.20 (CPI) instead of £100.65 (Rossi) in FY 2012	£1.53 per week, £30.60 worse off over five months, and £1.46, £17.51 worse off over 3 months from April to June 2012 (income-based ESA)

Philip has lost £70.98 in the last eight months

What didn't we account for?

Changing status

Over the past few years, although Philip has been out of work, his former employer has 'kept him on the books' – without pay – with the view of allowing Philip to return to his job should his condition improve again. However, he was recently requested by his employer to undergo an occupational health medical, which

determined that he would be unable to come back to work in the foreseeable future. He reports that the last time he went to Jobcentre Plus he was still being retained by his employer, so they told him they would be in touch with him again in six to 12 months. Now he is no longer retained, Philip will have to undergo the full range of job-search requirements inbuilt into ESA as he is part of the WRAG group.

Previously, Philip had had several appointments with a Pathways to Work provider (the predecessor of the Work Programme), where he investigated the possibility of part-time self-employment, but he told us nothing came of it. He then volunteered with a housing provider for around a year – arranged by the Pathways to Work provider – but had to stop when he fell and smashed his elbow. He tells us he last heard from the provider about nine months ago, when they told him their welfare to work contract was up for renewal and to wait to hear from them. He heard nothing further, and reports that the offices they used are now empty – so he assumes they lost the contract.

Philip is convinced he is unable to work. Despite this, he has begun sending out his CV to potential employers and recruitment agencies: ‘I have to do something about [the change in ESA] financially. Even though I’m not capable [of working]... I wouldn’t [recruit me] if I was them,’ he says. Philip’s situation is made more difficult because he now faces a challenge in describing his work history: as he has been on the books of his last employer since his condition deteriorated, he has, on paper, an unbroken work record. But, the reality is that he hasn’t been able to work for several years – something any prospective employer would soon find out. Philip believes he has to try to find work but remains unsure how to do so with employers, given his work history.

Mortgage deal

At present, Philip is on an interest-only deal with his mortgage provider, and he receives SMI from the Government so his full mortgage is covered. However, the arrangement with his mortgage provider expires in July 2012, and he believes he will have to convert to a repayment mortgage, which he estimates will

cost around £650 per month. If the Government continues to pay the interest through SMI, Philip estimates he will have to pay around £400 per month to cover the remaining amount, and is unsure how he will be able to do this.

Health

Philip's health has deteriorated; he had two seizures in early 2012. When we last spoke to him, he was awaiting the result of a sleep study to monitor his erratic sleeping patterns (when we last spoke to him, he had, that week, slept from Tuesday morning through to Thursday afternoon). Philip was worried that if the study found that his sleeping problems were down to the anti-convulsive medication he takes for his epilepsy, and not, as he suspected, because of a sleep disorder like narcolepsy, this would increase his chances of being found fit for work at his next assessment.

When we revisited Philip in May 2012, he told us the study had found that his sleeping patterns were exacerbated by his medication. In addition to the anti-convulsive medication that he takes for his epilepsy, Philip is also on anti-psychotic medication to help manage his mental health problems. Philip worries this will mean he will be found fit for work when he next has a Work Capability Assessment.

Summary

Out of all the people we have spoken to for this series, Philip has always been the most accepting of the suggestion that the Government needs to cut public spending to reduce the deficit. He has said all along that he is very proactive at minimising his own costs and living within his means. Now, his future is much more uncertain than it was before as a result of his change in employment status and resulting urgency to find work before his benefits are withdrawn. 'It's not today that concerns me; it's the next three, 12, 16 months ahead.'

Box 5

How many people are in Philip's situation?

We know that 288,950 claim, like Philip, a combination of ESA and DLA. However, the DWP does not provide figures of how many in this group claim Philip's particular combination of DLA and ESA. Philip claims low mobility and middle care, which accounts for 15 per cent of DLA claimants. We will assume that all of those claiming ESA and DLA at these rates are in the WRAG group rather than Support Group (and low and middle rate DLA is likely to mean the DWP deems you fit to work at some point in the future).

The best estimate for this group is, therefore, that there are 44,787 people like Philip, who are £3.1 million worse off as a group in the last eight months, or £65.2 million worse off since the emergency budget of 2010.

What does the future hold for Philip?

Philip, too, will have his DLA reassessed during 2013 or 2014. His combination of DLA – low mobility and middle care – is the largest group of current claimants, numbering 450,000. There will be no 'low mobility' category in the new PIP benefits regime, but if we assume 'middle care' claimants will become 'standard daily living' in PIP, their number claiming all levels of mobility will fall by 90,000. As Philip claims low mobility, he is most at risk of losing this benefit.

In April 2013, Council Tax Benefit will be replaced by localised support for Council Tax, run by local authorities, within a 10 per cent reduction in costs built in, so Philip may see this benefit change too.

As Philip has now moved onto the income-based ESA WRAG group, he will need to go through another reassessment shortly. Given the results of his latest health test, he may be found fit to work.

Carla: a single disabled woman

These things will come back to bite them...

- Carla is a single disabled woman who lives alone.
- Carla worked through the 1980s and 1990s before she suffered a mental breakdown, after which she was sectioned for a while and then diagnosed with recurring depressive disorder.
- She applied for DLA and was initially turned down. She appealed the decision and lost twice, before attempting suicide.
- Her case was taken up by a local law centre, which pursued the decision to tribunal at which point she was awarded DLA.
- She now receives:
 - DLA (higher rate care and lower rate mobility)
 - Incapacity Benefit
 - Income Support and Severe Disability Premium
 - the housing element of income support
 - Council Tax Benefit.

As she lives alone and receives higher rate DLA care but has no one to help care for her, Carla is entitled to the Severe Disability Premium. She lives in her own flat and receives the housing element of Income Support to cover her mortgage payments – at about £57 per week.

What did we expect?

All of Carla's benefits have been increased by a lower than expected amount in April 2011, but as she is currently receiving Incapacity Benefit, she could at any point be reassessed as part of the Government's plans to move Incapacity Benefit claimants onto ESA. When we spoke to her in autumn 2011, Carla was aware of the forthcoming replacement of DLA with PIP, but unaware of the introduction of ESA to replace Incapacity Benefit three years ago, and was upset when we told her. The idea that she may have to undergo another medical assessment shocked her – following her assessment for Incapacity Benefit in 2003, her doctor had told her she would not have to undergo such an assessment again.

Table 4 **The amount by which Carla's family's income has been reduced since we last saw her**

Family benefits	Reforms to benefits from April 2011	Worse off in 2011? to June 2012?
DLA – low mobility	Benefit increased by CPI instead of RPI – from £18.95 in 2010 to £19.55 per week (CPI), instead of £19.82 (RPI) in FY 2011 then to £20.55 (CPI) instead of £20.64 (RPI) in FY 2012	27p per week, £5.40 worse off over five months to April 2012, and 9p, £1.14 worse off over 3 months from April to June 2012
DLA – high care	Benefit increased by CPI instead of RPI – from £71.40 to £73.60 per week (CPI), instead of £74.68 (RPI) in FY 2011 then to £77.45 (CPI) instead of £77.72 (RPI) in FY 2012	1.08p per week, £21.60 worse off over five months to April 2012, then 27p, £3.26 worse off over 3 months from April to June 2012
Incapacity Benefit	Benefit increased by CPI instead of Rossi – from £91.40 to £94.25 per week (CPI), instead of £95.70 (Rossi) in FY 2011 then to £99.15 (CPI) instead of £100.65 (Rossi) in FY 2012	£1.45 per week, £29 worse off over five months to April 2012, and £1.51 or £18.11 worse off over 3 months from April to June 2012
Income Support (+ £57 towards housing costs)	Benefit increased by CPI instead of Rossi – from £65.45 to £67.50 per week (CPI), instead of £68.46 (Rossi) in FY 2011 then to £71 (CPI) instead of £72.09 (Rossi) in FY 2012	96p per week, £19.20 worse off over five months to April 2012, then £1.09 or £13.08 worse off over 3 months from April to June 2012
Severe Disablement Premium	Benefit increased by CPI instead of RPI – 53.65 to 55.30 instead of 56.11 (RPI) in FY 2011 then to £58.20 (CPI) instead of £58.39 (RPI) in FY 2012	81p per week, £16.20 worse off over five months to April 2012, and 20p per week or £2.36 worse off over 3 months from April to June 2012

Carla has lost £129.35 in the last eight months.

Carla told us that she is hoping she will be old enough to avoid some of the Government's reforms to working-age benefits, though in fact she will not have reached 65 by the time PIP is rolled out nationally nor at pensionable age before she is moved onto ESA (or found fit to work). Carla turned 60 this year.

When we last spoke to Carla she mentioned her real concerns at the prospect of losing her freedom pass, as the local authority have cut free travel passes for people with mental health problems because of council cuts. The council have openly admitted that scrapping these passes will save the local authority hundreds of thousands of pounds. But for people like Carla, this will have a profoundly detrimental effect. 'Having a freedom pass is a lifeline,' she told us. She has reapplied for the pass but has not yet heard whether she will be awarded one. If she is unsuccessful, this will have a significant effect on her finances.

What didn't we account for?

Health

Carla's health has fluctuated over the past six months: 'It's ups and downs... that's the nature of the beast,' she said. An episode in which she says she was bullied by a previously close friend had a big impact on her wellbeing; she became agoraphobic and scared to go out. As a result, Carla had to go on an increased dosage of medication. Her condition has improved recently, and she is now able to reduce the dose.

Statutory services and charity support

During our research for *Destination Unknown: Autumn 2011* Carla informed us that she had heard her benefits agency and law office was closing down because of 'lack of funding'. This she found distressing; she credits the agency with 'saving her life' by taking on her case for DLA and securing her benefits. Six months later and Carla is still unsure as to the fate of the law centre. When she sought advice elsewhere, she was given 'wrong information', which, she says, should have been provided by professional staff, but who had instead been replaced with volunteers.

Disablism

Over the past few months Carla says there has been increasing talk in her community about rising incidences of disability hate crime. As well as being bullied by her own friend, another friend of hers, who is blind, was recently harassed by a local gang who, at one point, threatened to kill him. When asked whether he took this up with the police, Carla responded: 'Take this to the police? Where are the police?' Following cuts to London's police numbers, there are over 150 fewer police officers in Carla's borough. Carla has found disability hate crime a new phenomenon: 'People are scared to intervene... I had never heard of disability hate crime before.' When asked about Government public spending cuts, Carla is critical: 'These things will come back to bite them,' she remarked.

Box 6

How many people are in Carla's situation?

We know there are 433,590 people who like Carla claim DLA, Incapacity Benefit and Income Support. Of these, 369,930 don't have children.

So, we can see that people like Carla are £47 million worse off as a group in just eight months, and £99.6 million worse off since the emergency budget of 2010.

What does the future hold for Carla?

Carla's DLA will be reassessed in 2013, and as part of the reduction of 500,000 DLA claimants over a one-year period, it is possible that she will lose her low-rate mobility entitlement. The DWP envisages that people with 'enhanced daily living' and no mobility entitlement will increase by 80,000 people, suggesting about 80,000 of those with higher rate care (like Carla) will lose their mobility component. As Carla claims low rate mobility, she is at greater risk of this loss than those claiming higher rate mobility.

Carla will also have her Incapacity Benefit reassessed before 2014, and her Incapacity Benefit and Income Support will be replaced by ESA, or, if she is found fit to work as around 36 per cent of claimants are, JSA.

Steve: a social care user

We're all getting punished.

- Steve is in his late 40s. He has secondary progressive multiple sclerosis, which has worsened over the last five years. He used to work, but retired because of his poor health and was given an early pension, worth £12,000 per year, in 2005.
- He lives with his wife, who works full time as a nurse.
- They have a mortgage but no other substantial debts.
- Steve receives:
 - High DLA mobility and care
 - ESA Support Group
 - direct payments of around £980 each month, which he uses to purchase 30 hours of care.

What were we expecting?

When we last spoke to Steve in October 2011, he had recently been told that, following a Work Capability Assessment, he would be placed in the Support Group of ESA.

On revisiting him in June 2012, he reports he was transferred from Incapacity Benefit to ESA in November 2011. This is set at £105.05 per week – an increase on the £99.15 that he used to get while on Incapacity Benefit – so he is now slightly better off. However, as he must now pass a substantial amount of his DLA income to the local authority as a contribution to his care, he is not better off overall as a result of this small increase in benefits income.

What didn't we account for?

Personal budgets

Steve had a reassessment for his care needs in December 2011, which found he required 30 hours of care instead of 21 hours of care to meet his personal budget care plan. He says his condition is slowly getting worse – ‘a gradual regression’. His care hours were revised as he needed more support to undertake

Table 5 **The amount by which Steve's income has been reduced since we last saw him**

Steve's benefits	Reforms to benefits from April 2011	Worse off in 2011? to June 2012?
DLA - high mobility	Benefit increased by CPI instead of RPI - from £49.85 to £51.40 per week (CPI), instead of £52.14 (RPI) in FY 2011 then to £54.05 (CPI) instead of £54.27 (RPI) in FY 2012	74p per week, £14.80 worse off over five months to April 2012, then 23p per week, £2.74 over 3 months from April to June 2012
DLA - high care	Benefit increased by CPI instead of RPI - from £71.40 to £73.60 per week (CPI), instead of £74.68 (RPI) in FY 2011 then to £77.45 (CPI) instead of £77.72 (RPI) in FY 2012	1.08p per week, £21.60 worse off over five months to April 2012, then 27p, £3.26 worse off over 3 months from April to June 2012
ESA - Support Group	Incapacity Benefit was 94.25 per week until April 2012, then £99.15 thereafter Steve now receives £105.05 per week	An increase in income of £112 from November 2011 to April 2012, then an increase of £70.80 from April to June 2012

Although Steve lost £42.40 because of lower DLA uprating, he gained £182.80 in eight months by being placed on the Support Group of ESA. However, he lost a further £804.10 in DLA income because he has contributed towards his care since October 2011 - a total of £663.70 lost in eight months. This also does not take into account his lower direct payment.

physiotherapy, which he receives twice weekly, as well as help in the morning, afternoon and going to bed.

Despite this, Steve reports that the amount he receives as a direct payment has fallen, from £1,100 per month to £900. He believes this is because he contributes to his care from his DLA. As we reported in our autumn 2011 update, Steve's local authority had passed a budgetary change requiring care users to contribute 50 per cent of the middle rate of the DLA care component, if

they were receiving it. From April 2011, this was £24.65 per week, and from April 2012 this has increased to £24.90 in line with the increased benefit rates. Steve reports that although he used to pay this contribution with a cheque, the contribution is now taken from his direct payment directly, so he received less – the equivalent of being ‘taxed at source’ – at the same time as his reassessment. This, he tells us, is when his direct payment fell from £1,100 per month to £900 per month. At the time of writing, Scope and Demos do not know why this might have happened, and plan to investigate further. In the meantime, Steve tells us he buys his care from a local agency, which charges £13 per hour, so his £900 direct payment only secures around 17 hours per week. The confusion Steve has about how much he is getting paid, and why, demonstrates the confusion experienced by many of the people we spoke to in this project when faced with the complexity of the benefit and care systems.

While Steve accepts that he must contribute some of his DLA care towards his care needs, he feels it is unfair that other recipients of DLA, with no care needs, do not have the same obligations: ‘I know that’s what DLA is for, but you see other people just banking their money.’

Financial shock

Steve reports he has also received a gas bill of £500, which came as a huge shock – Steve’s gas provider admitted they had carried out inaccurate meter readings and undercharged him in the past, leading to a lump sum bill to correct this error. This, he says is ‘another hurdle to get over’.

Steve tells us he and his wife are now having to make certain sacrifices: ‘To cope, we don’t go out for meals, don’t go out to the pub; don’t socialise, really.’ Last time we spoke to him in autumn 2011, he told us that the tyres for his powered wheelchair needed replacing. Eight months later, they still do as he cannot afford to replace them: ‘I’m going to wait until they [the tyres] shred and buy some new ones.’ Before his council charged him part of his DLA to cover his care, Steve would use his DLA to pay for adaptations and maintain his wheelchair. Now, he is no longer able to do this.

Summary

Steve's feelings about the Government's cuts are mixed; he does not see himself as personally affected and believes the Government needs to cut spending because of borrowing by the (previous) Treasury, but 'we're all being punished'.

Box 7

How many people are in Steve's situation?

Steve claims the same combination of benefits as Philip, but with a higher rate of DLA. Like Steve, 16 per cent of DLA claimants claim higher rate mobility and care. We know that 288,950 claim a combination of ESA and DLA, and 16 per cent, or 46,232 of those claiming DLA, are at the higher rate. As the Government does not break down DLA claimants by their ESA phase, we have to make an assumption. There are over 150,000 people in the Support Group of ESA, but only 40,000 (around 26 per cent) who, like Steve, are previous Incapacity Benefit claimants. So we can assume that these 26 per cent of these 46,232 higher care and higher mobility claimants, fall into the Support Group (previous Incapacity Benefit).

This means 12,020 people are better off, like Steve, by £140 in the last eight months. They have gained, as a group, just over £480,000.

However, before Steve was moved to ESA and placed in the Support Group at the end of 2011, he was an Incapacity Benefit and DLA claimant. At the end of 2011, there were 433,590 people claiming that combination of benefits. If we assume (again) that 16 per cent of this group were claiming higher rates of DLA mobility and DLA care, there were 69,374 people like Steve who, in the period before transferring to the Support Group of ESA, would have lost £117.97 each as Steve did last year between April and November.⁴¹ This means this group lost £8.1 million last year. The 12,020 of those lucky enough to move onto ESA support group would have lost around £1.4 million, wiping out the £480,000 gains made by this small subset of the group from November 2011 to May 2012.

Overall, since the emergency budget of 2010, the 12,020 people like Steve will have lost £938,000 overall, despite their newly increased incomes.

We must also remember that Steve loses a considerable amount of income because he has to contribute his DLA to his care costs. Previous Demos research found that all but three local authorities now took DLA income into account when calculating care costs,⁴² but we do not know how many people this affects. We do know, however, that over 19,000 care users live in Steve's local authority, all having to contribute around £25 per week from their DLA. Those in this group are worse off by around £15.2 million in the last eight months, or £28.8 million since the emergency budget, and this is just in one local authority.

What does the future hold for Steve?

Steve currently receives high care and high mobility components of DLA. When this benefit is replaced with PIP in 2013, it is possible he will be one of the unlucky 10,000 that the Government predicts will lose their higher rates when PIP is introduced.

Steve uses his DLA mobility component to pay for his adapted Motability car, which his carers use to drive him to physiotherapy appointments – one four miles away, the other eight – twice a week. He says that in four years he will have to get a new car.

As Steve has already been through his reassessment for Incapacity Benefit and awarded the ESA Support Group, he does not have to comply with the ESA's job search criteria, but he will be reassessed in the future to ensure his work capability has not changed.

'In extremis' – Helen: a disabled mother caring for her disabled child

They would prefer for my son to go into residential care.

In our earlier research, we interviewed Helen not as a 'typical' disabled person but as an illustration of how difficult life can be for some disabled people when relying on benefits and public services.⁴³ In 2010, Helen, who lives in Wales with her son, was concerned that her disability, and social service's limited support for her own and her son's disability, would lead to her son being taken into residential care. In April 2011, she was having difficulties with securing respite for her son, and trying to move from her poorly adapted house. When we revisited her in October, her housing problems had led her to take a drastic decision, which will have significant implications on her financial wellbeing.

- Helen is a disabled woman who suffers from neuralgia, epilepsy, migraines and rheumatoid arthritis.
- She has a 10-year-old son, who has epilepsy, low tone muscular problems, speech and language difficulties, atypical autism, ADHD, anataxia, complex learning difficulties and challenging behaviour.
- Helen bears the burden of most of her son's care as her husband left the family a few years ago, unable to cope with his son's disability. Helen worked in the past but is now classified as long-term unemployed because she has to look after her son.
- They live in a council house and receive:
 - DLA, low mobility, middle care for Helen
 - DLA, high mobility, high care for her son
 - Incapacity Benefit
 - Child Benefit
 - Housing Benefit
 - Carer's Premium

Table 6 **The amount by which Helen and her son's income has been reduced since we last saw them**

Household benefits	Reforms to benefits from April 2011	Worse off in 2011? to June 2012?
DLA (Helen) - low mobility	Benefit increased by CPI instead of RPI - from £18.95 in 2010 to £19.55 per week (CPI), instead of £19.82 (RPI) in FY 2011 then to £20.55 (CPI) instead of £20.64 (RPI) in FY 2012	27p per week, £5.40 worse off over five months to April 2012, and 9p, £1.14 worse off over 3 months from April to June 2012
DLA (Helen) - middle care	Benefit increased by CPI instead of RPI - from £47.80 to £49.30 per week (CPI), instead of £49.99 (RPI) in FY 2011 then to £51.85 (CPI) instead of £52.06 (RPI) in FY 2012	69p per week, £13.80 worse off over five months to April 2012, then 21p, £2.53 worse off over 3 months from April to June 2012
DLA (Helen's son) - high mobility	Benefit increased by CPI instead of RPI - from £49.85 to £51.40 per week (CPI), instead of £52.14 (RPI) in FY 2011 then to £54.05 (CPI) instead of £54.27 (RPI) in FY 2012	74p per week, £14.80 worse off over five months to April 2012, then 23p per week, £2.74 over 3 months from April to June 2012
DLA (Helen's son) - high care	Benefit increased by CPI instead of RPI - from £71.40 to £73.60 per week (CPI), instead of £74.68 (RPI) in FY 2011 then to £77.45 (CPI) instead of £77.72 (RPI) in FY 2012	1.08p per week, £21.60 worse off over five months to April 2012, then 27p, £3.26 worse off over 3 months from April to June 2012
Incapacity Benefit (+£15 age addition)	Benefit increased by CPI instead of Rossi - from £91.40 to £94.25 per week (CPI), instead of £95.70 (Rossi) in FY 2011 then to £99.15 (CPI) instead of £100.65 (Rossi) in FY 2012	£1.45 per week, £29 worse off over five months to April 2012, and £1.51 or £18.11 worse off over 3 months from April to June 2012

Table 6 **The amount by which Helen and her son's income has been reduced since we last saw them – *continued***

Household benefits	Reforms to benefits from April 2011	Worse off in 2011? to June 2012?
Incapacity Benefit (+£15 age addition) <i>continued</i>	Age addition of £15 reduced to £13.80 in 2011 and £11.70 in 2012	£1.20 per week, £54.60 worse off over five months to April 2012, and £3.30 or £66 worse off over 3 months from April to June 2012
Housing Benefit	Benefit increased by CPI instead of Rossi - from £65.45 to £67.50 per week (CPI), instead of £68.46 (Rossi) in FY 2011 then to £71 (CPI) instead of £72.09 (Rossi) in FY 2012	96p per week, £19.20 worse off over five months to April 2012, then £1.09 or £13.08 worse off over 3 months from April to June 2012
Carer's Premium	Benefit increased by CPI instead of RPI - from £30.05 in 2010 to £31 per week (CPI), instead of £31.43 (RPI) in FY 2011 then to £32.60 (CPI) instead of £32.73 (RPI) in FY 2012	43p per week, £8.60 worse off over five months to April 2012, and 14p per week or £1.63 worse off over 3 months from April to June 2012
Child Benefit	Benefit frozen - so no increase from £20.30 per week in 2010; would have increased to £21.23 with RPI in FY 2011 and £22.41 in FY2012	93p per week, £18.60 worse off over five months to April 2012, and £2.11 per week or £25.32 worse off over 3 months from April to June 2012

Helen and her son have lost £319.41 over the past eight months.

What were we expecting?

Like others in our case studies, all Helen's benefits have been increased by a lower amount than before the Government's reforms. Helen also suffers a substantial loss because her Child Benefit has been frozen from April 2011 and her Incapacity Benefit age addition has been cut from £15 to £13.80 per week in 2011 and £11.70 in 2012.

Until late last year, Helen and her son had been living in council housing, which she says had been recognised by the local authority as being unsuitable to Helen's son's care needs. When we spoke to Helen in October 2011, her son had recently had an operation, making her house even less suitable for him. She had been on the waiting list for an adapted bungalow for several years, but she told us she was considering taking a dramatic step of leaving her council accommodation and moving into a privately rented property – even though her housing benefit would not cover the rent.

When we spoke to Helen again in May 2012, she reported that in December 2011 she had moved with her son to a new property. The move has been a big improvement for them both, as Helen's son now has more room and space to move around, and access to safer areas 'to diffuse the situation' when his behaviour becomes challenging.

However, this switch has had a significant impact on the household's finances, as their new home costs £400 per month more than the amount they receive in Housing Benefit, which is set at a two-bedroom rate. The reason for this gap is that Helen decided to rent a property with an additional third bedroom for a carer, as her son requires two-to-one care. However (as we describe in more detail below), the local authority has yet to formally approve financial support for this, and her housing benefit is set at the two-bedroom rate.

Helen recently applied for discretionary Housing Benefit, which would provide her with some extra money to help cover the rent, but was refused. The only way that Helen can afford to cover this shortfall in her rent is by using her son's trust fund, which she established with the money she obtained in her divorce settlement. This is a limited amount, though; ultimately, living in the property is unsustainable. 'We'll be lucky if we're

there for another two and a half years... It has made a heck of an improvement... but what's heart-breaking is that I won't be able to keep this up for much longer.'

What didn't we account for?

An ongoing legal challenge

The household has had a turbulent relationship with social services over the past few years. Problems revolve mostly around the social care arrangements for her son. When we first spoke to Helen in 2010, she told us that social services had recognised that her son requires two-to-one care, but had not put this into a legal statement. Helen effectively had to subsidise her son's care, to give her some respite, from her own direct payments. She had received an apology from social services, but for the last year has been embroiled in a drawn out court case, which has just recently been brought to trial, to secure more care for her son.

These proceedings have taken their toll on Helen. 'I haven't been very good at all,' she says, stressed from court proceedings and 'endless meetings'. Helen's son needs help with feeding, using the toilet, dressing and playing – help which, Helen says, cannot be provided by one person on their own. Helen's son needs constant attention: 'I can't go to the bathroom on my own,' she says. Speaking to her, it is clear she feels victimised by social services. 'Because I stood up and pushed for things, we are being punished,' she says. She says there are frequently gaps in the rotas of the carers who are supposed to be looking after her son. He should be getting help 24 hours a day, seven days a week, she says, 'Now social services won't provide someone to help me until he's attacking me.'

Helen's son's health has worsened recently; he frequently complains about pain (the result of recent surgery) and feeling ill. At times, he has been physically sick. He has had to start taking medication for his autism and ADHD, and his behaviour has become increasingly challenging. Helen recently had to physically restrain him – using techniques she has been taught by social services – during a hospital appointment, as he was a threat to other children nearby, and was criticised for doing so by

another team within the hospital. Social services threatened that if she couldn't look after him, Helen's son would go into care.

Financial shocks

In addition to this significant increase in rent, Helen and her son recently experienced another financial shock: a £370 gas bill – an amount double that of the bills she usually received while living in the previous property. She has also had to pay £120 to have the garden levelled, so her son, who is 'unstable on his legs', is able to access and use it.

Even the new property is not fully designed to meet Helen's son's needs. There is a bath in the bathroom, but no showerhead, which Helen's son, who is incontinent, needs. All he needs is a showerhead to be installed over the bathtub (a shower cubicle would not give him adequate room for movement), but, despite having the initial assessment by an occupational therapist in December 2011, they are still waiting for this to be built. Another assessment was carried out in April 2012, but when we spoke to her in May, Helen still hadn't heard anything about when this might be installed.

Summary

The past 24 months have been extremely difficult and turbulent for Helen. For two years she has battled to secure more care for her son. And while the court proceedings have now gone to trial, this is having a profound effect on the household's wellbeing and there is no way of telling whether the house will be secured for the family in the near future. Helen's decision to move into privately rented housing is draining her one source of assets – her son's trust fund – and cannot last long into the future: 'I'm extremely worried and frustrated.'

Box 8

How many people are in Helen and her son's situation?

Helen and her son's situation is not typical, and so we do not include this household's losses in our modelling. In any case, we do not know how many disabled parents are caring for

disabled children, and the DWP does not collect statistics on how many carers also claim disability benefits themselves. We do know, however, that over 190,000 carers claim a combination of benefits that the DWP does not collect data on – so there may be large numbers of carers coping with a disability themselves.

What does the future hold for Helen and her son?

From next year Helen will be liable to have her DLA reassessed. Helen's son will not, as he is under 16. Helen's DLA – low mobility and middle rate care – is, like Philip's, the most common combination of DLA. There will be no 'low mobility' category in the new PIP benefits regime, but if we assume 'middle care' claimants will become 'standard daily living' in PIP, the number claiming all levels of mobility will fall by 90,000. As Helen, like Philip, claims low mobility, she is most at risk of losing this element of her benefit.

Helen will also have her Incapacity Benefit reassessed at some point before 2014, and may move to ESA or be found fit to work.

In April 2013, Local Housing Allowance rates will be increased in line with CPI inflation instead of the market rents in each area, so the connection with actual rents will be lost. This may see Helen's housing benefit increase by far less than expected each year.

3 What have we seen? An overview

When we began this project, we were able to categorise the information we received from the six households into the following four areas:

- the moderate (but cumulative) losses in benefits income as a result of changes to uprating
- more substantial financial impacts as a result of other predicted welfare reforms
- the negative effects of cuts we had not predicted or taken into account
- a more tenuous financial position, increasing debts or less ability to deal with unexpected costs

Once we began updating our findings and speaking to the households more regularly, further themes emerged: in addition to the financial vulnerability of the households in our study, we saw the unexpected negative effect of administrative errors and delays in services, and the complexity of the health and care and benefits systems causing financial hardship and emotional distress.

We also saw how some disabled households began resorting to charity and family support in the absence of state help, but how these often proved short term fixes rather than sustainable solutions.

In this, our final report, a full two years after the first cuts to disabled people's incomes were announced, we are beginning to see what we might describe as the 'legacy' of welfare and service cuts – the beginning of longer term trends that we expect will define our six households' experiences for the foreseeable future. We have identified these as an even-diminishing civic and community life, the end of the safety net, deteriorating mental health, and the burden of care.

An ever-diminishing civic and community life

Over the course of our update reports we have seen our disabled households becoming more socially isolated, losing their opportunities to engage in civic and community life, and gradually reducing their lives to the very basics of survival – often within the confines of their homes. People have had to sacrifice the more essential aspects of life – such as hospital and therapy appointments, as well as ‘luxuries’ such as volunteering, socialising and training, all in the last 18 months. Our disabled households are increasingly reporting living hand to mouth, one day at a time, with repairs to equipment (which keep people mobile) and their homes put off for as long as possible. This gradual contraction of social experience also undermines family life. As Aisha’s mother put it: ‘It puts a strain on family and married life. Time together [between me and my husband] is just gone.’ Steve also commented that he and his wife no longer go out, as they simply can’t afford to socialise.

As resources dwindle ever further – and in particular in 2013/14 when some of these households may lose their DLA – we expect this situation to become worse. The Government’s welfare reductions may therefore create greater isolation and exclusion from civic and community life as disabled people, their families and carers cannot afford to engage with their wider networks. This is entirely at odds with the Government’s vision of the Big Society and legislation like the Localism Act and its innovations such as community budgets, which are designed to empower and, importantly, bring together strong self-organising communities.

The end of the safety net

The households we have been describing in our update reports are more frequently reporting the closure of services, both statutory and voluntary. This is symptomatic of the wider environment of local authority and departmental budget cuts: on the one hand, people have to travel further to access medical or social care support; on the other, help from charitable sources (the only recourse for those whose formal support or income is cut off) is drying up. So we see, for example, Carla’s welfare

advice centre closing down, and her dissatisfaction with the volunteer staff put in place of the trained advisers. We see Aisha's care reduced from five to four mornings a week as the charity providing that extra day has to cut back on staff, Albert and Lucy's GP closing and the primary care trust unable to provide a psychiatric nurse. This is on top of reports from earlier Destination Unknown updates regarding charitable grant schemes drying up and local clinics and charities closing.

The retrenchment of state-provided support and services, which leads to the reduction in the availability, accessibility or affordability of local support services, has the greatest impact on the most vulnerable social groups. It is clear that the concept of the 'safety net' provided by the state no longer resonates with the households in this study. As this safety net is removed, so too is a very valuable source of reassurance for vulnerable households – that should the worst happen, the state would step in and help. As this is no longer guaranteed, households in our study (and no doubt across the country) are realising they must reach breaking point before any help is provided. Helen and Aisha's mother, both caring for disabled children, have commented that their local authorities now expect them to cope, even when they beg for help, and only at the point of physical collapse or crisis will something be done. It is difficult to see how any semblance of a normal family life, physical or emotional wellbeing can be maintained when this is what the state offers.

As state services become less generous or are simply shut down, we have seen how disabled households need to rely more on charitable organisations for support – indeed, this is a somewhat intentional outcome of the Government's Big Society agenda. However, as reduced investment in state provision *coincides with* reduced investment in the third sector, so the flaw to this plan is immediately obvious: the Big Society cannot pick up what the Big State once provided unless adequate investment is made to enable it to meet the growing demand for help. The Government may think a community-led, rather than state-led, support framework will be cheaper – but it certainly is not free.

The combination of retrenched state support with underfunding in the third sector means that millions of people

fall through the gap. We have seen at first hand our households who have been refused charitable grants and care services from charities no longer able to provide the support they once offered.

As year-on-year local authority budget cuts are implemented, which will inevitably include grants to third sector organisations, we are likely to witness a steady retrenchment of local *and* voluntary services. This will vary locally, with more innovative local authorities taking steps to invest in their third sectors through local area coordination, for example.⁴⁴ Community grants may also create greater opportunities to allow the third sector to flourish. But the postcode lottery of such developments means the stakes are high for disabled households – live in the wrong area, and one could be entirely without a safety net of community-based support.

Deteriorating mental health

All of the households in the study have reported stress, anxiety, fear, a sense of persecution or depression at some point during the course of the project. It is clear the financial uncertainty caused by a prolonged period of significant welfare changes, combined with a shifting local support environment (such as closures) and higher costs of living (utility and fuel bills), have been compounded by fluctuating health typical of so many disabled people to create a perfect storm of mental distress. Aisha's mother's mental health has deteriorated, and she is now on medication. Carla has had to increase her medication too. Helen is feeling at her wit's end fighting for the proper support for her son, and even Philip – who had hitherto always been supportive of the Government's deficit reduction plan and stoical about the financial sacrifices he needed to make – is now worried about his next work capability assessment and feels his benefit income is under threat.

The burden of care

In this report, perhaps more than in previous updates, we gained a stark insight into the physical, emotional and financial burden

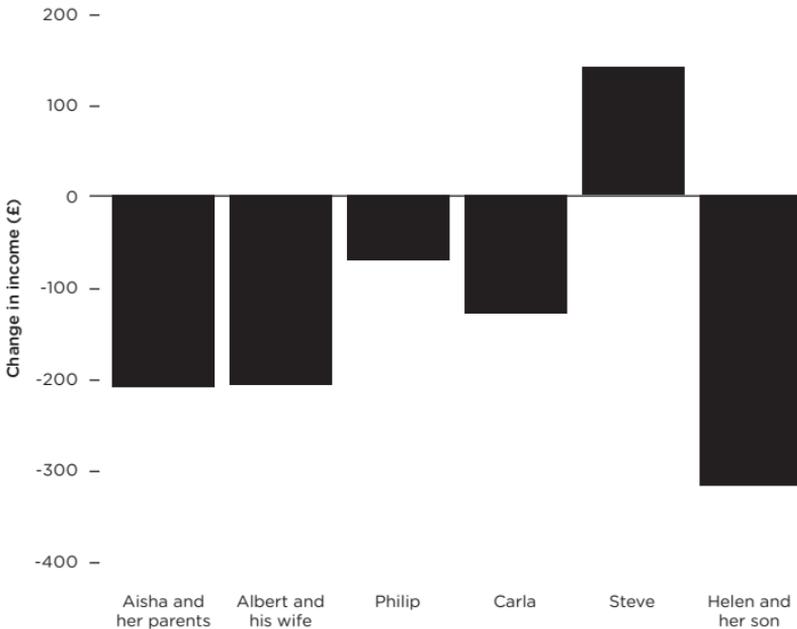
placed on informal carers. It is clear Aisha's parents are suffering emotionally, and family relationships are strained. Aisha's father's collapse and her mother's mental health deterioration, combined with her shoulder injury, and the need to sleep in different rooms, show the very real physical burden placed on this couple. We even see Marie, at age 10, join the estimated 700,000 children in the UK who are young carers, at greater risk of missing school and social opportunities. While Helen, disabled herself, is struggling to cope with her disabled son, again emotionally and in a more practical and physical sense. And yet both of these families have been denied additional formal support – they have been told they should be able to cope with their current care burden. Helen uses her direct payment to purchase respite care for her son. It is also possible – although at the time of writing we have yet to investigate – that Steve's direct payment has been reduced because he has a wife, whose informal care input may have been taken into account when he was reassessed at the end of 2011.

This shift to greater reliance on informal care is an inevitable and predictable outcome of reductions in social care funding, which leads to increases in unmet need and the commensurate increase of family members to step into the breach. This is certain to continue until a new funding regime is introduced to resolve the problems of a chronically underfunded care system. With the imminent white paper on social care already ruling out a plan for care funding, a funding solution appears to be some way off. In 2013, 500,000 people will lose their DLA – a benefit known to be used for purchasing a range of support services by those ineligible for formal social care funding. We suspect that this benefit change will trigger a further increase on the reliance of informal care and the burden carried by 9 million people across the country.

Summary of losses

Over the last eight months, our six disabled households are worse off by between £70 and more than £1,200:

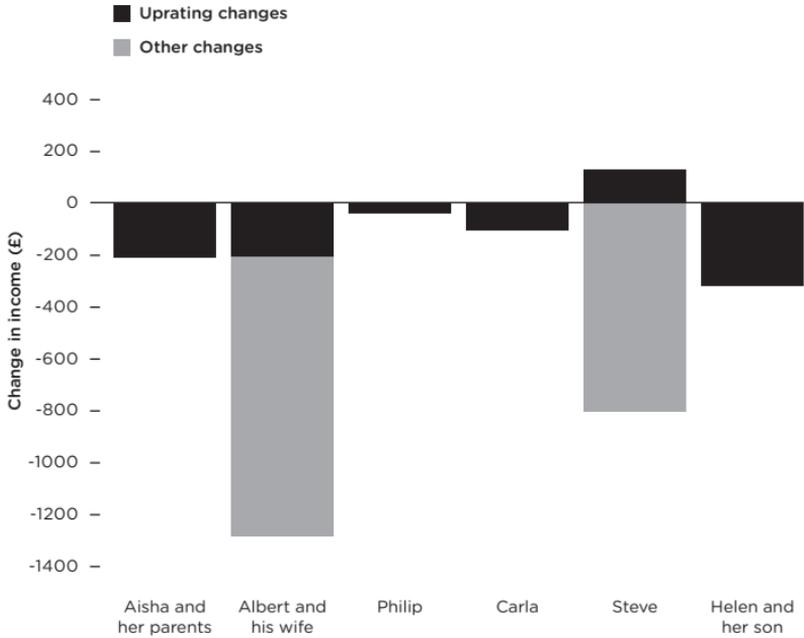
Figure 3 **Change in benefits income for the six families over the past eight months**



- Aisha and her parents – £211.09
- Albert and his wife – £1,285.12
- Steve – £663.70
- Philip – £70.98
- Carla – £129.35
- Helen and her son – £319.41

While Steve loses a considerable amount of benefits income following changes in the social care system in his local authority, his benefits levels actually increased slightly this year as he was moved to the support group of ESA. This £5 per week increase means he gained an additional £180 in ESA, while at the same time losing £800 in DLA, resulting in a net loss of £663.70 in

Figure 4 **The total loss in income for the six families over the past eight months**



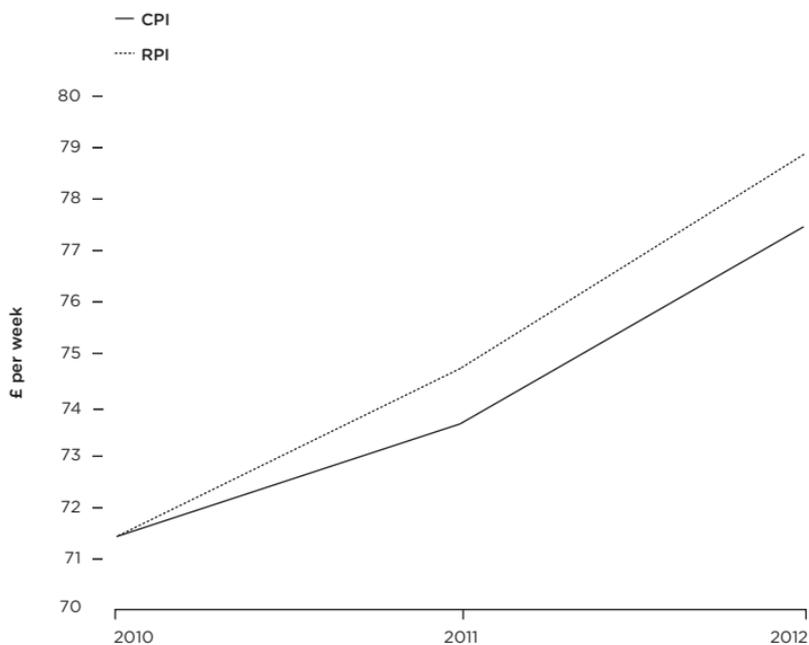
eight months. This also does not take into account his lower direct payment.

Figure 3 shows the change in income from benefits in the last eight months for the six households we have covered, and figure 4 shows the total loss in income for these households during this period.

The change in uprating

A consistent theme in each of our update reports has been the small year-on-year reductions in expected income disabled households face as a result of benefits being uprated by the lower inflation rate (CPI) rather than the RPI or Rossi rates being used before 2010. As a result of this, Lucy, the only

Figure 5 **The divergence between CPI and RPI uprating for DLA high care**

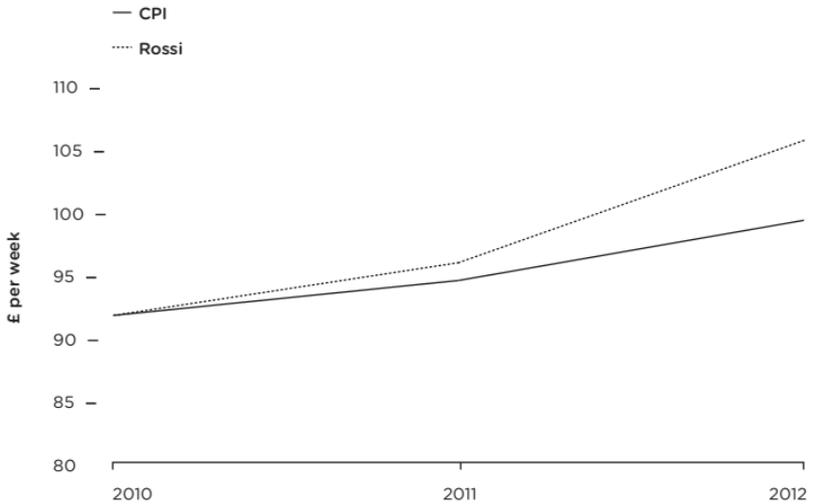


pensioner in the study, will find her pension increases less than expected.

In each update report, we report the foregone income of six (or in this case, eight) months where the households receive a slightly lower amount (sometimes it is a matter of pence) each week. These very small changes do not seem noteworthy when we report them in regular intervals, but when they are accumulated, a different picture emerges. This is because while in 2010 benefits started at a set base, as each year passes, so the CPI uprated benefits will increase at a slower rate than RPI uprated benefits. Figure 5 shows the divergence between DLA high care uprated by CPI and RPI over two years. This divergence will grow (the two lines will get further apart) over time.

If we consider a benefit previously uprated by the 'Rossi' index⁴⁵ before 2010, such as Incapacity Benefit and Income

Figure 6 **The divergence between CPI and Rossi uprating for Incapacity Benefit**



Support, we can see a wider divergence already, because the Rossi rate in September 2011 was very high, so benefits like Incapacity Benefit would have increased substantially (figure 6).

A press release by the IFS concludes:

Benefits that were formerly indexed to the RPI and the Rossi will be about 1.8% and 3.1% lower respectively in 2012–13 as a result of the indexation change which took effect from April 2011 (in the absence of other policy changes in relation to those benefits). For example, the rate of Jobseeker's Allowance, which was formerly indexed to the Rossi, will be £71.00 per week rather than £73.25 per week for a single person.⁴⁶

The bottom line – by how much has the income of these households been reduced since we began this project?

As we bring this project to a close, we can review how much our six households have lost since we began it in October 2010, bearing in mind that benefits changes only started to take effect in April 2011. We have, therefore, a period of 14 months to

Table 7 **Comparison of the RPI, Rossi and CPI inflation rates, September 2010 and September 2011**

	RPI inflation	Rossi inflation	CPI inflation
September 2010	4.6%	4.8%	3.1%
September 2011	5.6%	6.8%	5.2%

review. Table 8 shows the total losses to each of the households' incomes. We can see that our pensioner and social care user are experiencing the largest losses, then families with children, then single adults. This demonstrates the cumulative effect of multiple cuts – those using the widest range of services and/or relying on the largest number of benefits lose more than those less reliant on these services.

Concluding thoughts

Since October 2010, Demos has been highlighting the negative effects a series of welfare reforms will have on the quality of life of disabled people. Through our work, we were able to estimate that the 3.6 million disability benefit claimants in this country would lose £9 billion in benefit income by the end of this parliament. We also threw fresh light on the cumulative impact of the cuts on disabled households, which had hitherto been overlooked.

Now, 20 months later, almost all of the first proposals for welfare reform have passed into law. Even the most controversial – such as the time limitation of contributory ESA and the blanket reduction of DLA by 20 per cent – have been secured.

However, when it comes to the plight of disabled people it is clear that the whole is more than the sum of its parts. Changes to pensions, mortgage support, transport subsidies, policing cuts, charity closures, adult education subsidies, social care budget reductions – the list goes on – create a perfect storm whereby disabled people are left with fewer resources to draw on,

Table 8 **The total losses to the incomes of the six households we have covered, April 2011 to June 2012**

	Aisha's family	Albert and Lucy	Philip	Carla	Steve	Helen and her son
Total loss	£410.61	£2,066.67	£145.68	£269.45	£1,282.48	£558.23

lower incomes, increased living costs, and no safety net as state services are retrenched. The ingenuity that we witnessed among many of these disabled households in sourcing support from the third sector (financial and in kind) seems to have all but dried up, and the burden has fallen to family carers and disabled people themselves. This takes a toll in the form of physical and mental hardship.

We leave our six households facing an uncertain future – some of the biggest changes, such as the introduction of PIP, continued transition to ESA and introduction of Universal Credit are still to come. What is clear is that these households, and millions like them across the UK, have no idea what will happen when these and other changes take effect. There seems no guarantee, either, that a minimum quality of life – a safety net – will be upheld. As formal support is denied them, disabled people are no longer under the illusion that things can only get ‘so bad’ before the state steps in, and face the grim realisation that nothing short of a physical or mental crisis or family breakdown will prompt action by the state. Under such circumstances, maintaining normal family life seems impossible.

At the same time, media stories about benefits scroungers have increased in frequency – with the Government accused of actively encouraging this through the strategic release (and on some occasions, misrepresentation) of benefits statistics by the Chair of the Work and Pensions Select Committee, Anne Begg MP,⁴⁷ as well as many others. Carla reported the first instance in our study of disability-related abuse, and in February 2012 a coalition of disability charities spoke out against the

Government's inaccurate and irresponsible statements on the level of fraud in the system and directly attributing this to increased reports of disability-related abuse and crime. Scope's regular poll of disabled people found that in September two-thirds said they had experienced recent hostility or taunts, up from 41 per cent four months before. In the last poll almost half said attitudes towards them had deteriorated in the past year.⁴⁸

These two factors – financial uncertainty and concern at home combined with a hostile political and media environment – have left our six disabled households, and no doubt many like them, feeling unfairly treated, persecuted even, and struggling to cope financially and emotionally.

We believe the Government must learn from the difficulties encountered in passing the Welfare Reform Act and the criticisms that have been made about it, and bear in mind that even if the level of cuts to welfare spending – and to disability welfare in particular – are necessary in this current economic environment, the way in which this has been articulated and implemented leaves a lot to be desired. The same cuts, built on a more constructive narrative rather than one seeking to build popular support by encouraging public anger over workshy fraudsters, would no doubt have saved millions of people much distress and confusion, without costing any more. The saga of the Lords defeat, the Spartacus report and other campaigns, petitions and demonstrations might have been avoided or at least reduced. Perhaps, more ambitiously, if disabled people themselves were involved more closely in developing these plans, the same levels of cuts might be achieved but with less collateral damage – a point Liam Byrne MP brought up when describing how consultation with disabled people would form part of the welfare reform strategy for Labour's policy review.⁴⁹

Pursuing a negative and paranoia-based media narrative to garner popular support for welfare reform will have many negative unintended consequences, not least a hardening of attitudes towards disability and a reduction in the levels of social cohesion, compassion and trust. If the Government is serious in its commitment to enable disabled people to lead more independent lives in the workplace and community, it must

adopt a more constructive and enabling explanation for the media of the importance of reform. If not, the short-term goal of winning voter support for welfare cuts will undermine the longer-term objective of creating a more inclusive labour market and community for disabled people.

A second point to bear in mind is that disabled people are often financially vulnerable, and many have to cope with significant instability in their lives simply in managing their condition or impairment. Changes as vitally important as replacing or reducing benefits must be communicated and explained in a way that allows disabled people and their families time to prepare and adapt. Financial stability, clarity and certainty are vital for those with unexpected health crises and related expenses. Leaving the content of welfare reform to one side, it is clear that the way in which it has been communicated has been inadequate at easing the minds of and helping disabled people engage positively with the upcoming changes.

The households in our study were frequently unaware of the significant changes on the horizon, and were often passive recipients of services and benefits – being ‘done to’ rather than ‘done with’. They were buffeted by events – often the victims of administrative error, miscommunication between agencies and financial shocks for which they were unable to prepare. The households were not sure what they were entitled to, and why they did or did not receive what they were expecting, and found the channels through which to challenge decisions, or amend errors, an uphill struggle. For those already coping with financial hardship and caring responsibilities, such additional stress is too much to bear.

The Universal Credit may be the solution to this, but we suspect the problem lies not just in the complicated administration of the current regime, but also in the culture of gate-keeping and suspicion that can lead to the guarding, rather than distribution, of entitlements. This has only been exacerbated by the emotive narrative the Government has employed about fraud in the system.

Third, the Government must remember disabled people do not live their lives within the boundaries of departmental

responsibility. Disabled people in our study certainly did not define themselves by the benefits they claimed, but rather saw this as the vehicle and facilitator through which they were able to live a normal life. A good benefits regime should be the means, not the end. The DWP should oversee the framework through which disabled people access employment, education and other public services, and the Government should have a level of overview to ensure one does not detract from the other. And yet we see that this is the case – financial hardship brought about through reductions in benefits income has negatively affected our households' health and access to health services, their ability to lead a community life, to stay in employment, to care for their children. It is vital that the Government takes a step back to ensure their drive to reduce welfare spending does not generate costs elsewhere (such as in the health or care system).

Remembering that people are not defined by benefits income is also important when considering the cumulative impact of the reduction in benefits and service spending, and local authority budgets. While the DWP is seeking to meet its cost reduction targets, the departments of Health and Education, Ministry of Justice and every local authority in the country are trying to do the same. A loss of £1.50 a week to someone's DLA income is tiny – the DWP will think this is a cut with minimal impact. But a £1.50 loss of DLA, combined with a freeze in Child Benefit, a closure of a local community health service, a charitable grant no longer being provided, a school closing after-school clubs and the council cutting its education and leisure subsidies, adds up to a very significant impact on a person's quality of life. Disabled households are not benefits recipients – they are parents, employees, students, home owners, older people, and citizens. They rely on the same diverse range of services as everyone else, but the Government's failure to grasp the whole picture beyond the welfare reform agenda can lead to an underestimation of the cumulative impact these hundreds of individual cuts can have on each household using multiple services. Disabled people are most vulnerable to this accumulation of cuts simply because they are more likely to rely on several benefits and several public services.

It is only through looking at individual households, to witness how several different cuts converge, that one gets a proper grasp of these phenomena. So, our final lesson is that the Government's impact assessments must move from a 'horizontal' outlook to a 'vertical' one. By this, we mean that impact assessments should not just consider the *aggregate* impact of *one* cut – they should look also at the *individual* impact of *several* cuts with the use of typical households as case studies. At the moment, we know that 500,000 people will lose their DLA in 2013. And we know that 36 per cent of people will lose their Incapacity Benefit by 2014. We know, too, that the number of councils funding support for people with 'substantial and critical' needs only has risen from 78 per cent to 81 per cent from 2010/11 to 2011/12, and that only three local authorities no longer take income from DLA into account when assessing how much a person has to pay towards their care. But do we know – do we have even the faintest idea – how many people will suffer from all four of these budget-driven changes, and what this will do to their household income and quality of life? Until the Government is able to answer such questions, and start thinking about the cumulative household impact of reform rather than each in isolation, the human cost of the austerity measures will remain overlooked and policy will be all the worse for it.

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A central plank of the Coalition Government's legislative programme is fundamental reform of the welfare system. Since the first changes to benefits were announced in 2010, Demos has explored the impact of these on disabled people through the Destination Unknown series, reporting twice a year on how six disabled households have been faring. The study found that disabled people stand to lose £9bn in benefits alone over the course of this Parliament. This fourth and final instalment of the project provides an overview of the experiences of these families and identifies the risks they and other disabled people face in the near future.

Shockingly, it reveals that the worst is yet to come. Since we last caught up with our six families, the Welfare Reform Act has gained Royal Assent. Budget cuts have already had a significant effect but the act contains a number of measures that will reduce the material income of disabled people and their families over the next two years.

By speaking to families themselves, this report reveals the human cost of this loss in income: from increasing isolation and mental health problems to a greater burden on informal carers. It concludes that the Government must change impact assessments so that they do not just consider the aggregate impact of one cut, but assess the cumulative impact of several cuts on individual households. Until the Government is able to understand the household-level impact of multiple changes to benefits and services, the human cost of the austerity measures will remain overlooked and policy will be all the worse for it.

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