

“Tracking the lives of
disabled families
through the cuts...”

**DESTINATION UNKNOWN:
SPRING 2011**

Claudia Wood
Eugene Grant

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Claudia Wood
Eugene Grant
April 2011

The disability in austerity study

Six months ago, Demos and the disability charity Scope sought to explore how cuts to welfare and public spending would affect disabled people in Britain. We calculated how the welfare reforms and cuts to benefits – announced in the Emergency Budget and in the run up to the Spending Review – would affect five typical disabled families. Our research showed that, far from being protected from the worst of the cuts, disabled families across the country faced dramatic reductions in their household incomes. Losses of two to three thousand pounds over the course of the next parliament were typical; overall, we estimated that disabled people would lose £9 billion in welfare support in the next five years.

The numbers paint a bleak picture. But what is life like for Britain's disabled families and how is it changing as the cuts set in?

The Disability in Austerity Study is a new longitudinal project, following five disabled families through the course of this Parliament and tracking the impact of fiscal tightening on their lives. This project brings to the fore the real impact the cuts are having on the everyday lives of disabled people and reveals first-hand experiences of disabled families living on the edge of uncertainty, financial difficulty and disability poverty.

The families

Over the next five years we'll be producing updates on how our five tracker families are doing. Taking part in the study are:

A young disabled child (A) cared for by her mother and father

A is a four year-old girl, who lives in Spalding, Lincolnshire. She is quadriplegic, has epilepsy and cerebral palsy. She lives with

her parents and five other siblings - the youngest of whom is two. She and the other children are looked after by their mother, who cares for them full-time; as she has got older, her father has had to take more unpaid leave from work to help with caring responsibilities.

A disabled man (P) and his wife who cares for him and also has moderate disabilities

P is 50 and suffered a stroke in March 2006. He now has left-handed weakness, uses crutches often, had two heart defects and related surgery and his left leg often locks. P also has memory loss. He was self-employed for 9 years but hasn't been able to work since the stroke. He hopes to improve his employment prospects by doing a part-time Open University course in psychology. P lives with his wife who is also his carer. His grown-up step-children live away from home. P's wife was made redundant 2 years ago.

A single disabled man (E)

E is 48, separated, and lives alone in Edinburgh since separating from his wife. He has lifelong epilepsy, which deteriorated in 2008. Before that he worked full time. E has two children aged 21 and 23.

A single disabled woman (C)

C is 28 and is single. She lives in Didcot, renting her own place from a housing association. She has cerebral palsy and has been a wheelchair user all her life.

A middle-aged, disabled man (S) who is a social care service user

S is 48 and has MS (secondary progressive). His MS has worsened over the last 5 years so he has been pensioned off (a third of his income) from work since 2005. S is married and his

wife is a full time nurse. They have three adult boys, two at university and one who lives at home.

Beginning this April, Demos will publish the results of how these five families are faring every six months.

Executive summary

The Coalition Government will soon mark its first year in office. During this time it has embarked on a programme of radical reforms to the welfare system and imposed significant cuts on central government departments and local authorities. The government insisted that these cuts would be tough but fair, and that the most vulnerable in society would be protected. Yet the gap between rhetoric and reality is increasingly being tested – particularly in relation to the tightening of disability benefits.

Six months ago, we sought to explore this issue by calculating how the welfare reforms announced in the emergency budget and the run up to the spending review would affect five typical disabled families. Our research demonstrated that, far from being protected from the worst of the cuts, disabled families across the country faced substantial reductions in their benefits income as a result of changes to uprating and other more radical reforms related to reassessments of Incapacity Benefit and Disability Living Allowance (DLA). Losses of £2,000–3,000 over the course of the next parliament were typical; we estimated that disabled people would lose £9 billion in welfare support overall in the next five years. We questioned whether the Government had intended the budgetary axe to fall so heavily on this group and whether, by attempting to ‘incentivise work’ for the majority, they had overlooked the disproportionate effect welfare cuts would have on those who were less able to join the labour market.

However, we were aware that our initial research only told half of the picture – we had only been able to model the impact of welfare cuts on disabled people as it had been too early to consider the implications of cuts to public services and local authority budgets. Moreover, the government announced a raft of new welfare cuts after the spending review, so the scale

of the losses we had estimated were, if anything, an underestimate.

We decided therefore to revisit the five families that featured in our first report – *Destination Unknown*¹ – six months on, to see how their lives had changed. We spoke to:

- a young disabled child (A) cared for by her mother and father
- a disabled man (P) and his wife who cares for him and also has moderate disabilities
- a single disabled man (E)
- a single disabled woman (C)
- a middle-aged, disabled man (S) who is a social care service user.

In revisiting these families, we had the opportunity to consider both the early effects of public service and local authority cuts and the impact of several new government reforms which were announced after *Destination Unknown* was published. The most important of these include:

- the replacement of means-tested benefits with the single Universal Credit
- the abolition of DLA and the introduction of the Personal Independence Payment
- time-limiting contributions-based Employment and Support Allowance (ESA) to one year
- the removal of the DLA mobility component from care home residents
- the removal of special ‘youth provisions’ for contributions-based ESA
- the abolition of crisis loans and community care grants.

Although some of these new reforms will not be introduced for a number of years, April 2011 is an important time for a number of reasons: benefits were uprated by the lower inflation rate of the Consumer Price Index for the first time, with millions of benefits recipients receiving lower increases than before; the time limitation of ESA and national Incapacity Benefit reassessments began; Housing Benefit caps were imposed, and

with the new financial year, new local authority budgets ushered in the largest cuts to local services in a generation.

The findings in this report show that disabled families are already feeling the effects of these very early changes – we have been able to calculate not just the losses arising from the lower than expected increases in benefits (which will see all of our case study families £200–300 worse off this financial year), but also the immediate impact of other government reforms which, although not directly related to disability benefits, have proven to have a significant impact on our families' financial wellbeing:

- As a result of cuts to Support for Mortgage Interest (SMI) from 6.08 per cent to 3.63 per cent, P and his wife are £200 a month worse off. The large shortfall between their SMI payment and their actual mortgage costs means they are now £7,000 in arrears.
- P's wife has also had her pension payment delayed by eight months as a result of the government increasing the pension age for women – this delay will cost them £3,104 in income in total.

We have also seen that, although new local authority budgets only began this month, early cuts have already affected our families:

- A's bedroom was incorrectly modified by her local authority, but they cannot afford to correct the error and A's family can only appeal in five years' time.
- A's power chair will not be paid for by the local authority, even though her friend in a neighbouring authority received a free chair.
- S has been asked to provide details of his DLA so his council can calculate his contribution to his care – his council has joined a few others in taking the step of making people contribute £24.65 of this benefit each week to pay for their social care. S will be £1,281.30 worse off this year as a result.

Our case study families paint a rich picture of the precarious financial position disabled people find themselves in. We found that all but one of our case studies households was in

debt – and that this debt had increased for all of them between interviewing them in autumn 2010 and April 2011. Many had suffered a ‘financial shock’ – higher than expected utilities bills, a boiler breakdown, the need for a replacement wheelchair battery and so on – for which they had no savings to act as a financial safety net. The ‘hand-to-mouth’ existence described by our families, using their benefits income to pay daily costs with none left over (and often a shortfall), is particularly concerning – the reduction of a few pounds per week in benefits income, or an unexpected expense, could have severe and lasting financial consequences.

However, we must remember we are only in April 2011: disabled people have yet to feel the full force of many of the government’s reforms and the effects of cuts to public services are unlikely to come to fruition for a while yet. We should see the results of these first update interviews very much as ‘the calm before the storm’ – with only small initial losses and hardship. Even then, some of our case study families have already experienced dramatic changes to their lives – as in the case of P and his wife being pushed into mortgage arrears and receiving written warnings from their lender.

In six month’s time, in October 2011, we will revisit our case study families again in order to see how their lives have changed. The coming months will be an extremely important time for them – whereas October 2010 to April 2011 was a time of announcements, April 2011 to October 2011 will be a time of implementation. When it comes to our case study families, we might see the following:

- From April 2011 Incapacity Benefit reassessments are being rolled out across the country. There is a chance that by the time we revisit them in October, P, C and H could have been reassessed and moved onto the newly time-limited ESA or the lesser benefit of Jobseeker’s Allowance (JSA).
- S has already been asked to submit his DLA details in order to assess his contribution to his social care costs – it is likely he will have begun to contribute to his care and lost around £26 a week in DLA by the time we speak to him again in October.

- P and his wife could well be facing repossession if their arrears continue to accumulate.
- All of our families will have experienced six months of lower than expected benefits, while H and A's parents will have had six months of frozen Child Benefit.

However, although these are all 'predictable' negative outcomes, the more significant risks our families face are those we are unable to foresee.

This report has demonstrated that even though specific benefits cuts can be modelled and their impact quantified, the 'real life' experience of cuts is a much more holistic phenomenon, which cannot be so easily modelled. The breadth and depth of some of the *unexpected* consequences of the government's fiscal and welfare reforms have hit disabled households hard. Few could have foreseen that the bedroom built for A would be built to a miscalculated specification, and that the local authority would declare itself to be financially unable to help rectify this situation. Yet, unexpected and difficult situations like these are the unpredictable ramifications of across the board cuts to public spending and local authority budgets, and cause much damage to disabled people's quality of life.

By October 2011, our families will have experienced six months of new local authority budgets, which may result in local service closures, increased charges, and tighter eligibility criteria for support. Although we are already seeing the initial negative effects of these reduced budgets, by October there is a considerable risk that our case study families (and indeed, disabled families across the country) will experience increasing financial hardship and social isolation, caused by events we simply cannot predict. The sense of uncertainty and vulnerability in the face of these unexpected costs was perhaps the most striking message that emerged from this research, and a lack of what might be described as 'financial resilience' – the ability to absorb or recover from financial shocks due to savings or accessible credit – is a cause for concern in the unpredictable months ahead.

This report begins by recapping the range of new reforms and cuts to welfare benefits that *Destination Unknown* took into

account when we modelled the losses to disabled families. We then provide an overview of new reforms and cuts, announced by the government in the intervening period between *Destination Unknown* and this report. Finally, we present each of our case study families, and describe the ‘predictable’ losses to their benefits (primarily as a result of a change in uprating), the unexpected losses and impact of local cuts, and the ‘financial shocks’ they have undergone, which illustrate their lack of financial resilience at a time of economic uncertainty.

1 Introduction: Destination Unknown

In the emergency budget of June 2010, and in the run up to the spending review of October 2010, the Coalition Government announced several radical reforms to disability and wider welfare benefits. Although the government rhetoric behind these reforms focused on ‘incentivising work’, some expressed concern about the disproportionate impact on those with the lowest incomes,² as well as those who are least able to work and most vulnerable, such as disabled people.³ Questions were raised as to whether the government had fully anticipated and calculated the impact of the cuts on disabled people, which were likely to be cumulative and far reaching. Demos set out to explore this issue by quantitatively mapping the impact of key welfare reforms on disabled people in a report entitled *Destination Unknown*.⁴ In this report we modelled changes to benefits on the incomes of four disabled households, provided by the disability charity Scope, which could be considered typical from the packages of benefits they each received. These disabled households were:

- a disabled young person (L) and his parents as carers
- a disabled man (P) and his wife, who cares for him and also has moderate disabilities
- a single disabled man (E) on Employment and Support Allowance (ESA)
- a single disabled woman (C) on Incapacity Benefit.

We also modelled the impact on a fifth case study, H: a disabled woman with a disabled child. Although H does not represent a typical disabled household, the case of her and her son served as an illustration of just how deep and profound the effects of cutting services and support across the board can be.

Our modelling provided predictive estimates of the losses in benefits income our households would see over the course of the next parliament. Using further modelling, we calculated an aggregate figure in line with the number of people receiving the same package of benefits. For example, in the case of P and his wife, the reforms meant that at the time of calculation the couple would be £5.80 worse off per week by 2011, £19.52 worse off per week by 2015. By the end of this parliament they will have lost out on about £3,143 of income. P alone would be £2,436.92 worse off over the next five years. As there were some 516,460 people receiving the same benefits as P, overall this group would lose about £1.25 billion.

However, we realised that the real impacts of the government's cuts would not be fully captured by this work. First, we primarily focused on changes to welfare benefits in *Destination Unknown*, as it was simply too early to predict how changes to local authority spending and central government cuts would affect public service delivery. We were therefore unable to paint the full picture of the impact of cuts on disabled people. Second, the Government announced several new cuts and reforms to disability benefits after the publication of *Destination Unknown* in October 2010 – so if anything our calculations had underestimated the full extent of the impact.

This report, therefore, seeks to update and broaden the scope of the analysis in *Destination Unknown* by revisiting the five disabled families featured in our first report to see how they have fared in the past six months and what changes they are seeing to both their benefits income and their quality of life more broadly as a result of cuts to public services and local budgets.

2 The Coalition Government's reforms

May to October 2010: a summer of cuts

Almost immediately after entering office in May 2010, the Coalition Government set out two key agendas: accelerating the reduction of the structural deficit, and reforming the welfare benefits system so as to move people off benefits and into work. One of the first announcements made by the Work and Pensions Secretary Iain Duncan Smith, in May 2010, was that all claimants of Incapacity Benefit would be reassessed on their readiness for work and those determined to be fit for work would be moved onto Jobseeker's Allowance (JSA).⁵ In June 2010, a deficit reduction plan was set out in an emergency budget, identifying £85 billion of cuts – £11 billion of which were to be taken from the welfare bill.⁶ The cuts to welfare benefits, the Chancellor promised, would deal with the 'explosion in welfare costs' and 'improve incentives to work, and reduce the incentives to stay out of work'.⁷ The government announced that although departments – with the exception of those providing foreign aid and financing the NHS – would face budget cuts of around 25 per cent, this figure could be reduced if the Government was able to find additional savings in the welfare budget.⁸ The measures contained in the emergency budget were, it was insisted, 'tough but fair' and designed to protect 'the most vulnerable in our society'.⁹

Yet following closer inspection many concluded the measures outlined in the emergency budget were regressive.¹⁰ Disabled people were quickly identified by commentators – and even cabinet ministers – as likely to be among those hardest hit by the reforms.¹¹ This is because this group, at substantially greater risk of living in poverty than non-disabled people, is disproportionately more reliant on welfare benefits than other low-income groups.¹²

Table 1

Fiscal and welfare reforms before the spending review, October 2010

Change	Effect
A cap on the maximum amount of benefit claimed by a household	Households can only receive a combined benefits package of up to £500 per week – set at the average income of a working family. ¹³ This limit will apply to Jobseeker's Allowance (JSA), Employment and Support Allowance (ESA), Housing Benefit (HB), Council Tax Benefit (CTB), Child Benefit (CB) and Child Tax Credit (CTC). It also includes Carers' Allowance (CA), but households with a disabled member receiving Disability Living Allowance (DLA) are exempt from this measure. ¹⁴
A change in the basis used for uprating benefits	Whereas before, benefits were uprated in line with the Retail Price Index (RPI) or Rossi Index, they are now to be uprated in line with the lower Consumer Price Index (CPI). For disabled people particularly, this is likely to affect DLA, CA, JSA, ESA and HB, and the disability elements of CTCs and Working Tax Credits (WTCs) – ultimately reducing their value. ¹⁵
Reassessing Incapacity Benefit claimants on their readiness to work	Beginning with pilot reassessments in Aberdeen and Burnley, the Government plans to reassess 1.5 million Incapacity Benefit claimants and move those fit for work onto JSA. Others will be moved onto ESA. Reassessments are conducted via the controversial work capability assessment (WCA), and will be rolled out nationwide in April 2011. While Department for Work and Pensions (DWP) data for 2008/09 show some 66 per cent of claimants were found 'fit for work' and moved to JSA, in the initial pilots only 29.6 per cent were assessed as being immediately fit for work. ¹⁶
Reassessing all working-age DLA claimants	It was announced that all new and existing claimants of DLA would be reassessed using a 'medical test'. ¹⁷ Underlying this plan is the aim of reducing caseload and expenditure on DLA by 20 per cent. ¹⁸
Realigning Support for Mortgage Interest (SMI) payments	SMI provides people who claim specific means-tested benefits with support meeting their mortgage interest payments. Before October 2010 SMI payments were frozen at 6.08 per cent. ¹⁹ From October 2010, they were aligned with the Bank of England's average mortgage rate: 3.63 per cent. ²⁰ This was predicted to have a major impact on disabled people who, as a cohort, often have less access to affordable credit (as a result of having less predictable employment histories). ²¹
Capping Housing Benefit and reducing Local Housing Allowance (LHA)	Housing Benefit weekly rates will be capped to set levels for different sized properties and LHA will be reduced from April 2011 so it covers only 30 per cent of private rents (before this LHA covered 50 per cent of private rents in the local area). ²² Around half of all households in the private rented sector claiming HB have a member with a disability. ²³

The particular plans that at the time appeared most likely to heavily impact on disabled people are outlined in table 1. At this point it should be noted that following the spending review, some of the policies subsequently changed – for example the idea of cutting Housing Benefit by 10 per cent for those claiming JSA for more than a year was subsequently dropped. In table 1 the only major change has been in the policy to reassess DLA – which we discuss in more detail in the following section.

October 2010 to March 2011: a winter of austerity

Since the launch of *Destination Unknown* several new policies have been announced, set out in the spending review of October 2010; the Welfare Reform Bill – introduced into parliament in February 2011; and separate ‘stand alone’ welfare announcements. These are discussed in turn below and summarised in table 2 at the end of this chapter.

The spending review

The spending review outlined another £7 billion worth of welfare cuts on top of those in the emergency budget.²⁴ The IFS concluded that overall the measures set out in the spending review would ‘hit those in the bottom half of the income distribution more as a share of their income than those in the top half’.²⁵ Having already asserted that the tax and benefit changes announced before the spending review could be considered ‘regressive’, the think tank added that this finding was ‘unsurprisingly reinforced’ when the new measures in the spending review were factored in.²⁶ The spending review contained a plethora of cuts and new policies, including significant changes to tax credits, but two announcements in particular have serious ramifications for disabled people.

Time-limiting contributory ESA to disabled claimants in the Work Related Activity Group for 365 days

In order ‘to reinforce the fact that ESA is a temporary benefit for the majority’, this change in policy applies to new and existing

ESA claimants who are allocated to the Work Related Activity Group (WRAG).²⁷ From 2012/13, all new ESA claimants in the WRAG will have their claims limited to one year, including the 13-week assessment phase.²⁸ For existing claimants, the period of time they have spent in the WRAG by April 2012 will be taken into account in order to calculate how much of the one-year period they have left.²⁹ This means that in April 2012, those who have already spent a year or more in the WRAG of contributory ESA will lose their entitlement immediately.³⁰ The DWP estimates that by 2015/16 around 700,000 people will lose their entitlement to contributions-based ESA; on average, their income is expected to drop by £36 per week.³¹ Of those affected, around 60 per cent will continue to receive or become eligible to receive income-based ESA,³² but the rest will not qualify for this because they or their partner have other income.³³ People in this situation will be able to retain National Insurance credits by claiming 'credits-only' ESA.³⁴ This is predicted to save the Treasury £2 billion a year by 2014/15.³⁵

Underlying this shift in policy is the aim of encouraging disabled people in the WRAG to return to work.³⁶ According to the impact assessment for the policy, conducted by the DWP, the time limit of 365 days was 'selected as the best balance between providing people claiming contributory ESA in the WRAG with enough support and reducing the cost of contributory ESA'.³⁷ However, the decision to restrict this benefit to a year was met with much opposition from the voluntary and community sector and the disability lobby.³⁸ Such a measure, Citizens Advice announced, 'betrays people who have paid contributions all their working lives and become sick or disabled'.³⁹

Removing the Disability Living Allowance mobility component from disabled people in residential care

As of 2013, disabled people receiving state-funded residential care will lose entitlement to the mobility component of DLA, which, when it comes into effect, is expected to result in 80,000 people losing a substantial amount of their income.⁴⁰ This decision has fuelled much criticism and consternation from the disability lobby.⁴¹ Recent research has brought to the fore

concerns that those care home residents who do not have their mobility needs met are likely to experience isolation and social exclusion.⁴² Fortunately, this policy does not affect any of the case studies from *Destination Unknown*, which we revisit below, but remains a central issue for those living in residential care and facing a substantial drop in benefits.

Separate policy announcements

Although the spending review and the Welfare Reform Bill (discussed below) set out the bulk of the government's fiscal and welfare reforms there were also two policy changes announced separately, which also have major consequences for disabled people. These were the replacement of means-tested benefits with the single Universal Credit in October 2010 and the plan to abolish DLA entirely and replace it with a new allowance – the Personal Independence Payment (PIP) – announced in December 2010.

The introduction of the Universal Credit

In October 2010, the government announced plans to replace a range of means-tested benefits with a single, overarching payment – the Universal Credit – to be introduced in 2013.⁴³ The Universal Credit will consist of a basic payment with additional payments for disability, children, housing and caring responsibilities.⁴⁴ Although some of the final details of the Universal Credit are still to be revealed, at this time there are some features that are particularly important for disability benefit claimants.

First, the controversial WCA test will still act as the gateway to the disability components of the Universal Credit. However, claimants who have already undertaken a WCA before the implantation of the Universal Credit will not need to be assessed again.⁴⁵

Second, as it stands, the new proposed rate for the equivalent component to the ESA support group will be much higher than the current ESA rate. The government plans to increase the weekly rate so it will be ultimately worth £74.50 per

week, on top of the basic payment similar to the JSA rate.⁴⁶ Together, this could amount to around £139.95 per week, which would mean that disabled people receiving the support component of the Universal Credit would end up about £43 better off each week than those currently receiving ESA at the support group rate.

Third, the cash additions available to families with disabled children will be aligned with those available to disabled adults. These weekly additions are set at a lower rate of £25.95 (equivalent to the current ESA WRAG rate) and a higher rate of £74.50 (equivalent to the new support component outlined above). Eligibility for these additions will depend on the child receiving DLA and at what rate.⁴⁷

Fourth, under the Universal Credit, individuals will only be able to qualify for either a disability addition *or* a carer addition – not both. This decision has been made so as to ‘reflect the fact that the additions are being paid in respect of not being able to work through either a medical condition or by virtue of caring responsibilities’.⁴⁸ Potentially, individuals in similar situations to P’s partner, who are disabled and provide care for a partner, could be affected.

Finally, claimants of the Universal Credit will be subject to a new set of sanctions. Under government plans, job advisers can compel jobseekers to undertake a month of unpaid, full-time work within a new mandatory work activity scheme – inspired by Workfare initiatives employed in the USA.⁴⁹ Should claimants be unable to comply with these requirements, they potentially risk of losing their benefit for three months (six months for a ‘second offence’, up to three years for a third).⁵⁰ As part of a ‘claimant contract’ recipients must also adhere to a series of ‘work-related requirements’ – including participating in a ‘work-focused interview(s)’; undertaking ‘work preparation’ activities such as attending a skills assessment; ‘work search’ activity like registering with an employment agency; and being ‘able and willing to immediately take up paid work’. Such a regime could prove particularly challenging for disabled people (even those deemed ‘fit for work’) to adhere to.⁵¹

The abolition of Disability Living Allowance

In December 2010 the Government announced its decision to abolish DLA entirely and replace it with a new allowance: the PIP. This is to be introduced in 2013/14 and will coincide with the reassessment of all working-age DLA claimants.⁵² The new benefit is to be divided into two elements: the mobility and the daily living components, which are to be set at two rates each (currently, the DLA care component of DLA is set at three).⁵³ Under the DLA system, claimants with particular impairments or conditions are instantly eligible for the benefit, but under the new PIP regime there are no automatic entitlements.⁵⁴ The consultation on PIP has only recently ended, so many of the details remain unclear. Whereas previous documentation suggested that claimants would only be eligible for PIP if they could prove that the functional impact of their impairment met the criterion for six-month periods before and after applying, at the time of writing this may be subject to change.

It is important to note at this stage that since the Chancellor's assertion in the emergency budget that DLA claimants would be reassessed via a 'medical' test, during recent months there has been a shift in rhetoric away from any mention of 'medical' tests (and parallels to the WCA) towards an emphasis on 'objective' assessments. Indeed, central to the administration of PIP will be an 'objective assessment of individual need'.⁵⁵ This 'will focus on an individual's ability to carry out a range of key activities necessary to everyday life', including planning and making a journey, managing personal care, and accessing food and drink.⁵⁶

The language used in government documentation, and also by the Minister for Disabled People, Maria Miller, suggests that the assessment for PIP will centre on individual 'need'.⁵⁷ Recent research, however, has demonstrated that a disabled person's disability costs are not significantly linked to functional capacity or need, but rather explained by a multiplicity of 'drivers' of disability costs – many of them external factors – including whether a disabled person owns or rents their home; whether their home is suitable for their needs; whether they are employed, or look after children; whether they have access to public transport or have to rely on alternatives; and so on.⁵⁸ At

this point, there is a risk that the new assessment for PIP – if designed solely on the basis of need (determined by the functional impact of a person's impairment), could result in an ill-suited match between the level of benefit a disabled person receives, and the additional disability costs they incur.⁵⁹ This could result in disabled people who have been determined as having a low functional impact of their impairment but high disability costs missing out on much-needed support.

The Welfare Reform Bill

The Welfare Reform Bill was introduced into parliament on 16 February 2011. If it becomes law, many of the new reforms outlined above will be implemented. However the bill also:

- scrapped plans (announced in the emergency budget) to cut Housing Benefit by 10 per cent for people who had been claiming JSA for a year⁶⁰
- postponed the removal of DLA mobility component from disabled people in residential care to 2013⁶¹
- announced the removal of 'special arrangements' that allowed young disabled people to claim contributions-based ESA⁶²
- announced the abolition of the 'discretionary payments' of the Social Fund – two of which, crisis loans and community care grants, were designed to provide financial support to vulnerable people in emergency situations⁶³
- introduced a 'size criteria' for working-age HB claimants living in the social rented sector, effectively reducing a claimant's HB according to the number of 'extra' rooms in their property.⁶⁴

The first reform noted above came as a welcome announcement; the second is still cause for concern – plans to remove the DLA mobility component from care home residents are still very much in place – but provides some reprieve for those receiving support. However, the third and fourth policies will be particularly detrimental to disabled people.

Repealing the ESA 'conditions relating to youth'

At present, there are special arrangements within the ESA system

that allow young (16–19-year-old) disabled people to qualify for contributions-based ESA without having paid the minimum amount of National Insurance contributions because of their age.⁶⁵ Abolition of these provisions, which is to take effect in April 2012, is designed to ensure that those eligible are ‘on the same contributory footing as everyone else claiming contributory ESA’.⁶⁶ Furthermore, as of April 2012, the 365-day time limit to contributory ESA will also apply to ESA ‘youth’ claimants.⁶⁷ Of those affected, 20 per cent are expected to be eligible to receive the same amount of benefit on income-based ESA instead.⁶⁸ Around 70 per cent will be able to move onto income-based ESA at the same rate or lower – overall, losing around £25 per week.⁶⁹ About 10 per cent will not qualify for income-based ESA – perhaps because they have a partner who works.⁷⁰ The resulting reduction in spending ESA for this group is estimated to save the Treasury around £11 million a year.⁷¹

Possible unintended effects of this reform include young people spending their savings in order to remain eligible for income-based ESA;⁷² alternatively, recipients’ partners who are working may reduce their hours to become eligible for income-based support. The rationale behind the policy has been criticised by analysts who point out that young people aged 16–19 have not had the same chance as older people to build up enough National Insurance contributions to be eligible.⁷³ On losing contributions-based ESA, a small number of disabled young people will see their weekly income drop by up to £100.⁷⁴

The abolition of discretionary payments of the Social Fund

The bill set out plans to abolish budgeting loans, crisis loans and community care grants from 2013.⁷⁵ The recipients of crisis loans and community care grants are very likely to be disabled people: DWP data for 2009 show that around a third of community care grant and crisis loan final decisions were made for disabled people.⁷⁶ In 2009/10 crisis loans were awarded to over 800,000 disabled people; more than 210,000 disabled people received a community care grant that same year.⁷⁷

Community care grants are available to people receiving income-related benefits in difficult situations. For households

Table 2 **Fiscal and welfare reforms announced within and after the spending review in October 2010, and their effects**

Change	Effect
The introduction of the Universal Credit	The Universal Credit will take the place of a variety of means-tested benefits, including income-based JSA and ESA, HB, Income Support (IS), and Child and Working Tax Credits. DLA will not be affected. ⁸⁴ Over 33 per cent of the Universal Credit caseload is expected to be households with a disabled member. ⁸⁵
The abolition of DLA	DLA is to be discontinued from 2013/14, and will be replaced by PIP. There are currently around 1.8 million working-age disabled people claiming DLA. ⁸⁶
Time-limiting contributions-based ESA for 365 days	Contributions-based ESA WRAG is to be limited to one year. By 2015/16, about 700,000 people will lose this benefit; weekly net income is expected to drop by £36. ⁸⁷
Removal of DLA mobility for disabled people in state-funded care homes	As the plans stand, all those receiving state-funded residential care will lose their eligibility for DLA mobility component. Around 80,000 disabled people will be affected. ⁸⁸
The removal of special arrangements for 'youth' contributions-based ESA	Disabled young people aged 16-19 (20-25 for those in education or training) will no longer be eligible to receive contributions-based ESA. This is expected to affect 15,000 young people by 2015/16. ⁸⁹
Replacing community care grants and crisis loans with 'locally-based' provision	The impact of this shift remains to be seen and will vary across local authorities, but breakdowns of recent caseloads suggest several hundreds of thousands of disabled people could be affected.
Introducing a percentage reduction of HB based on number of extra bedrooms	The HB of claimants whose home is deemed to be larger than they need will be cut. Under these rules, people in social homes could see their benefit cut by 15 per cent if they have an extra bedroom - 25 per cent if they have two. ⁹⁰ Around 108,000 disabled people will be affected by these measures; those unable to afford the rent will have to move to a cheaper property. ⁹¹

with a disabled member, the grants can help ‘ease exceptional pressures’ placed on the family, or provide financial support for people trying to establish themselves or remain in the community.⁷⁸ Crisis loans are given to people who need financial help in an emergency, so as to prevent serious risk or damage to a person’s health and safety – or that of their family. Crisis loans can help enable disabled people coming out of residential care, who have been awarded a community care grant, to meet their rent in advance, in order to help establish themselves in the community.⁷⁹

These loans are to be replaced by a ‘combination of locally-based provision’.⁸⁰ As with many of the plans outlined in the Welfare Reform Bill, the details have not yet been refined, but as it stands this ‘locally-based provision’ is thought likely to take the form of ‘Emergency Grants’, which will be administered – probably on referral only (the current system allows for people in need to apply for support) – by local authorities. However, the bill contains plans to remove the statutory duty that requires local authorities to deliver this service⁸¹ and monies will not be ring-fenced.⁸² The bill also abolishes the office of the social fund commissioner who serves as the head of the Independent Review Service for the Social Fund.⁸³ Combined, these policies create great uncertainty over whether local authorities will provide such a service; whether the monies transferred from central government will be used to this purpose; and how such services will be monitored and reviewed.

The latest changes – budget 2011

Although not a substantial welfare reform announcement like the spending review, it is worth noting that in the March 2011 budget, the Government announced an increase in the tax personal allowance by £1,000 to £7,475, as part of the government’s ambition to move towards a personal allowance of £10,000.⁹² From April 2012, people’s personal allowance will increase to £8,105 a year. Those paying 20 per cent tax (the basic rate) will gain £126 a year; those paying 40 per cent tax (the higher rate) will gain £48 a year.⁹³ Those whose incomes are

already below the tax threshold remain unaffected.⁹⁴ The decision to increase the personal allowance was greeted by the Institute for Fiscal Studies as 'a progressive way of cutting income tax bills'.⁹⁵ However, policy analysts at the Joseph Rowntree Foundation warned the decision to change the basis for uprating tax thresholds from RPI to CPI – which was also announced in the budget – would act 'as an effective tax increase' and would 'soon cancel out the benefits of increasing the personal allowance'.⁹⁶

More than welfare: the wider impact on services and support

In the wake of so many radical new changes to welfare benefits, it can be easy to lose sight of the bigger picture – the Government's plans to reduce the budgetary deficit also includes unprecedented cuts to many public services and local authority budgets. In the October spending review, Chancellor George Osborne announced that councils nation-wide would face annual budget reductions of 7.1 per cent.⁹⁷ Writing in the *Guardian*, Amelia Gentleman paints a bleak picture of what this will mean for local services in Camden:

*Over the next three years rubbish will be collected less frequently, some daycare centres for older people will close, two children's centres will shut their doors, play services will see most of their funding removed, some libraries will be wound down, school buildings will not be maintained as regularly, council flats will be left unrepaired for longer, residents will have to start paying for some services that have previously been free and about one council position in five will be lost, with 970 jobs being cut.*⁹⁸

Social care

The cuts with the most direct impact on disabled people will undoubtedly be in social care. Last October we observed that while NHS and foreign aid budgets were to be exempt from the reductions in government spending, adult social care departmental directors warned of cuts to their services of up to 40 per cent over the three years.⁹⁹ And while the Chancellor pledged in the spending review to set aside an additional £2

billion for social care provision, decisions to not ring-fence this money leave little guarantee that cash-strapped councils will use such funds specifically for social care services.¹⁰⁰ A recent report by the King's Fund reveals that as a result of the 27 per cent cut in local government funding, local social care services will face a funding gap of over £1.2 billion by 2014 – a scenario they suggest will have knock-on effects on the NHS.¹⁰¹

In April 2011, new local authority budgets were imposed, revealing the local impact of the cuts on many elderly and disabled service users. In Birmingham, for example, the City Council recently announced plans to cut its adult social care budget by £51 million over the next 12 months; over 14,000 adult social care service users will have their social care needs reassessed.¹⁰² The council originally sought to increase the eligibility threshold for social care to a 'super critical' level, which would mean that anyone needing anything other than full residential care would have lost support. In the face of massive protest, the council decided not to go ahead with this controversial decision; but will still set its threshold at 'critical' needs only. Around 4,100 people receiving council-funded care are expected to lose their care provision as a direct result of the rise in the eligibility threshold.¹⁰³

But Birmingham is not an exceptional case. Research by *Community Care* suggests that 80 per cent of local authorities are expected to provide services only to those with 'substantial' or 'critical' needs. To put this increase in perspective, in 2006, more than half of councils still provided care for those assessed as having 'moderate' needs.¹⁰⁴

Cuts are also resulting in the closure of local services. In the north London borough of Camden, four of six local day centres will have their funding cut; in Hounslow there are plans to axe two of the area's four centres; in Leeds, the council recently approved a budget that included measures that left four residential care homes and four day care centres facing closure; in Southampton, the decision to withdraw £400,000 of day care funding is reported to result in the closure of around 21 day centres that were run by a not-for-profit care company.¹⁰⁵

Furthermore, the costs of care for social care users who are still eligible for support are increasing significantly because of

increased charges for home care and meals on wheels. In Southampton, the local authority increased prices by 38 per cent – from £3.47 for a full meal to £4.78¹⁰⁶ while in Romford service users have seen an increase of 33 per cent.¹⁰⁷

Local support services

Disabled people are also particularly reliant on support from voluntary and community sector organisations. In October 2010, the National Council for Voluntary and Youth Services published a report on the impact of the cuts on voluntary services, which highlighted how councils were cutting funding for third sector organisations in London, among other places:

*A London Voluntary Service Council Study revealed that charities and voluntary groups in London have experienced funding cuts totaling about £50m in the past 12 months; Greenwich Council has warned that its voluntary sector grant budget could be slashed by 50 per cent or more from next year and Lambeth Council has confirmed it plans to cut nearly £90m from its budget over the next five years.*¹⁰⁸

It is predicted that crucial services for children and families will also be dramatically affected: a recent survey by 4Children and the Daycare Trust revealed approximately 250 (7 per cent) Sure Start children's centres are set to close this year; another 2,000 (56 per cent) will have to cut back on the services they offer to parents and children.¹⁰⁹ In Liverpool, government funding for children's centres has been cut by £12 million over the next two years; four children's centres in the least deprived areas are facing possible closure; and funding for voluntary groups has been drastically reduced by almost 50 per cent (£18 million).¹¹⁰

The small selection of examples outlined above illustrate how the government programme to reduce the deficit and cut public spending will affect not just welfare benefits but a wide variety of social care, health, children and adult services, as well as charities and voluntary organisations across the country. Disabled people, particularly those on low incomes, with care

and support needs or both, are disproportionately reliant on public services, social care and the support from voluntary sector organisations.¹¹¹

3 Revisiting our disabled households: the lived experience of cuts

This report is the first in a series of follow up publications succeeding *Destination Unknown* that aim to reveal the real ‘lived’ experiences of disabled people as the cuts to services and the changes to welfare benefits begin to take full effect, and bring to the fore first-hand experiences of living on the edge of uncertainty, financial difficulty and, in some cases, disability poverty.

We chose April 2011 for our first update report because many of the welfare reforms announced are due to begin this month: Incapacity Benefit reassessments are to be rolled out nation-wide; people’s benefits will be uprated in line with the Consumer Price Index (CPI) for the first time; caps on housing benefit will be applied, and the one-year time limit for current Employment and Support Allowance (ESA) claimants will begin. As the beginning of the new financial year, April is also when new local authority budgets are enforced, this year bringing with them substantial cuts to services and grants to voluntary organisations.

In this report, we return to four of the original five case study households presented in *Destination Unknown* to see how their income, health, housing and other circumstances have changed since we interviewed them in 2010. In addition to the four original case studies, we present two new ones. ‘A’ – a disabled child being cared for by her parents – replaces L (whose parents were unfortunately unable to continue to participate in the research because of their caring obligations), and ‘S’ – a disabled man who is a social care service user. In light of the dramatic changes occurring in social care provision, we thought it important to include S to establish what effects these changes were having on disabled people in receipt of such services.

Our case studies are:

- a young disabled child (A) cared for by her mother and father
- a disabled man (P) and his wife who cares for him and also has moderate disabilities
- a single disabled man (E)
- a single disabled woman (C)
- a middle-aged, disabled man (S) who is a social care service user.

Many of the welfare reforms already outlined have clear and predictable effects on our case study families. In particular, the change in uprating benefits by CPI is easily calculated and although the weekly figures of these reductions may seem small, over time their cumulative effect can be substantial.

However, by speaking to these families about their experiences over the preceding six months, we have been able to gain an insight into the wider impact of government reforms that have had more significant financial consequences – for example the huge reduction in Support for Mortgage Interest (SMI) payments, the delay in pension payments, and the requirement of one of our case study families to use their Disability Living Allowance (DLA) to contribute to their social care. What is striking is that changes in SMI and pensions are not directly relevant to disabled people, in the way scrapping DLA might be, yet they are proving extremely important to our disabled families – demonstrating why including disabled people in the impact assessments of wider policies is so crucial.

We have also been able to see first-hand how cuts to local authority budgets and local services are starting to affect disabled people. In *Destination Unknown*, we focused primarily on quantifying welfare benefit cuts; in this report we have taken a broader view and considered how cuts in the round are affecting people's quality of life.

In our interviewing we were also struck by the fact that all of the case study families experienced a 'shock' of some kind – including accidents or worsening health requiring treatment, or financial shocks – home repairs, utilities bills and other 'lumpy' costs, which disabled households have no savings to cover.

Almost all of our case study participants had debts when we spoke to them in 2010, and these had all increased when we spoke to them again this year. The clear message from this is that the disabled people we spoke to are not making ends meet, and have little or no safety net in the face of life's uncertainties.

In the following case studies, we consider:

- the predictable impact of the Government's welfare reform – including but not exclusively the transfer to CPI uprating
- the less predictable impact of the Government's budgetary cuts and the wider economic climate
- the events that demonstrate the precarious situation our families are in, both financially and related to their health and wellbeing.

A: a disabled child, cared for by her parents

If there are further cuts to benefits it will have to come from heating and food bills as there is nothing else we can cut back on.

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

The predicted losses resulting from welfare reforms

The primary impact we predicted in *Destination Unknown* was the loss in a range of benefits as a result of increasing benefits by September 2010's CPI (3.1 per cent) instead of Retail Price Index (RPI) (4.6 per cent) or Rossi (4.8 per cent). This took effect on 1 April 2011. However, A's parents also receive Child Benefit for

Table 3 **The predicted effects of Coalition Government welfare reforms on A's family**

Family benefits	Reforms to benefits from April 2011	Worse off in 2011?
Disability Living Allowance – high mobility	Benefit increased by CPI instead of RPI – from £49.85 to £51.40 per week (CPI), instead of £52.14 (RPI)	74p per week, £38.48 per year
Disability Living Allowance – high care	Benefit increased by CPI instead of RPI – from £71.40 to £73.60 per week (CPI), instead of £74.68 (RPI)	1.08p per week, £56.16 per year
Child Benefit	Benefit frozen – so no increase from £87.30 per week in 2010; would have increased to £91.31 with RPI	£4.01 per week, £208.52 per year
Carer's Allowance	Benefit increased by CPI instead of RPI – from £53.90 to £55.57 per week (CPI), instead of £56.37 (RPI)	82p per week, £42.64 per year
		By a total of... £345.80

their other children – which the government has now frozen at 2010 rates for the next three years. As the cost of living (reflected in RPI inflation of 5.5 per cent in April 2011) is so high, this is the most significant loss for the family. See table 3.

What didn't we account for?

In *Destination Unknown* we were able to model the potential losses to benefits income driven as a result of announced reforms. However, the impact of other cuts (to public services) was an unknown quantity until after the settlement had been

announced in the spending review and local authorities set their budgets for the coming financial year. Six months on, at the beginning of the new financial year and the imposition of new local budgets, we are starting to see the first impacts on our case study families.

A had a new bedroom designed by an occupational therapist but the designs were incorrect: the door is obstructed by the bed, there is not enough room to get around the bed to give A chest therapy, which she needs four times a day, and not enough room for her hoist. The local authority's Children with Disabilities team admitted liability for these mistakes but has told A's family that they *do not have the budget to fix the room properly* – they can make small amendments now and A's parents can formally challenge the authority's decision in five years' time.

A's mother told us she had to 'fight' for another hour of care for A, so A now receives one hour every school morning to allow A's mother to help her other children leave for school. They receive no other support from their authority. Feeling this was wrong, A's mother asked for A's care needs to be assessed, but the social worker found that A's needs were being met – because A's mother is a full-time carer. Although 'carer blind' assessments and 'whole family assessments' are increasingly accepted as best practice, A's mother feels A's assessment took no account of the needs of the rest of the family (including A's five other siblings being cared for by A's mother) in concluding that A's needs were met with just one hour of care for five mornings a week.

A is now old enough for a motorised wheelchair but A's family has been told they will have to buy this themselves or contact a charity to provide one. Yet a family friend in a different part of the country with a child in a similar situation had her wheelchair paid for by the local authority – A's family feels this geographical variation is deeply unfair.

No safety net – coping with financial shocks

We must bear in mind that this recession has not just been about cuts – it has also been exacerbated by increased costs to basic

foodstuffs due to poor harvests and energy prices as a result of instability in the Middle East. These increases affect us all, but disabled people are often more reliant on cars, because of the inaccessibility of public transport, and also use more electricity and heating to help them run equipment and manage their conditions (see below). Disabled people have therefore been hit particularly badly by higher energy prices.

Although the most recent budget reduced fuel duty by a penny per litre, fuel duty increased by 0.76p on 1 January 2011. This, combined with the VAT increase, means prices actually increased by around 3.5p per litre.¹¹² This followed a succession of increases, resulting from energy crises and instability in the Middle East, so that in March 2011 a litre of petrol cost 130p and diesel 135.44p – almost the all-time high.¹¹³ A's family relies heavily on their car to take A to a variety of outpatient appointments to manage her condition – and their experience is by no means atypical of a disabled person who finds public transport inaccessible. The details of their journeys and associated costs (box 1) illustrate how higher fuel prices have a disproportionate impact on those most reliant on their cars through necessity.

Box 1 The costs of transport for A's family

A's family now spends around £150 per month on diesel taking A to appointments at three different hospitals:

- *The first is 12 miles away, where A has three appointments a month. A's father drives or they have to pay £20 for a taxi. There are no direct buses and buses do not allow A's wheelchair on board if they are already carrying buggies.*
- *The second is 40 miles away, where A must attend once a week. It costs about £90 for a taxi if A's father is not free to drive them (which he does about half the time).*
- *The third is 70 miles away, where A attends twice a year. The family drives, but the trip and appointment take all day so they also have to pay around £15 for childcare for the other children.*

It is clear from this that A's DLA mobility benefit (around £200 per month) will not cover these basic appointment travel costs in the face of record highs in fuel prices, let alone any other transport A may require (going to school, other appointments like dentist, or leisure).

In addition to dealing with these higher prices, A's family has experienced another financial shock: their boiler broke in winter and as A has cerebral palsy, a condition that can leave people very susceptible to cold, it had to be repaired immediately. British Gas repaired the boiler within two hours but this cost the family £200.

Finally, and as a result of the turmoil over A's bedroom, A has become less in control of her anxiety and depression, so she might have to go back onto medication. She has also started suffering monthly chest infections and needs regular antibiotics (generating further travel costs to the GP, expenditure on non-prescription medicines, and so on).

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

We're waiting for more trouble everyday.

- P was a self-employed businessman but he suffered a stroke in 2006. This left him with a weakness in his left hand, his left leg often locks, and he has two heart defects, which required him to have surgery. He also now suffers from regular memory loss.
- P's wife is his carer, who was made redundant two years ago. She has arthritis.
- They have a £137,000 mortgage and £54,000 debts.
- They receive:
 - DLA for P (high mobility, middle care)
 - DLA for P's wife (low care)
 - Incapacity Benefit
 - Income Support
 - Carers Allowance (for P's wife)
 - SMI

The predicted losses of welfare reforms

As with our other case study participants, P and his wife have received lower than expected increases to their benefits this April as a result of the switch from RPI to CPI. However, P's Incapacity Benefit 'age addition' of £15 per week (given to him as he became disabled before he turned 45) is also to be cut to £13.80 this year, creating a larger than expected drop. Yet for this family, the reduction in SMI has led to the most significant hardship. 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 much lower than the previous SMI rate of 6.08 per cent, set in December 2008.

P's mortgage is around £137,000. As he cannot work and his wife cares for him they rely on SMI to cover their mortgage payments. Until October 2010 they were receiving £426 in SMI – though they told us when we spoke to them in September 2010 that this did not cover the total mortgage cost. But as a result of the government's reform, they now only receive £226 per month in SMI, and this £200 reduction in monthly SMI payments is creating a larger shortfall in mortgage payments, which means P and his wife are now *£7,000 in arrears* and are receiving letters threatening them with charges. In addition, as P receives Incapacity Benefit, he will also be due for a reassessment – the national rollout of Incapacity Benefit reassessments using the Work Capability Assessment began in April 2011. See table 4.

What didn't we account for?

Since April 2010, the Government has been gradually increasing the pension age from 65 to 66, though the Coalition Government has proposed to accelerate this as part of the Pension Bill 2011. P's wife was supposed to have received her state pension of £97 per week on 6 November 2010, but this has been delayed to 6 July 2011. This eight-month delay will mean a loss of £3,104 in pension income.

No safety net – coping with financial shocks

The same forces that have driven up petrol and diesel costs in recent months (with particular impact on A and her parents,

Table 4 **The predicted effects of Coalition Government welfare reforms on P and his wife**

Family benefits	Reforms to benefits	Worse off in 2011?
Disability Living Allowance – high mobility	Benefit increased by CPI instead of RPI – from £49.85 to £51.40 per week (CPI), instead of £52.14 (RPI)	74p per week, £38.48 per year
Disability Living Allowance – middle care	Benefit increased by CPI instead of RPI – from £47.80 to £49.30 per week (CPI), instead of £49.99 (RPI)	69p per week, £35.88 per year
Disability Living Allowance – low care for P's wife	Benefit increased by CPI instead of RPI – from £18.95 to £19.55 per week (CPI), instead of £19.82 (RPI)	27p per week, £14.04 per year
Incapacity Benefit (reduced by £140 per month Third Party Payment – see below)	Benefit increased by CPI instead of Rossi – from £91.40 to £94.25 per week (CPI), instead of £95.70 (Rossi); age addition allowance of £15 reduced to £13.80 so total benefit £108.05 instead of £110.78 (combining both losses)	£2.73 per week, £141.96 per year
And due for reassessment from April 2011		
Income Support	Benefit increased by CPI instead of Rossi – from £107.30 to £110.60 per week (CPI), instead of £112.45 (Rossi)	£1.85 per week, £96.20 per year
Carer's Allowance for P's wife	Benefit increased by CPI instead of RPI – from £53.90 to £55.55 per week (CPI), instead of £56.37 (RPI)	82p per week, £42.64 per year
		By a total of... £369.20

above) have also driven up household fuel costs. Suppliers have all increased their gas and electricity prices by between 6 per cent and 10 per cent in the months from December 2010 to March 2011.¹¹⁴ Many disabled people have higher usage of these utilities, for a number of reasons: they are more likely to be home during the day (because of their higher unemployment rates), have specialist equipment to run, and feel cold through immobility – many common conditions (cerebral palsy, multiple sclerosis, arthritis and those recovering from strokes) include sensitivity to cold. Therefore the price hikes in gas and electricity as a result of oil crises and Middle East instability have hit disabled people particularly badly.

Because of their conditions, P and his wife require a well-heated house; over this particularly cold winter, and as a result of increases in electricity and gas prices, P and his wife faced the significant financial shock of three large utilities bills: a £465 gas and £300 electricity bill, and a £643 water bill. P estimates their monthly bills have increased by £30 (electric) and £15 (gas). P has not been able to pay these bills, and has no savings and some debts; these ‘lumpy’ costs could not be met without coming straight from the couple’s benefits income. P’s Incapacity Benefit is therefore automatically reduced as part of the third party payment scheme, at a rate of £140 per month.

When we spoke to P and his wife last year they expressed concern that they were living hand to mouth and just making ends meet, and it is likely large unexpected costs, like a gas bill, could negatively tip this delicate financial balance. Last year they told us they would be unable to fund the money for the TV licence, which was up for renewal, and that their house was in desperate need of repair – their damaged windows likely to be increasing their heating bills. Six months on, it is perhaps unsurprising that P’s credit card debt has risen by £9,000 from £45,000 to £54,000 as they struggle to cope, while their house falls further into disrepair.

Like most of our other case study participants, P and his wife experience bouts of poor health, which affects their financial, physical and emotional wellbeing. P’s wife’s arthritis in her spine is getting worse, so she now has to have injections

every six months. P collapsed in January shortly after receiving some electrical treatment. He will be seeing a neurologist shortly.

E: a single disabled man

- E is in his late 40s and lives alone. He has lifelong epilepsy, but this deteriorated in 2008 and left him unable to work. He separated from his wife.
- He has a mortgage of £73,000 and a £7,000 credit card debt, £4,800 overdraft and owes his brother £7,100.
- He receives:
 - DLA (low mobility; middle rate care)
 - ESA (Work Related Activity Group; WRAG)
 - Council Tax Benefit

The predicted losses of welfare reforms

Like other disabled people, E will see a smaller increase in his DLA as a result of uprating by CPI instead of RPI – however, the bigger impact for E will be the new time limit for claiming the WRAG rate of ESA. From 1 April 2011 people can only claim WRAG for one year. So E now only has one year left to claim ESA – in April 2012, his benefit will cease and if he cannot work, he will have to apply for Jobseeker's Allowance (JSA) instead (£26 less per week than his current benefit of £91.40). See table 5.

No safety net – coping with financial shocks

Although E believes he manages his finances well and always shops around, he has a significant level of debt, which has increased by £1,200 since we last spoke to him. He is less likely to make ends meet following April's upratings and more likely to fall further into debt. And like other households we interviewed, E suffered a setback with his health. He had a fit in the middle of an icy street in January, and fell and smashed his elbow. He needed surgery, but had a fit on the operating table. After surgery, he told us 'the results fell apart' and he had to have

Table 5 **The predicted effects of Coalition Government welfare reforms on E**

Family benefits	Reforms to benefits from April 2011	Worse off in 2011?
Disability Living Allowance - 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)	27p per week, £14.04 per year
Disability Living Allowance - middle care	Benefit increased by CPI instead of RPI - from £47.80 to £49.30 per week (CPI), instead of £49.99 (RPI)	69p per week, £35.88 per year
ESA WRAG rate	Benefit increased by CPI instead of Rossi - from £91.40 to £94.25 per week (CPI), instead of £95.78 (Rossi)	£1.53 per week, £79.56 per year worse off - and only eligible for this benefit for one more year
		By a total of... £129.48

corrective surgery again (twice in four weeks). This may make E even less able to find employment, though he now only has one year left on ESA to do so.

C: a single disabled woman

- C has been a wheelchair user since her childhood. Now in her late 20s, she lives alone and rents her own place from a housing association but stopped claiming Housing Benefit after receiving an inheritance.
- She receives:
 - DLA (high mobility; middle rate care)
 - Incapacity Benefit

Table 6 **The predicted effects of Coalition Government welfare reforms on C**

Family benefits	Reforms to benefits from April 2011	Worse off in 2011?
Disability Living Allowance – high mobility	Benefit increased by CPI instead of RPI – from £49.85 to £51.40 per week (CPI), instead of £52.14 (RPI)	74p per week, £38.48 per year
Disability Living Allowance – middle care	Benefit increased by CPI instead of RPI – from £47.80 to £49.30 per week (CPI), instead of £49.99 (RPI)	69p per week, £35.88 per year
Incapacity Benefit (+ £15 age addition)	Benefit increased by CPI instead of Rossi – from £91.40 to £94.25 per week (CPI), instead of £95.7 (Rossi); age addition of £15 reduced to £13.80 so total benefit £108.05 instead of £110.78 (combining both losses)	£2.73 per week, £141.96 per year And due for reassessment from April 2011
		By a total of... £216.32

The predicted losses of welfare reforms

C will see lower than expected increases in her DLA and Incapacity Benefit as a result of linking them to CPI instead of RPI inflation, and, like P, will see the age addition to Incapacity Benefit fall from £15 to £13.80 per week. However, more important for C is her impending Incapacity Benefit reassessment. From 1 April 2011, the national reassessment of Incapacity Benefit claimants began – C is aware of this and believes she may be placed in the WRAG group of ESA but the uncertainty of this, and not having a date for reassessment, is making her very concerned. See table 6.

What didn't we account for?

Although C does not receive any support from social services, local authority budgetary cuts are affecting her in another way. She currently volunteers at her local Citizens Advice Bureau, but this has had to relocate to new premises and, because of local authority cuts to grant funding, it may soon close. This will leave C without an opportunity to contribute to her community and may increase her risk of social isolation. Volunteering builds confidence and social networks, and helps people ready themselves for paid employment – this will be particularly important if C finds herself moved to the ESA WRAG group in the near future.

No safety net – coping with financial shocks

Like A's family and P and his wife, C also experienced an unexpected financial shock this year when she found she needed a new battery for her electric wheel chair. The NHS did not cover this cost so she had to pay £200 for the battery and £30 fitting, using her benefits income.

C's health has deteriorated, as she has had a lot more spasticity due to new medication, and she cannot bend one of her legs any more. This makes transfers from her wheelchair harder, but as she is ineligible for state-funded social care she has to cope alone.

S: a social care user

Although we did not include S in *Destination Unknown*, we did interview him in 2010. We have included S in these updates and will do so in subsequent updates in order to establish what impact local authority budgetary cuts have on social care users.

- S is a man in his late 40s. He has secondary progressive multiple sclerosis, which has worsened over the last five years. He used to work, but retired on health grounds 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.
- S receives:
 - DLA (high mobility; high care)
 - Incapacity Benefit
 - direct payments for social care, which he uses to purchase 21 hours of home care per week

Predicted impact

S's benefits will be increased by a smaller amount than predicted this year – but the bigger impact for S may be the reassessment of Incapacity Benefit claimants, which began in April 2011. Jobcentre Plus told S about the impending reassessment last year, but unlike C, S is not concerned. Whereas C feels she may be moved onto the time-limited WRAG groups of ESA, S believes he will be moved onto the Support Group. This group is reserved for those who are not expected to find a job. However, nothing is certain, and S will only know what support he will be entitled to once he has undergone the reassessment.

Current statistics on this issue are a poor guide, as only 9 per cent of new claimants are placed in the support group, and Iain Duncan Smith estimates 19 per cent of Incapacity Benefit claimants when reassessed will be placed in the Support Group.¹¹⁵ Interim results of the Incapacity Benefit reassessment pilots (running from October 2010) found that around a third of those reassessed were placed in the Support Group, a third in the WRAG group, and a third had their Incapacity Benefit withdrawn as they were deemed fit for work. However, as these figures were based on the first 1,200 reassessments, it may prove to have little relevance for S.¹¹⁶ See table 7.

What didn't we account for?

In April 2011 local authority budgetary cuts are only just being implemented, as we are early in the new financial year, so we had not expected to see any changes to S's care at this stage (resulting from changes to his eligibility). However, in February 2011 S was asked to declare his savings and benefits income, so

Table 7 **The predicted effects of Coalition Government welfare reforms on S and his wife**

Family benefits	Reforms to benefits from April 2011	Worse off in 2011?
Disability Living Allowance – high mobility	Benefit increased by CPI instead of RPI – from £49.85 to £51.40 per week (CPI), instead of £52.14 (RPI)	74p per week, £38.48 per year
Disability Living Allowance – high care	Benefit increased by CPI instead of RPI – from £71.40 to £73.60 per week (CPI), instead of £74.68 (RPI)	1.08p per week, £56.16 per year
Plus contributing to care costs at £24.65 per week		
Incapacity Benefit	Benefit increased by CPI instead of Rossi – from £91.40 to £94.23 per week (CPI), instead of £95.78 (Rossi)	£1.55 per week, £80.60 per year
By a total of... £175.24		

the local authority can determine the contribution he must make to his care funding. His local authority has recently announced that it will require people to make a contribution to their care from their DLA at a rate of £24.65 per week, from 11 April 2011, in order to make £7 million in savings over the next year.¹¹⁷ S's benefits income is set to be reduced substantially as a result of local authority budget cuts – by £1,281.30 in 2011.

No safety net – coping with financial shocks

Although S and his wife are in a relatively stable financial position, in that S's wife works full time, S reported to us last

year that they were just coping financially and the savings they had built up over the years that they were both working were not being used on everyday living costs. It is possible we will see S's financial situation deteriorate rapidly as a result of the new contribution he must make to his care costs.

In extremis – H: a disabled mother caring for disabled child

I don't have a choice, I have to cope; I have to survive in life.

In *Destination Unknown* we interviewed H not as a 'typical' disabled household but as an illustration of how difficult life can be for some disabled people when relying on benefits and public services. In 2010, H was concerned that her own 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. This year, things have not improved.

- H is a disabled woman who suffers from neuralgia, epilepsy, migraines and rheumatoid arthritis.
- She has a nine-year-old son who has epilepsy, low tone muscular problems, speech and language difficulties, atypical autism, ADHD, anataxia, complex learning difficulties and challenging behaviour.
- H 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. H 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)
 - Incapacity Benefit
 - Child Benefit
 - Housing Benefit
 - underlying Carer's Allowance

The predicted losses of welfare reforms

As with our other case studies, all of H's benefits have been increased by a lower amount than before the Coalition Government's reforms. H also suffers a substantial loss as 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. See table 8.

What didn't we account for?

Housing adaptations have proven to be a 'continuous battle' for H. Although she lives in a council house, she needs a bungalow, but the local authority has refused to carry out the adaptations recommended by H's GP. Many of the adaptations the local authority claim to have carried out in her home have not been done, or were inappropriate. She had to buy her own handrails when the old ones fell off of the wall.

H's son needs 2-1 care, but is not getting it, and social services have refused to provide H with respite support. Following an incorrect core assessment of her son and no care plan being put in place, H received an apology from the local authority, but must now go to court in order to secure more care for her son.

As a result of this lack of support, H has resorted to using her own direct payments (intended to pay for her care) to purchase care for her son so she can rest.

H already has to travel some distance to attend appointments for herself and her son. Like A's parents, she is likely to incur significant fuel costs as H must also use her car to travel. She must already travel 40 miles for neurological appointments for her son, but now her local paediatric and continence support clinic is closing following local cuts, so she will have to travel to a hospital further away and pay for a carer to look after her son when he is in the backseat.

No safety net – coping with financial shocks

H has also had some bad luck in recent months – the four hours respite care she secured from a children's charity was withdrawn

Table 8 **The predicted effects of Coalition Government welfare reforms on H and her son**

Family benefits	Reforms to benefits from April 2011	Worse off in 2011?
Disability Living Allowance – 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)	27p per week, £14.04 per year
Disability Living Allowance – middle care	Benefit increased by CPI instead of RPI – from £47.80 to £49.30 per week (CPI), instead of £49.99 (RPI)	69p per week, £35.88 per year
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); age addition of £15 reduced to £13.80 so total benefit £108.05 instead of £110.78 (combining both losses)	£2.73 per week, £141.96 per year And due for reassessment from April 2011
Housing benefit	Benefit increased by CPI instead of Rossi – from £65.45 to £67.50 per week (CPI), instead of £68.59(Rossi)	£1.09 per week, £56.68 per year
Underlying Carers Allowance	Benefit increased by CPI instead of RPI – from £30.05 in 2010 to £31 per week (CPI), instead of £31.43 (RPI)	43p per week, £22.36 per year
Child Benefit	Benefit frozen – so no increase from £20.30 per week in 2010; would have increased to £21.23 with RPI	93p per week, £48.36 per year
		By a total of... £319.28

because her son had had a tantrum and the carers could not manage him. In addition, late last year the local authority failed to transfer the correct amount of direct payment to H's bank, and H received letters from her bank stating she was overdrawn. The error was only amended two months later after H chased the issue up with social services. H's lack of a financial safety net – in the form of even moderate savings – means simple administrative mistakes can have dire consequences.

4 What have we seen? An overview

The information our disabled families shared with us can be placed into four broad categories:

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

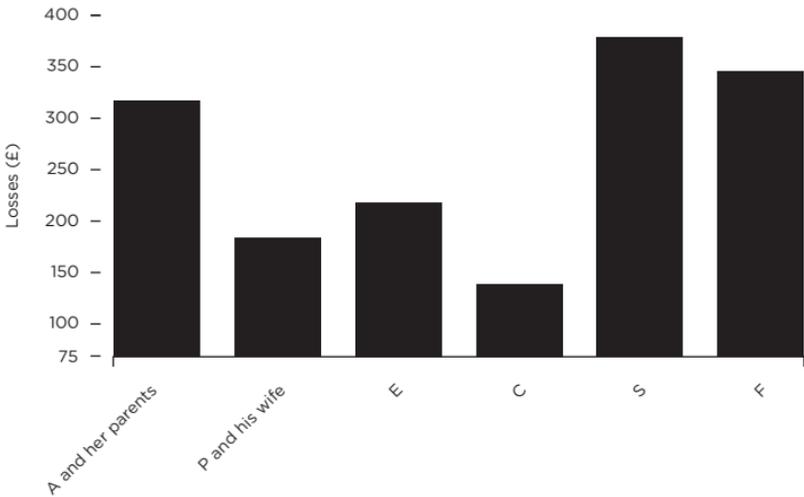
Increasing benefits by the Consumer Price Index – how they will affect our disabled families this year

Although these decreases are consistent for all of our case study participants (and will affect all disabled people receiving benefits), they are not the largest negative effects we have seen. Other reforms to welfare benefits announced by the Government will have a greater financial impact.

Additional reforms with a larger impact

P and his wife rely on Support for Mortgage Interest (SMI) to help them pay the mortgage – but as it is now being linked to the average mortgage rate (3.63 per cent), significantly lower than the previous SMI rate of 6.08 per cent, they are receiving £200 less support per month. Clearly P and his wife have a mortgage which is not at today's 'average' interest rate of 3.63 per cent – they are now £7,000 in arrears thanks to the SMI shortfall.

Figure 1 Weekly losses in income due to changes in uprating



Our Incapacity Benefit claimants (C, S and H) are all now due for reassessment and will be transferred onto Employment and Support Allowance (ESA). C is most likely to be transferred to the Work Related Activity Group (WRAG), or indeed straight to Jobseeker’s Allowance (JSA) if she is found fit to work.

If she is transferred to WRAG, she will join E in being allowed to remain on this benefit for one year without finding employment, after which it is automatically withdrawn. As E is a current WRAG claimant, he now has one year left to claim this benefit.

The time limitation of WRAG had not been announced when we wrote *Destination Unknown*, so we were unable to predict the severity of the situation faced by C and E.

We were also unable to predict or take account of several other developments in the lives of our case study participants, which are directly or indirectly caused by the government welfare reforms or local budgetary cuts. The most substantial of these include P’s wife’s pension being delayed for eight months, leading to a substantial loss of income (£3,104), which they had

been relying on, and S being required to contribute to his care funding at a rate of £24.65 of per week from his Disability Living Allowance (DLA) – resulting in a substantial drop in income for S and his wife.

The wider damage caused by government cuts

In this report we looked beyond welfare cuts to consider the impact that local authority budgetary cuts were having on our families' quality of life. Even though we are at the very beginning of the financial year, service closure and the tightening of eligibility is already a feature of their lives, with S perhaps most affected with the prospect of losing nearly £30 a week in DLA to contribute to his care funding.

Difficulty in dealing with financial shocks

Finally, we were also struck by how precarious our case study participants' lives were – they had little or no protection against unexpected costs, such as the need for repairs or payment of unexpectedly large bills. Most had reported they had debts last year, and all of these debts had increased when we interviewed them again this year. These financial shocks were compounded by the fact that all of our case study participants have suffered deterioration in their condition over the winter – demonstrating how vulnerable disabled people can be to changes in their circumstances and ability to work.

An overview

Table 9 presents an overview of the losses for our case study households in the last six months as a result of changes in uprating in 2011, and the expected and unexpected impacts of service cuts and reforms.

Table 9 Predicted losses of case study households arising from changes in uprating in 2011, and expected and unexpected impacts of service cuts and reforms, October 2010 to April 2011

Case study	UK households with same benefit package	Impact of other welfare reforms	Unexpected impacts from service cuts and reforms we had not taken into account	Financial shocks	Predicted losses due to a change in uprating in 2011	Total predicted losses to group
A and her parents	351,635		Local authority cannot afford to correct errors in adapted bedroom	Boiler repair – £200 from benefits and considerable diesel cost increases	£185,83	£65,344,332
P and his wife	508,700	SMI – paid £200 less per month and now £7,000 in arrears	Pension delayed by eight months – loss of £3,104	Three large utilities bills (£1,408 in total) and house repairs	£369,20	£187,812,040
E, a single man	134,780	Only one year left to claim ESA WRAG benefit		Accident and failed surgery	£129,48	£17,451,314

C, a single woman	480,260	Incapacity Benefit due for reassessment	Possible closure of CAB and loss of volunteering opportunity	New wheelchair battery - £230 from benefits	£216.32	£103,889,843
S, a social care user	480,260	Incapacity Benefit due for reassessment	Contribution of DLA to care costs - loss of £1,281.30 in 2011		£175.24	£103,889,843
H and her son - in extremis	N/A	Incapacity Benefit due for reassessment	Closure of local clinic necessitating greater travel, and difficulties in securing respite and adaptations	Administrative error on direct payments leading to overdraft	£319.28	N/A

5 Conclusion: recommendations and looking ahead to October

Mitigating the worst effects of the cuts on disabled households – where should the government focus its attention?

The findings from this first update report are starting to create a rich and varied picture of the lives of disabled people through a period of welfare and local service cuts. In *Destination Unknown*, we made several recommendations designed to mitigate the worst effects of welfare reform for disabled people over the long term, however, our latest findings point to new issues emerging which also require attention. If the government hopes to avoid driving disabled households further into untenable financial situations and critically undermine their quality of life, we would recommend the following:

1 Scrap the proposal to limit ESA WRAG claims to one year

In the current economic climate and given the additional difficulties disabled people face in accessing suitable employment, it would seem exceptionally short-sighted to impose a time limit for disabled people to find a job. There seems to be no evidence base as to why one year has been chosen as the limit, other than the Government feels it reasonable that one year is long enough for anyone to find a job. This takes no account of the varying challenges people face in getting into employment – including different disabilities, different regional labour markets, and the fact that some of those who have a one-year limit imposed on them may have been unemployed for several years. These factors and many more mean a blanket one year timeframe seems arbitrary and unhelpful.

Once ESA has been withdrawn, unemployed disabled people will then be able to apply for income-related ESA, though the government estimates that 40 per cent will not be eligible for this. This 40 per cent – around 280,000 people¹¹⁸ – will have to claim JSA – leading not just to a significant drop in their income, but more importantly, an interruption and removal of the welfare to work support they receive. Yet once someone has been claiming ESA for a year, support should arguably be *increased* to help facilitate a return to work. The government is proposing withdrawing support at the precise moment that support should become more intensive.

A wider issue that could be raised is that the time limitation of contributory ESA undermines the contributory principle. Two of our case studies – E and P – had been working all their lives up until around 2005–6, when E’s epilepsy deteriorated and P had a stroke. Up until then, P told us, he ‘had never had a day off sick’. P currently claims IB but will be reassessed and transferred to ESA at some point in the future and may well be placed in the WRAG group. E on the other hand already claims contributory ESA and now only has one year left with this support before it is withdrawn. Given both of these men, in their 50s, have been working and paying taxes all of their lives, it seems unfair in principle that unemployment support provided by the state in recognition of their ill health be limited to one year.

2 Maintain the system of Community Care Grants and Crisis Loans

As we have seen, these loans provide vital financial support to disabled people in emergency situations or when faced with unexpected costs. The findings in this report show real financial vulnerability on the part of our case study households, with almost all of them faced with a significant unexpected cost over the past six months which they had no savings to cover. From C’s wheelchair battery to P’s gas bill, financial shocks are a way of life for those with no financial safety net. Given the current economic climate, and widespread reductions in welfare income, it will likely be harder for disabled households to make ends meet and they will therefore be even more vulnerable to financial

shocks. It is an unacceptable risk, therefore, to remove the safety net of this loan system and to transfer it to local provision, without the protection of ring-fencing or the oversight of the Social Fund Commissioner. It is likely local budgetary pressures will reduce the provision of this support, and make it far more geographically variable, at a time when such emergency, targeted support is needed more than ever.

3 End the inclusion of DLA as a contribution to social care funding

In July 2011, the Dilnot Commission on Funding of Care and Support will report and present recommendations for a new care funding system. The inclusion of benefits such as DLA and Attendance Allowance (AA) has been considered. In the meantime, some cash-strapped local authorities are already requiring disabled people to give up a proportion of their DLA to pay for their care – as we have seen in the case of S. We recognise that social care is a means tested public service, however, even if DLA was treated as a form of income and taken into account by that means test, it is unlikely that disabled people would be above the income threshold which requires them to pay for their own support. Therefore, deducting a proportion of people's DLA to pay for their social care is not in line with the means testing system, and unfairly penalises those receiving this benefit even though they may be below the means test threshold.

This is clearly based on a normative judgement that DLA should be used to pay for care, which wholly undermines the premise of DLA, which is that it is a non-ring fenced allowance (i.e. people should not be forced to use their DLA to pay for any particular service) given to people to help towards the extremely diverse range of disability related living costs. It is not a means of paying for what should be state-funded care.¹¹⁹ Demos therefore recommends that local authorities are directed to end this practice as swiftly as possible, perhaps coinciding with the Dilnot Commission's final report on care funding.

4 Review the single rate of SMI

P and his wife are moving further into arrears as a result of SMI being set at 3.63 per cent, down from 6.08 per cent. This has created a shortfall of £200 per month. Clearly, P has a high interest mortgage, considerably higher than the 3.63 per cent at which the government has set SMI. However, it may be that some people will have *lower* interest mortgages, and SMI is providing too much money to these home owners. The point is that a universal SMI rate, even one set at the Bank of England average rate, is likely to over- and under-pay large numbers of people, rendering it an inefficiently targeted form of support. Due to inconsistent employment histories and low incomes, disabled people are often charged a higher interest on their mortgages – meaning that disabled people will fall into the ‘underpaid’ category far more often.¹²⁰

It would seem both fairer on disabled people, who are at a disadvantage when it comes to securing affordable mortgages, and a more efficient use of limited funding if SMI was actually linked to an individual’s mortgage rate. Whilst this may prove more complex to calculate, savings would be made by reducing the numbers of people paid too much SMI. The government already bases several benefits on income and savings, and tax credits change every year based on income. People applying for SMI already have to prove they are on low income to be eligible for the benefit – they could simply provide evidence of their mortgage agreement and monthly payments along with this, and the amount of SMI they receive could be based on that information.

5 Ensure assessment for the new Personal Independent Payment reflects costs, not just a determinant of ‘need’.

As mentioned earlier in this report, DLA, the allowance given to disabled people to recognise the additional costs of living with a disability, will soon be replaced by PIP. Central to the administration of PIP will be an ‘objective assessment of individual need’¹²¹ which ‘will focus on an individual’s ability to carry out a range of key activities necessary to everyday life’, including planning and making a journey, managing personal care, and accessing food and drink.¹²²

Yet the case study families in this report have told us about a range of costs that are not dependent on their need or their level of disability. Costs such as transport, childcare, utilities bills and equipment – are certainly linked to their disability, but driven primarily by a range of other circumstances. P, for example, told us his windows were in desperate need of repair, and his heating bills were so high *not just* because his condition means he needs to stay warm, *but also* because his house is so poorly insulated. A's parents have such high diesel costs not because of the functional impact of A's disability, but due to their rural location, meaning attending different hospitals and clinics requires lengthy car journeys. H has significant home adaptation costs because she lives in rented accommodation and cannot secure a more suitable home from her council. All of these examples add weight to original Demos analysis carried out in 2010, which found that disability related costs do not correlate to the level of need for care and support, nor the functional impact of a person's disability.¹²³ We also found that those disabled people living in residential care had a range of costs associated with getting to hospital appointments and spending time in the community – highlighting the potentially damaging effect of the government's proposal to scrap DLA mobility for care residents.

All of our case study families receive DLA, and it is vital that the variety of their living costs is taken into account with the new PIP benefit. Yet we believe an eligibility assessment based on 'need' or complexity of impairment will be too narrow a benchmark to ensure those with the highest living costs receive the highest amounts of PIP. This may mean people like H, a disabled woman with a disabled son, will lose out. H has significant living costs due to her inappropriately adapted housing, energy inefficient heating, the need for childcare, and significant transport costs as both her and her son have to attend different hospitals and clinics at significant distances from her home. She currently receives DLA low mobility and middle care. As she has neuralgia, epilepsy and migraines, it is possible that a PIP assessment looking at her 'functional ability' will deem that H does not experience a significant impact as a result of her conditions, and therefore give her low levels of PIP, which will

create a significant shortfall between her income and her living costs. We are also concerned about C, who, as an electric wheelchair user, may have her PIP reduced due to the fact she has equipment which reduced the functional impact of her disability. Yet we have seen that equipment does not permanently reduce living costs – C recently spent £130 to have a new battery fitted. Other costs associated with equipment - like maintenance and insurance, power usage and so on, may well be overlooked by PIP which takes into account the presence of equipment and adjusts payments accordingly.¹²⁴

6 Carry out a proper review of local level cuts

This report gives an insight into the varied and unexpected nature of the impact of local cuts on disabled people. As such, and unlike welfare benefit cuts, it is impossible for national government to predict or quantify how disabled people might be affected in different local areas. We strongly recommend, therefore, that local authorities look into this matter themselves and carry out their own impact assessments to ensure the cumulative impact of the full range of local cuts (not just the most obvious and visible, like social care cuts) is considered in relation to the wellbeing, social inclusion and independence of disabled people.

Whilst these six issues seem the most pressing based on the findings from this report, we should also bear in mind that our five case studies do not reflect the diversity of experiences of the entire disabled population, nor have we considered the longer term implications of welfare reform. In *Destination Unknown*, we took a more long term view, and the recommendations presented in that report reflected this wider scope. All of these recommendations still stand, but perhaps the most important remains:

The need for more targeted employment support for disabled people, and in particular an expansion of access to Work Choice.

The government's aim to incentivise work by reducing out of work benefits is understandable. However, it can only really

be justified if there is a commensurate increase in welfare to work support for those facing a reduction in benefits. Disabled people experience a complex interaction of medical, psychological, social and practical barriers to work, and need a holistic and targeted strategy to overcome these. In *Destination Unknown*, we identified the Work Choice programme – a modular employment support programme which dealt with these various issues in a holistic way – as a potentially highly effective method of achieving sustained employment. We recommended that Work Choice be automatically integrated into the welfare-to-work pathway and available to all WRAG claimants. The current application of Work Choice, however, is extremely limited, reserved for only those with ‘most difficulties’ – estimated to be around 13,000 people per year,¹²⁵ whilst the rest rely on the mainstream Work Programme. We are not convinced the Work Programme will provide adequate specialist support for disabled people, reliant as it is on large prime providers like PwC and Serco to commission specialist partners in each area to help specific client groups. Previous evaluations of this method found prime providers lacked the skills and confidence to deal with disabled groups (particular those with mental health problems), and identified a lack of local specialist groups to assist them.¹²⁶ Increasing access to the specialist and highly effective support Work Choice can provide is even more crucial now that ESA WRAG payments are time limited.

Central to improved employment support should be an assessment process which is refined enough to identify the variety of obstacles to employment a person faces. Whilst the Work Capability Assessment remains under review,¹²⁷ it seems unlikely an assessment premised on measuring a person’s functional ability will be able to capture more fluctuating conditions or the other barriers – practical, psychological – that make it harder for disabled people to find employment. It would seem more efficient to broaden the WCA from a simple gateway to ESA, into an assessment of distance from the labour market, and remove the need for an additional assessment to be carried out later for the purposes of the Work Programme or Work Choice. This could streamline the system and reduce

administrative costs, plus also enable employment support to be put in place more rapidly – straight after the WCA – so that disabled people are not unemployed and unsupported for weeks or months before they are assessed again and placed on the appropriate support programme.

In the six months between *Destination Unknown*, published in October 2010, and this first update report, we have seen the implementation of some new policies – like the reduction in Support for Mortgage Interest (SMI) payments; but more importantly we have seen the announcement of several new policies. Those most likely to have a direct impact on disabled people are:

- the replacement of means-tested benefits with the single Universal Credit
- the abolition of Disability Living Allowance (DLA) and the introduction of the Personal Independence Payment
- time-limiting contributions-based Employment and Support Allowance (ESA) for one year
- the removal of the DLA mobility component from care home residents
- the removal of special ‘youth provisions’ for contributions-based ESA
- the abolition of crisis loans and community care grants.

However, as we are only in April 2011, disabled people have yet to feel the effects of many of these reforms – benefits were uprated by the lower inflation rate of the Consumer Price Index for the first time this month, and the Incapacity Benefit reassessments, time limitation of Work Related Activity Group ESA and housing benefit caps have only just begun. Moreover, the effects of cuts to public services are unlikely to come to fruition for a while yet. We should, therefore, view the findings of these first update interviews very much as ‘the calm before the storm’ – with only small initial losses and hardship reported. Even then, some of our case study participants have already experienced dramatic changes to their lives. As a result of

changes to SMI, P and his wife have now accumulated £7,000 of mortgage arrears and are receiving written warnings from their lender.

In six month's time, October 2011, we will revisit our case study families again in order to see how their lives have changed. The coming months will be an extremely important time for them – whereas October 2010 to April 2011 was a *time of announcements*, April 2011 to October 2011 will be a *time of implementation*. When it comes to our case study families, when we revisit them in October we might see:

- P, C and H having been reassessed and moved onto ESA or Jobseeker's Allowance (JSA) following the Incapacity Benefit reassessments that started in April 2011
- S possibly having lost around £26 a week in DLA; he has already been asked to submit his DLA details in order to assess his contribution to his social care costs
- P and his wife facing repossession if their arrears continue to accumulate
- the effects on all our families of experiencing six months of lower than expected benefits, while H and A's parents will have had six months of frozen child benefit.

However, although these are all 'predictable' negative outcomes, the more significant risks our families face are those we are unable to foresee.

This report has demonstrated that even though specific benefits cuts can be modelled and their impact quantified, the 'real life' experience of cuts is a much broader phenomenon, which cannot be so easily modelled. The breadth and depth of some of the *unexpected* consequences of the Coalition Government's fiscal and welfare reforms have hit disabled households hard. For example, few could have foreseen that the bedroom built for A would be built to a miscalculated specification and that the local authority would declare itself to be financially unable to help rectify the situation. Yet, it is unexpected and difficult situations like these which are the unforeseen ramifications of across-the-board cuts to public

spending and local authority budgets, and which cause serious damage to disabled people's quality of life.

By October 2011 our families will have experienced six months of new local authority budgets, which may result in local service closures, increased charges, and tighter eligibility criteria for support. Although we are already seeing the initial negative effects of these reduced budgets, by October there is a risk that our case studies (and indeed, disabled families across the country) will experience increasing financial hardship and social isolation, caused by events we simply cannot predict. Our families' vulnerability to the impact of unexpected costs was perhaps the most striking message that has emerged from this research. A lack of what might be described as 'financial resilience' – the ability to absorb or recover from financial shocks with savings or accessible credit – is a cause for concern in the unpredictable months ahead.

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Six months ago, *Destination Unknown* explored how cuts to welfare and public spending would affect disabled people in Britain. It calculated how the welfare reforms and cuts to benefits – announced in the Emergency Budget and in the run up to the Spending Review – would affect five typical disabled families. Our research showed that, far from being protected from the worst of the cuts, disabled families across the country faced dramatic reductions in their household incomes to the tune of £9 billion.

This research only told half of the story – we could only model the impact of welfare cuts on disabled people and not the implications of cuts to public services and local authority budgets, or the further cuts to welfare announced after the Spending Review. This meant that the losses we estimated were, if anything, an underestimate.

This pamphlet is the first report in a new tracking study, following five disabled families through the course of this Parliament and documenting the impact of fiscal tightening on their lives. The project brings to the fore the real consequences the cuts have for the everyday lives of disabled people and reveals the first-hand experiences of disabled families living on the edge of uncertainty, financial stress and disability poverty.

Claudia Wood is Head of the Public Services and Welfare Programme at Demos. Eugene Grant is a Junior Associate of Demos.

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