

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

**DESTINATION UNKNOWN:
AUTUMN 2011**

Claudia Wood

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

In 2011, our work is focused on five programmes: Family and Society; Public Services and Welfare; Violence and Extremism; Public Interest and Political Economy. We also have two political research programmes: the Progressive Conservatism Project and Open Left, investigating the future of the centre-Right and centre-Left.

Our work is driven by the goal of a society populated by free, capable, secure and powerful citizens. Find out more at www.demos.co.uk.

First published in 2011
© Demos. Some rights reserved
*Magdalen House, 136 Tooley Street,
London, SE1 2TU, UK*

ISBN 978 1 906693 89 3
Series design by modernactivity
Typeset by Chat Noir Design, Charente
Printed by Lecturis, Eindhoven

Set in Gotham Rounded
and Baskerville 10
Cover paper: Flora Gardenia
Text paper: Munken Premium White



DESTINATION UNKNOWN: AUTUMN 2011

Claudia Wood

Open access. Some rights reserved.

As the publisher of this work, Demos wants to encourage the circulation of our work as widely as possible while retaining the copyright. We therefore have an open access policy which enables anyone to access our content online without charge.

Anyone can download, save, perform or distribute this work in any format, including translation, without written permission. This is subject to the terms of the Demos licence found at the back of this publication. Its main conditions are:

- Demos and the author(s) are credited
- This summary and the address *www.demos.co.uk* are displayed
- The text is not altered and is used in full
- The work is not resold
- A copy of the work or link to its use online is sent to Demos

You are welcome to ask for permission to use this work for purposes other than those covered by the licence. Demos gratefully acknowledges the work of Creative Commons in inspiring our approach to copyright. To find out more go to *www.creativecommons.org*



Contents

Acknowledgements	7
Executive summary	9
Introduction	21
1 Shifting policy landscapes	25
2 Revisiting disabled households - the lived experience of welfare reform and local cuts	41
3 Conclusions, recommendations and a look ahead	83
Notes	91
References	101

Acknowledgements

This project would not have been possible without the funding and continued support from Scope. In particular, we would like to express our gratitude to Eugene Grant, who carried out the interviews with disabled people in six households, which provided the main insights in this report, along with Marc Bush and Amisha Koria for their input on the report draft. Thanks also to Phillida Cheetham, Jo Salter and Ally Paget for their research support, and Beatrice Karol Burks and Ralph Scott for seeing this project through the publication process. All errors and omissions remain solely those of the author.

Claudia Wood
November 2011

Executive summary

In October 2010, Demos sought to explore the impact of the Coalition Government's welfare reform agenda on disabled people. With the support of the disability charity Scope, in the report *Destination Unknown* we modelled the impact of this agenda on the incomes of four disabled households that could be considered 'typical' among the disabled population, according to the packages of benefits they each received, and one additional household, which was in a particularly difficult situation.¹

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

We remedied this in a major study we carried out in the summer of 2011, resulting in the report *Coping with the Cuts*, in which – again with the support of Scope – we analysed responses to hundreds of freedom of information requests we had issued to local authorities in England and Wales.²

This local snapshot complemented the national analysis we presented in *Destination Unknown*. The combination of reduced benefit income and reduced availability and affordability of services paints a bleak picture for disabled people, which is not static. As government's policies evolve, are implemented and 'bed down', so the fortunes of disabled people change from month to month and indeed from week to week.

To capture the shifting policy landscape, we decided to embark on the Disability in Austerity study – a six-monthly update following the lives of six disabled households in different

situations, in different parts of the country. In April 2011, we published our first update, revisiting the five households from the original work reported in *Destination Unknown* in October 2010 to see how they had fared over the subsequent six months. They reported the changes they were seeing to their benefit income and quality of life more broadly, as a result of cuts to public services and local budgets.³

The first update report following *Destination Unknown* (called *Destination Unknown: Spring 2011*) challenged our predictive methodology. We found that although we could calculate and predict the financial impact of a shift in the uprating of benefits from the retail price index (RPI) to the lower consumer price index (CPI) inflation rate, for example, several other reforms were affecting the households in our study which we had not taken account of, including pensions and mortgage repayments, social care funding policy, closure of local services, increases in fuel prices, and so on. We were able to paint a far richer picture of the circumstances in which these disabled households found themselves, and were struck by their financial vulnerability in their daily lives, and the oppressive sense of uncertainty that they had to live with, which clearly jeopardised their emotional wellbeing. Although nearly everyone faces tough times in this current economic climate, disabled people are hit particularly hard as a result of lower income, higher costs, fewer support services and unpredictable health conditions.

Nonetheless, we were aware that the situation we described in *Destination Unknown: Spring 2011*, published in April 2011, was the relative calm before the storm, coming as it did in the same month that new local authority budgets and a range of welfare reforms were only just set in motion.

This report is the second in the series of follow-up publications following the original *Destination Unknown*, tracking the same households as the cuts to services and changes to welfare benefits begin to take full effect. Our case studies report on:

- a young disabled child (Aisha) cared for by her mother and father
- a disabled man (Albert) and his wife, who cares for him and has moderate disabilities herself

- a single disabled man (Philip)
- a single disabled woman (Carla)
- a middle-aged, disabled man (Steve) who is a social care service user
- a disabled mother (Helen) caring for her disabled child

Our findings cover:

- the predictable impact of the Government's welfare reform – including but not exclusively the transfer to CPI uprating, reassessment of Incapacity Benefit (IB), etc
- the less predictable impact of the Government's budgetary cuts and the wider economic climate on local services
- the events that demonstrate the precarious financial situation disabled households face, including administrative errors
- how well the household is coping and the sources of alternative – but unsustainable – support being used

The predictable impact of welfare reform

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

- Aisha and her parents lost £199.52
- Albert and his wife lost £781.55
- Steve lost £618.77
- Philip lost £74.70
- Carla lost £140.10
- Helen and her son lost £238.82

These losses arise from a combination of lower than expected benefit increases (linked to the government policy of uprating benefits by CPI instead of RPI from April 2011), and other more significant reforms – Albert and his wife have lost benefits in income as a result of their new pension income, which means overall they are worse off by around £33 per week. This couple has lost over 7 per cent of their total income in six

months. Steve's large loss has arisen because he now has to contribute nearly £25 per week towards his care, and he has lost the equivalent of almost 10 per cent of his total income over six months. This is a highly significant amount – the equivalent of a working person, on an average wage of £24,000 per year, being docked £2,256 or £188 per month.

Negative effects of other government reform agendas

Perhaps the most significant development in this update report is the fact that Albert and his wife are soon to be evicted from their home, having fallen £13,000 into arrears since the Government decreased the Support for Mortgage Interest (SMI) payments by linking them to the average mortgage rate (3.63 per cent), significantly lower than the previous SMI rate, which was based on the Bank of England base rate plus 1 per cent (6.08 per cent), which left the couple with a £200 shortfall each month. Their financial situation was not improved by the delay in Albert's wife receiving her pension because of the increase in pension age from 65 to 66, only to find that, on receiving this pension, her Income Support and Carer's Allowance stopped – leaving the couple £33 worse off per week. Neither of these reforms is directly linked to disability benefits, but they demonstrate how disabled people are extremely vulnerable to the wider economic climate we are in.

We should also bear in mind that the people in our study claiming IB (Albert, Carla, Steve and Helen) are all now due for reassessment and will be transferred onto Employment and Support Allowance (ESA), while Philip, who is currently claiming ESA, has just six months left before he is moved onto income-based ESA (if he passes the means test). This prospect is daunting for those in our study, though they have all reported a willingness – and in Philip and Helen's case a strong desire – to find employment:

*I've always felt very guilty about being on benefits. Does it cause me a guilt problem?
Absolutely. Yes, it does.*

Philip

Difficulty in dealing with financial shocks

As in our April report, we were struck by how precarious the financial situations of the households in our study were; they had little or no protection against unexpected costs, such as the need for repairs or payment of unexpectedly large bills. Disabled people are more likely to be in such financially vulnerable situations because they have lower than average levels of savings, and less access to affordable credit, as a direct result of being less likely to be in work or to have a sustained work history. Six months on, the households in the study are still in a financially precarious situation, and we have seen Steve's modest level of savings wiped out, other households accumulating more debt, and one-off charitable grants being exhausted as there are now few avenues for emergency support available. This financial insecurity is compounded by fluctuations and deteriorations in the health of Albert and his wife, Aisha's mother, Helen's son and Philip, who all report worsening health since we spoke to them in April, demonstrating how vulnerable disabled people can be to changes in their circumstances and ability to work.

But alongside this, the effects of budget cuts in the wider environment are also making themselves felt:

- Carla is facing the prospect of losing her freedom pass as the local authority scraps concessions for those with mental health needs, and says her benefits agency is closing because of 'lack of funding'. Her local law office looks set to close for the same reason.
- The charitable trust Albert relied on to pay his water bill last year says it cannot help with his water bill two years in a row, as it is inundated with new claims for financial assistance. His local NHS trust has refused to provide him with a community psychiatric nurse through lack of funds, and has told him to go to a charity instead.
- Aisha's family is experiencing increased delays and difficulty in securing physiotherapy services and equipment; Aisha has been waiting for nearly six months for a standing frame and was refused a motorised wheelchair by her local authority.

The impact of bureaucracy – administrative error, confusion and having to ‘fight’

It is clear that the benefits and support systems that the households in our study have to deal with are extremely complex and administratively burdensome. This has had a number of negative impacts – for example, many of the disabled people in our study have reported having to ‘fight’ or ‘battle’ the administrative or professional systems surrounding the benefits they receive and services they use, and have encountered administrative errors and delays which make their lives harder.

For example, Aisha’s parents have fought to have her room adapted properly, and Aisha’s mother told us she ‘had another battle on our hands’ to have her lunchtime supervision need made a duty on her special education needs (SEN) statement at school. Helen has had an ‘ongoing battle’, as she describes it, in her attempt to be moved to a more suitable property, recently giving up and opting for the considerably more expensive route of renting privately. Yet her legal case to secure more care for her son still goes on. Albert and his wife’s SMI payments were suspended between June and October because of an administrative error – no doubt exacerbating the difficult situation with their mortgage lender, and they are now expecting to be evicted in February 2012. Carla found that her benefits agency closed down, without her being informed – leaving her with unpaid maintenance and insurance charges, while Philip has still not received the correct medication for his mental health condition as there is poor communication between hospitals.

These disruptions and delays might present an inconvenience for some people, but they can have a disproportionate impact on the finances and health of those with no savings as a financial cushion, or with physical and mental conditions that require consistent support. Aisha’s mother’s mental health has deteriorated since we last spoke to her, as a result of the stress of fighting for the right support for Aisha. Carla and Philip are very concerned about the prospect of medical reassessment as they move from IB to ESA. We are concerned that in the months ahead – as all the households in our study face a reassessment of some sort as a result of the government reform agenda – the risk of administrative

disruptions (not to mention the added stress and uncertainty) may prove too much for some of the people in our study.

Another negative effect of a highly complex system – combined with a rapid government reform agenda – is that many disabled people are confused about and unaware of the changes in the reform system that may soon affect them. Carla had never heard of ESA, despite the fact she may be transferred to this benefit imminently. The prospect of reassessment shocked her and she was wholly uninformed about these changes. So too was Philip, who had no idea he only has one year (now six months) to claim his ESA benefit. Steve also was under the impression he was not allowed to have any savings in order to be eligible for his social care package.

Although the Universal Credit has been heralded by the Government as a simplification of the benefits system to remedy much confusion and administrative error, we are under no illusion of the scale of disruption that will occur during the transition process to this radically new system. Moreover, the lack of a concerted communication campaign from the Government thus far on this change, or indeed on any of the other reforms currently in train, suggests that the households in our study, and many other disabled people across the country, remain in the dark and uncertain about their futures.

Other ways of coping

Perhaps the most striking development that is starting to become apparent in this update report is how several of the households in our study have sought different sources of financial assistance when faced with a reduction of state support.

Aisha's family has turned to a support scheme run by Aisha's father's employer, and held a fundraising event in their community to raise funds for Aisha's new wheelchair, while Albert and his wife managed to secure a charitable grant to pay their water bill last year.

Other disabled people in our study – Philip, Helen and Steve – have taken different routes. Philip has borrowed a substantial sum from his brother, and is being 'exceptionally

frugal' in order to pay off his debts. Steve, who has now used up his savings, says he will simply not buy things until he had more money, or get a loan. Helen on the other hand has resorted to using her son's trust fund to rent a suitable home.

This may be what the Government had in mind when it described the Big Society – community and informal supports being used to supplement the state's offer. In theory, this could be a positive vision designed to improve outcomes and reduce costs. However, a picture is emerging whereby community services are not just being used to supplement but to replace the welfare state, and to justify a removal of this safety net: Aisha's mother and Albert were both told to 'ask a charity' when refused state support (in Albert's case, by a psychiatric nurse from his local health trust).

Moreover, the limitations of the Big Society route, even when used to supplement support, are all too clear in our case studies – using up a trust fund and relying on credit are clearly unsustainable routes to take. The help the households in our study have secured from external and charitable sources are one-off steps to meet an urgent need, not ongoing sources of support or remedies for the underlying fact that they have insufficient income to meet their daily living expenses. This is perhaps demonstrated most clearly by Albert being refused a water grant for this year because the charity to which he applied was 'inundated' with requests and had to reserve its limited funding for those who had not been helped before.

This points to a wider issue – as grants to voluntary sector organisations are cut alongside statutory budgets, so the Big Society vision is starting to ring hollow as alternatives to state support for households in need are drying up. Carla's local law office, which she said 'saved her life' by fighting her case for Disability Living Allowance (DLA) and securing her benefits, may soon close down. As these disabled households start to exhaust alternative options to state support from overstretched charities, they will soon have nowhere left to turn.

Recommendations

The findings from this update report are starting to create a more varied picture of the lives of disabled people through a period of welfare and local service cuts. Given the level of uncertainty among disabled households and the difficulties experienced with the administrative processes surrounding the benefits system, it is clear that the Government needs to think seriously about how it is communicating the reform agenda to ensure those most affected by it – disabled people and in particular those disabled people who are unemployed – are fully aware of the implications of these changes. The introduction of the Universal Credit is the most significant change to the welfare system since it was created 60 years ago, and it is vital that people are prepared for this change. The fact that Carla was unaware of the introduction of ESA to replace IB, a change brought in three years ago, and Steve thought he had to spend his savings in order to remain entitled to social care despite his very low income – suggests that disabled people are not obtaining the information and advice they need, which results in them having poor levels of awareness of their rights and entitlements.

More fundamentally, the Government must engage in a more open and frank discussion about what people should expect from the welfare state. The Coalition Government and the opposition both talk about ‘something for something’ when discussing welfare payments, suggesting there is a growing consensus across the political spectrum that welfare is a conditional privilege, rather than a right for those who are vulnerable and unable to support themselves adequately, such as disabled people. This in itself is concerning, as it is leading to an undermining of the original purpose of the welfare state when it was founded 60 years ago. Moreover, although this has been expressed at senior government level, it has yet to be articulated in a way that makes sense to those most affected by this political shift – disabled people. The confusion and uncertainty among disabled people – generated by the public pronouncements of senior government and opposition spokespeople without any detail provided to those with the most at stake – is clearly causing emotional distress.

In our 2010 report *Destination Unknown* we made several recommendations designed to mitigate the worst effects of

welfare reform for disabled people over the long term. In our first update after that report, in April 2011, we made specific recommendations relating to the challenges the households in our study were facing at that time, which pointed to new issues emerging, which required attention if the Government hoped to avoid driving disabled households further into untenable financial situations and critically undermining their quality of life. Our recommendations in April included:

- Scrap the proposal to limit ESA Work Related Activity Group claims to one year.
- Maintain the system of community care grants and crisis loans.
- End the inclusion of DLA as a contribution to social care funding.
- Review the single rate of SMI and consider the claims of each case.
- Ensure the assessment for the new Personal Independent Payment (PIP) takes into account external drivers of disability costs, and not just the impact of impairment or condition.
- Carry out a proper review of local level cuts.⁴

In light of our latest findings, the case for each of these recommendations is stronger than ever. The negative effects of a one-size-fits-all approach to the level of mortgage payments granted under SMI – which within a year of it being implemented has led to one of the couples in our study facing eviction – are now very clear. So too are the limitations of the proposed PIP assessment to replace DLA. Just from the handful of households in our study, it is obvious that the costs of living with a disability are extremely varied and do not always coincide with the complexity of a condition or level of care required. It is unlikely the new assessment will be nuanced enough to take these variations into account. In light of the ongoing financial shocks disabled people are suffering and the limited alternative sources of support they are securing, we believe it is important to maintain a nationally guaranteed access to community care grants and crisis loans rather than devolving them to locally discretionary pots. The Government should therefore maintain

the statutory duty for local authorities to provide support and ringfence the funding available. Without these two conditions it is likely that some areas will not provide any crisis support.

Concluding thoughts

In this report we have seen local budget cuts taking effect: the disabled people in our study are struggling to get equipment, being refused community health services, and having to contribute a proportion of their benefits to services which had hitherto been free. Moreover – and unlike in our April report where we could only predict losses over 2011 – we now have concrete figures on how much worse off the households in our study are in the six months since benefit reforms started to be implemented. These losses range from £74.70 to a staggering £781.55 between April and October 2011, and some of the people we spoke to are now reporting they have to choose between fuel and food, to cancel appointments as they are unable to afford transport costs, and to let their houses fall into disrepair. It is clear that with each passing month the financial resilience of the households in our study decreases – savings are wiped out, debts accumulate, and one-off emergency grants are used up.

In six month's time, in April 2012, we will revisit the households in our case study again. We expect to see some significant – life changing – events occurring to the households in our study. By then:

- IB reassessments will be rolled out across the country, with Albert, Carla, Steve and Helen all liable for reassessment and being moved onto ESA or JSA.
- Albert and his wife will face eviction, after accumulating £13,000 in mortgage arrears.
- Philip will have his contributory ESA stopped, and will be no doubt be facing reconsideration for eligibility for the means-tested income-based ESA.

These are all 'predictable' negative outcomes – we believe the more significant risks disabled people face are those

developments we are unable to foresee. Time and again, we have found that the losses we predict are only the tip of the iceberg – and while we do not know what will arise when we revisit the households in our study in six months' time, we have no doubt some will have dire consequences for their health, wellbeing and financial security. We have already seen Aisha's mother put back on anti-depressants because of the stress of fighting for the support her daughter is entitled to.

These are the three developing themes we are now clearly seeing in this study:

- Financial vulnerability and lack of resilience to shocks – an issue that emerged in April is now reinforced as we see disabled people struggling to make ends meet and unable to pay relatively small but unexpected costs.
- Bureaucracy and administrative delays are having a significant impact. The benefit and care and support systems are complex and the households in our study are 'fighting' to receive services and financial support to which they are entitled, putting emotional and financial pressure on them. Administrative errors are having significant negative effects as there is no financial safety net, and widespread confusion about entitlements.
- The alternative sources of financial assistance disabled people are seeking in the face of inadequate state support are not sustainable and seem to be drying up, suggesting some of them may have exhausted the options open to them and have nowhere left to turn.

Introduction

Destination Unknown

Last year, the Coalition Government announced several radical reforms to disability and wider welfare benefits. Although the rhetoric behind these reforms focused on ending benefit dependency and entrenched worklessness, some expressed concern about the disproportionate impact on those with the lowest incomes,⁵ as well as those who are least able to work and most vulnerable, such as disabled people.⁶ A more important point was raised that, in the current economic climate, disabled people are often at the back of a very long queue for jobs – and that unwillingness to work was less of an issue than the availability of suitable jobs and employers willing to employ disabled people. It became clear, therefore, that the Government had not fully estimated the impact of the cuts on disabled people.

Demos set out to explore this issue in a series of reports. The first, *Destination Unknown*, modelled the impact of the Government's welfare reform agenda changes on the incomes of four disabled households, which could be considered 'typical' households among the disabled population according to the packages of benefits they each received, whom we contacted through the disability charity Scope.⁷

Our modelling provided predictive estimates of the losses to benefit income these households would face over the course of this parliament – up to 2015. Using further modelling, we calculated an aggregate figure, based on the number of people receiving the same package of benefits across the UK. We concluded that the 3.6 million people claiming disability benefits in Britain today would be £9 billion worse off by the end of the current parliament.

However, we realised that the real impact of the Government's cuts would not be fully captured by this work,

because we primarily focused on changes to welfare benefits in *Destination Unknown*, as it was too early to predict how changes to local authority spending and central government cuts would affect public service delivery. We were only able to see one half of the coin when it came to the situation among disabled people.

We remedied this in a major study we carried out in summer 2011, summarised in our report *Coping with the Cuts*, in which – again with the support of Scope – we analysed responses to hundreds of freedom of information requests we issued to local authorities in England and Wales asking about their levels of user charges, care eligibility and contribution criteria, and so on.⁸

We combined these data with data from the Department for Communities and Local Government on levels of local authority social care spending on older people, adults and children's services in 2010/11 and 2011/12 to see how they had increased or decreased. We then mapped the results across England and Wales and showed the extent to which financial cuts had changed front-line disability services (for example through closures, eligibility, contribution rules) in a new 'coping index'. This combined features such as user charges, contribution rules, eligibility criteria and so on with overall budgetary reductions, in order to gain a nuanced picture of the impact of budget reductions on disability services.

This local snapshot complemented the national analysis we presented in *Destination Unknown*. The two sets of findings combined – reduced availability and affordability of services and reduced benefit income respectively – paint a bleak picture for disabled people, which is not static. As government policies evolve, are implemented and 'bed down', so the fortunes of disabled people change from month to month and indeed from week to week.

Disability in Austerity

To capture the shifting policy landscape we decided to embark on the Disability in Austerity study – a six-monthly update to

Destination Unknown, following the lives of six disabled households in different situations, in different parts of the country. In April 2011, we published our first update, after revisiting the five households from our original research plus one new household (a social care user), to see how they had fared over the subsequent six months. They reported the changes they were seeing to their benefit income and quality of life more broadly, as a result of cuts to public services and local budgets.

This report, *Destination Unknown: Spring 2011*, challenged the predictive methodology we employed in the original *Destination Unknown* (published in October 2010). We found that while we could calculate and predict the financial impact of a shift in the uprating of benefits from retail price index (RPI) to the lower consumer price index (CPI) inflation rate, for example, several other reforms were affecting the households in our study, which we had not taken account of, including pensions and mortgage repayments, social care funding policy, closure of local services, increases in fuel prices, and so on. We were able to paint a far richer picture of the circumstances in which disabled people found themselves as a result of lower income, higher costs, fewer support services, and unpredictable health conditions. We were struck by the financial vulnerability of the households, the way they lived from day to day, and the oppressive sense of uncertainty that they had to live with, which clearly jeopardised their emotional wellbeing.

Nonetheless, we were aware that the situation we described in *Destination Unknown: Spring 2011*, was the relative calm before the storm, coming as it did in the same month that new local authority budgets and a range of welfare reforms were only just set in motion. The initial negative impacts we came across could be seen, regrettably, as our ‘baseline’ – with things only likely to deteriorate from that point onwards.

Now, six months later, we can clearly see the households in our study pushed to increasingly more desperate financial situations. In the next section we chart their lives of the six households in the six months which have passed since our previous April 2011 update report and calculate how much income they have lost as a result of the Government’s reforms

and the wider financial climate. First, however, we will recap the ongoing policy reform agendas which are affecting disabled people's lives.

1 Shifting policy landscapes

The rate at which policy reforms have been created and ushered in under the Coalition Government has been impressive to say the least. The new government wasted no time in setting out a series of radical reforms – announcing in the very same month that it was elected that all claimants of Incapacity Benefit (IB) would be reassessed on their readiness for work and those determined to be fit for work would be moved onto Jobseeker's Allowance (JSA).⁹ The following month, in June 2010, Chancellor George Osborne set out a deficit reduction plan in an emergency budget, identifying £85 billion of cuts – £11 billion of which would be taken from the welfare bill.¹⁰ The cuts to welfare benefits, he promised, would deal with the 'explosion in welfare costs' and 'improve incentives to work, and reduce the incentives to stay out of work'.¹¹

On reading the small print, many concluded the measures outlined in the emergency budget were regressive.¹² Disabled people were quickly identified by commentators – and even cabinet ministers – as likely to be among those hardest hit by the reforms.¹³

Fiscal and welfare reforms announced before the spending review, October 2010

These were the fiscal and welfare reforms announced before the spending review in October 2010:

- a cap on the maximum amount of benefit claimed by a household
- a change in the basis used for uprating benefits from the Retail Price Index (RPI) to the Consumer Price Index (CPI)
- reassessing IB claimants on their readiness to work

- reassessing all working-age Disability Living Allowance (DLA) claimants
- realigning Support for Mortgage Interest (SMI) payments to the Bank of England average mortgage rate
- capping Housing Benefit (HB) and reducing Local Housing Allowance (LHA)

However, more was to come. In October 2010 the spending review outlined another £7 billion worth of welfare cuts on top of those announced in the emergency budget.¹⁴ The Institute for Fiscal Studies 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’.¹⁵ 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.¹⁶ The spending review contained dozens of cuts and new policies, but two changes in particular were highly significant for disabled people:

- Time-limiting contributory Employment and Support Allowance (ESA) for those in the Work Related Activity Group (WRAG) for 365 days, so that those unable to find employment in this time will either be moved to the means tested income-based Employment and Support Allowance (ESA), or lose the benefit entirely and have to claim JSA. The Government estimated that 90 per cent of WRAG claimants would lose their contributory ESA, and 40 per cent of this number would not be entitled to income-based ESA. Predictions by the Department for Work and Pensions estimate 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,¹⁷ saving the Treasury £2 billion a year by 2014/15.¹⁸
- Removing the DLA mobility component from disabled people in residential care. As of 2013 (delayed from 2012 following public outcry), 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.¹⁹

In the intervening period between the spending review and our first update of *Disability in Austerity* in April 2011, a further two highly significant announcements were made: the replacement of means-tested benefits with the single Universal Credit and the plan to abolish DLA entirely and replace it with a new allowance – the Personal Independence Payment (PIP). This was followed up by the Welfare Reform Bill, 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 HB by 10 per cent for people who had been claiming JSA for a year²⁰
- postponed the removal of DLA mobility component from disabled people in residential care to 2013²¹
- announced the removal of ‘special arrangements’ that allowed young disabled people to claim contributions-based ESA²²
- 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 emergencies, for example women who are escaping domestic violence²³
- 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 property²⁴

The impact of this plethora of welfare-related reforms is discussed in detail in *Destination Unknown: Spring 2011*,²⁵ and table 1 summarises the most significant points from that analysis.

Disability in Austerity in autumn 2011 – latest policy developments

In April 2011, we warned that while the preceding six months had been a time of announcements, the subsequent six months

Table 1 **Fiscal and welfare reforms announced within and after the spending review in October 2010**

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 and Child and Working Tax Credits. DLA will not be affected. ²⁶ Over 33 per cent of the Universal Credit caseload is expected to consist of households with a disabled member. ²⁷
The abolition of DLA	DLA is to be discontinued from 2013/14, and will be replaced by the PIP. There are currently around 1.8 million working-age disabled people claiming DLA. ²⁸
Time-limiting contributions-based ESA for 365 days	Contributions-based ESA WRAG is to be limited to 1 year. By 2015/16, about 700,000 people will lose this benefit; weekly net income is expected to drop by £36. ²⁹
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. ³⁰
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. ³¹
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 the number of extra bedrooms	HB will be cut for claimants whose home is deemed to be larger than they need. Under these rules, the HB of people in social housing could be cut by 15 per cent if they have an extra bedroom - 25 per cent if they have two. ³² 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. ³³

would be a time of implementation when disabled people would really start feeling the effects of those changes to welfare and local services that had, until April 2011, only been on paper. Although this has certainly been the case, we had not factored in the response from disability charities, consumer groups and select committees to the announced reforms, which has produced a range of new analyses, inquiries and legal challenges to some of the proposed policies. We chart some of these latest developments in the Government's rocky road to the implementation of welfare reform below.

Abolition of Disability Living Allowance in favour of new Personal Independence Payment

In May 2011, the Government published the initial draft of assessment regulations for the PIP, the benefit destined to replace DLA from 2013.³⁴ Between May and August 2011, the Government asked for comments (rather than carrying out a formal consultation) on these draft assessment criteria, and also (controversially) piloted them before comments were received between May and September among a group of volunteers already in receipt of DLA. The consultation feedback and the results of pilots led to the publication of a second draft of the PIP assessment regulations, which was released just two hours before the Lords debate on the Welfare Reform Bill, giving the Lords little time to review the new proposals.³⁵ The new draft criteria have not taken on board the recommendations suggested by Scope, which were supported by a wide range of disability charities, welfare rights organisations and disabled people's organisations, to include social, practical and environmental factors.

This draft assessment is causing consternation in many quarters, as many organisations feel the assessment focuses too heavily on the medical and physical limitations of claimants despite government revisions, and would not adequately identify the additional costs of living with a disability (for which the DLA and PIP are designed to compensate).

In response, the Work and Pensions Committee launched an inquiry into the reform of DLA, and published 54 written

submissions following its call for evidence in September.³⁶ Most of the feedback received was highly critical, with many respondents identifying the medical and inflexible assessment, the need for reassessment, and the extended qualifying period (whereby disabled people must demonstrate they are likely to be eligible for PIP for six months after claiming, rather than three months under DLA) as issues likely to penalise disabled people unfairly. The Disability Benefits Consortium, a national coalition of over 50 charities and other organisations, was also particularly critical of the fact that the PIP reform is designed to achieve a 20 per cent reduction in DLA expenditure, an arbitrary reduction put in place without consideration of the implications this would have on disabled people.

Alongside this, the Disability Alliance, a coalition of 250 disability charities, pointed out that there are currently 652,000 working age low rate care DLA recipients, and as PIP only has two rates of payment and abolishes 'low rate', it is entirely possible that all of these people will lose their financial support. Moreover, the Disability Alliance estimates that the total annual expenditure on low rate care payments amounted to £663 million, which does not meet the 20 per cent expenditure reduction target. It estimates that 750,000 disabled people would need to lose financial support in order to achieve the 20 per cent expenditure cut.³⁷

Scope has been particularly concerned by the proposed PIP assessment criteria, and led the way in publishing plans for an alternative PIP assessment, one which attempted to measure more accurately the costs of a disability, rather than the functional and medical impact of a condition or impairment. The resulting document, *The Future of PIP: a social mode-based approach*, had 24 signatories, including leading charities outside the disability sector, such as the Citizens Advice Bureau and the Child Poverty Action Group, coalitions of charities, such as the Disability Alliance and the Learning Disability Coalition, disabled people's organisations and the National Association of Welfare Rights Advisors. The authors state:

There is widespread agreement across the disability sector that the assessment with which the Government plans to assess eligibility for PIP is not fit for purpose. The assessment – the principles underlying it; the activities it focuses on, and the draft descriptors – goes against the Government’s stated commitment to adopting a social model for DLA reform.³⁸

They suggest there should be an alternative assessment, which partly draws on research carried out by Demos on the costs of disability,³⁹ and which takes the form of a more multi-dimensional, co-produced approach, making use of the model of social care assessments and support plans, where the social drivers of disability costs are taken into account. Unfortunately, the Government did not take on board this alternative, which was given broad support by the disability sector, and the newly drafted criteria remain founded on a points-based PIP assessment, which many have compared to the much-criticised work capability assessment because of its focus on physical and functional limitations. The authors of the Scope report and this Demos report were called to the Work and Pensions Select Committee to give evidence, and expressed the opinion that aligning PIP to medical ‘need’ and need for care and support risked duplicating social care support – leading to a situation where the greatest financial support was concentrated on those with the highest care needs and would leave those with lower level needs (but not necessarily lower living costs) without support from either the benefits or the care system (as a result of increased eligibility criteria).⁴⁰

The time limitation of contributory Employment and Support Allowance

The time limitation of eligibility for contributory ESA (WRAG) to one year, which was announced in the October 2010 spending review, has proven highly controversial. In September 2011, the Liberal Democrats passed a motion at their party conference stating: ‘Liberal Democrats in government to oppose an arbitrary time limit on how long claimants can claim contributory ESA’.⁴¹ According to Liberal Democrat Party regulation, this

motion is now party policy and some suggested this may bolster the Liberal Democrat Lords' position to oppose this section of the Welfare Reform Bill as it passes through the parliamentary process. Nonetheless, in September 2011, the Disability Alliance reported that some contributory ESA claimants had received letters warning they only had six months left to claim their benefit before it was withdrawn in April 2012, leading to accusations that the Government was acting as if the Welfare Reform Bill had already been passed.⁴²

Moreover, in early November 2011, the section of the Bill related to the time limitation of contributory ESA passed unamended through the Lords committee stage – substantially reducing the chances of this policy being removed before the Bill is passed.⁴³ We should also bear in mind that the year time limit is also cumulative – therefore someone who spends six months in the WRAG, before being moved to the Support Group (because of their condition deteriorating for example), may well then move back into the WRAG on recovery – only to find they have just six months left to claim this benefit as their first six months count towards their one year total.

The Government's own equality impact assessment on this matter estimates that 90 per cent of contributory ESA claimants in the WRAG will be affected by the one year time limitation, and 40 of those (around 280,000 people over the course of the parliament) will not be eligible for income-based ESA and will therefore have to claim the only alternative out of work benefit – JSA – with the additional conditionality regime this entails, including requirements:

- to look for and be immediately available for any work regardless of type and salary, full time, and within 90 minutes of home
- to treat looking for work as their full-time job.⁴⁴

These requirements may be relaxed where the claimant has a health condition, or undergoes regular treatment, but does not have limited capacity for work.⁴⁵ This could prove a challenge for disabled people. The time limitation of contributory ESA would mean some disabled people may find themselves claiming

JSA, which under the Universal Credit will form an unemployment element. As JSA is given to those deemed 'fit to work', it is likely some disabled people will be wrongly grouped in the 'fit to work' category and fall foul of the conditionality rules outlined above. Moreover, even a disabled people who is fit to work (or rather, does not have 'limited capacity' to work) may still find it a challenge to be immediately available to work (given the additional organisation of travel arrangements that may be required) and to be able to travel for 90 minutes from their home.

The removal of Disability Living Allowance mobility element from those in residential care

The proposal in the Welfare Reform Bill to remove the DLA mobility element from those in residential care caused so many protests from disability charities and disabled people that the Government announced a review of this policy, and delayed its implementation by a year to 2013. Leonard Cheshire Disability and Mencap commissioned Lord Low of Dalston to carry out an independent review of the impact of this policy alongside the Government's review. In October 2011, following 12 weeks of evidence gathering and 800 submissions, the Commission concluded that there was no evidence that funding for those with mobility needs was duplicated by local authorities and the DLA mobility component – yet this was the key argument the Government made for scrapping mobility DLA for those in residential care. Lord Low's commission found the mobility needs of residents in care were not being met by local authorities' care funding or routinely included in residential care packages, and stated: 'If payment of the mobility component to people living in residential care ends, this will be a serious step backwards for disability rights.'⁴⁶

Coping with the cuts - how local services are affected

In the wake of so many radical new changes to welfare benefits, it can be easy to lose sight of the other side of the coin. However,

the Government's plans to reduce the budgetary deficit also include unprecedented cuts to many public services and local authority budgets. Therefore disabled people, who are disproportionately more likely to be dependent on benefits for a large proportion of their income *and* more reliant on public services (relating to not just health and social care, but also housing) and third sector organisations whose grants have also been cut, are essentially facing a double setback of reduced income and reduced access to support services. In the October 2010 spending review, annual budget reductions of 7.1 per cent for local authorities were announced,⁴⁷ with the first of these new local authority budgets coming into effect in April 2011. In our *Destination Unknown: Spring 2011*, it was too early to tell how these budgets would affect the five households in our study – although as we discovered, some were already feeling the effects of a prolonged period of underfunding in social care.⁴⁸

Although the Government pledged an additional £2 billion for social care provision, decisions not to ringfence this money left little guarantee that cash-strapped councils would use such funds specifically for social care services.⁴⁹ Indeed, these fears seemed to be confirmed by research conducted by the House of Commons Library, commissioned by Shadow Care Minister Liz Kendall, which concluded that the grant had not made it to front-line services. Kendall described the situation as a 'quiet crisis in social care'.⁵⁰

To throw some light on this issue, in September 2011 Demos and Scope published *Coping with the Cuts*, which collated data from a series of freedom of information requests sent to local authorities across England and Wales to explore how budget cuts were impacting front line disability services. These were some of the key findings for England:⁵¹

- The number of councils setting their care eligibility criteria at 'substantial and critical' needs only has risen from 78 per cent to 81 per cent from 2010/11 to 2011/12.
- Over half of the local authorities surveyed had closed some kind of disability support service.

- Only seven councils had decreased the charges people pay for services such as meals on wheels this year; 22 councils had kept charges frozen, while the remaining 123 had increased their charges by up to 400 per cent.
- Only three local authorities no longer take income from DLA into account when assessing how much a person has to pay towards their care.
- Over half of all local authorities give care users a personal budget that is worth less than the monetary value of the care they had been receiving before directly from the council.

Even this very large data gathering project did not capture the full extent of the breadth and variety of changes to services on which disabled people rely. For example, in October 2011 research uncovered large cuts to Supporting People – the funding stream given to housing providers to support vulnerable people, including those with learning disabilities, to live a supported independent life rather than stay in residential care.⁵² Though the Government made a notional cut of 12 per cent to Supporting People from 2011 to 2015, the funding stream is not ringfenced and councils are no longer required to collect outcomes data for users, leaving services open to far higher levels of reduction.⁵³

We must also remember that disabled people are particularly reliant on support from voluntary and community sector organisations – even more so in the wake of reductions in statutory service budgets. Yet further evidence was released over the summer on the impact of reduced local authority grants and funding for these (often financially vulnerable) organisations.

The third year of London Voluntary Service Council's survey 'The Big Squeeze' found a worrying trend of disproportionate cuts to cost-effective preventative services – especially advice, children and young people and health services.

Of the Voluntary Service Council organisations surveyed:

- 51 per cent had closed services in 2010/11; 54 per cent expect more services to close in 2011/12.

- 77 per cent expect public sector funding of their organisation to decrease in 2011/12 with those giving a figure expecting a median 31–40 per cent cut.
- 97 per cent said the economic climate had a negative impact on their service users in 2010/11.
- 81 per cent had found the demand for their services had increased in 2010/11; 86 per cent expect demand for their services to increase in 2011/12.
- 57 per cent were able to meet increased demand for their services in 2010/11; 77 per cent were not confident they could meet increases in demand in 2011/12.⁵⁴

Finally, a survey by KIDS and Mencap of 1,192 parents in England threw light on disabled children's services. It highlighted the fact that families with disabled children face a lack of appropriate holiday childcare and exorbitant childcare costs:

- One in ten disabled children were refused a place in childcare provision over the summer of 2011.
- One in three parents of disabled children received no childcare over the summer holidays.
- One in five families with a disabled child pay more than twice as much as the national average for their childcare.
- Two in three families found it difficult or very difficult to find appropriate childcare for their disabled child.⁵⁵

The studies outlined above are just a small selection of surveys and primary evidence published over the last six months, which serve to illustrate how the Government's programme to reduce the deficit and cut public spending is affecting 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 and/or with care and support needs, are disproportionately reliant on public services, social care and the support from voluntary sector organisations⁵⁶ and so are faced

with an extremely difficult situation: reduced income, and reduced support services to cope with this reduction. The findings from our interviews in the next section illustrate this predicament very well.

The fight back – legal challenges to local service cuts

Although the studies outlined above have stirred up much debate, we should also note that some disabled people have gone further and taken matters into their own hands. In May and October 2011, an estimated 8,000 and 5,000 disabled people respectively took to the streets in events in 12 major cities across the UK in protest of the cuts.⁵⁷ Others have taken their battle to the courts: in May 2011, four disabled residents launched a legal challenge to Birmingham City Council’s decision to impose more stringent care funding eligibility criteria.⁵⁸ 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 local authority financial support. However, the case was upheld in the High Court. Justice Walker declared that Birmingham City Council’s budget setting and decision to change its eligibility policy were unlawful on the grounds that they did not promote equality under Section 49A of the Disability Discrimination Act 1995 and their attempts at consultation were flawed.

Birmingham had not complied with its Disability Equality Duty in moving to critical needs only without proper analysis of the impact this would have on disabled people in the area and without proper consultation. Under the Duty, councils must give due regard to eliminating discrimination, promoting equality of opportunity, eliminating harassment, treating disabled people more favourably if necessary, promoting positive attitudes on disability and encouraging participation of disabled people.

Justice Walker stated:

There was no analysis of how and to what extent any mitigation measures would be effective in addressing adverse impacts. In particular, there was no consideration of the extent to which alternative resources in the community

*would be available for those with substantial needs, and no other steps to mitigate the impact on disabled people were identified.*⁵⁹

In October 2011, the legal challenge brought by the families of two autistic men was upheld in the case of the Isle of Wight's decision to raise its care eligibility thresholds to critical only. As in Birmingham, the judge deemed that the council had not complied with its own internal guidance in drawing up the new policy, and a consultation document did not contain sufficient information for people 'to give intelligent consideration and an intelligent response'. Changes had already been made to the care of 32 people as a result of the more stringent criteria, but they are now being offered a reassessment.⁶⁰

This came in the same week as a judgment ruling Sefton Council's decision to freeze care home fees for the second year in a row unlawful, stating that the council had failed to properly assess 'the actual costs of care'.⁶¹ In September, Stoke Council stepped down from its decision to make redundant a teacher for the deaf in response to the threat of a legal challenge by the National Deaf Children's Society.

Such legal cases, repealing local authority actions taken to lower costs in the face of substantial government budgetary reductions, clearly suggest the significance of the cuts being made at local level are, in some cases, too harsh. Demos's own research suggests local authorities have a variety of methods they might draw on to reduce costs, from back office efficiencies to steps that affect the front line, such as more stringent eligibility criteria for increased user charges, less generous contribution rules, or cost-efficiency measures placed on personal budgets.⁶² A combination of these, possibly alongside service closures or restrictions, need to be employed to enable local authorities to balance the wellbeing of their disabled, older and vulnerable populations and the realities of dealing with the harshest financial settlement from central government in a generation.

However, we ought to bear in mind that, even in the vast majority of local authorities where legal and indeed seemingly reasonable cuts are being made, individual households may fall

foul of the cumulative effect of local disability related service cuts like those outlined above, combined with wider non-disability cutbacks (to everything from pensions to transport subsidies), and cuts to welfare benefits. It is this cumulative and complex household-level effect which this longitudinal study of six disabled households seeks to better understand.

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

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

Our previous update, published in May 2011, was able to consider the range of welfare reforms that were due to begin in April 2011, including:

- Incapacity Benefit (IB) reassessments being rolled out nationwide
- benefits being uprated in line with the Consumer Price Index (CPI) for the first time instead of the Retail Price Index (RPI)
- caps on housing benefit being applied
- the start of a one-year time limit for current Employment and Support Allowance (ESA) claimants

As it was the beginning of the new financial year, April 2011 was the month when new local authority budgets were enforced reflecting the harsher new financial settlement presented by Government in the spending review. This brought in substantial cuts to service budgets and grants to voluntary organisations.

In this report we return to the six households to see how their income, health, housing and other circumstances have changed since we interviewed them in April 2011. We are looking at an additional household since the original 2010 report: in light of the dramatic changes occurring in social care provision, we thought it important to include Steve in our updates, to establish what effects the changes were having on disabled people in receipt of social care services. Also, we have revisited again for

this report a family ‘in extremis’ – Helen and her son. Their circumstances are not typical, but we wanted to see how a vulnerable disabled family whose quality of life has been undermined by ill-thought-through policy reforms is faring. In *Disability in Austerity: Spring 2011* we referred to our study participants by letters – P, C, E and so on. Following feedback, we have given people full names instead (though not their real names) to make discussions about their situations easier to follow.

Our case studies are:

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

Many of the welfare reforms announced in the emergency budget, spending review and subsequent months have had clear and predictable effects on the disabled households we are following. In particular, the change in uprating benefits according to the CPI means that, each April, the benefits increase is based on the previous September’s (lower) CPI inflation rate instead of the RPI rate. As a result of this change, in our first update in May 2011, the benefits of the disabled people in our study increased by 3.1 per cent instead of 4.6 per cent – a loss of 1.5 percentage points from each benefit. The loss was easily calculated in our first report and while these reductions will seem small when considered weekly, over time their cumulative effect can be substantial. We found that the households would be £200–300 worse off each by the end of the financial year (April 2012).

However, things may be even worse for the households in our study next year. In September 2011, the CPI rate was at an all time high of 5.2 per cent, while the RPI rose to 5.6 per cent. This

means that, from April 2012, benefits *should* be increased by a significant 5.2 per cent, and the loss to benefits claimants following the government switch from CPI to RPI uprating would be just 0.4 percentage points.⁶³

By speaking to disabled people about their experiences in the six months since our April 2011 update report, we have been able to gain an insight into the variety of ways in which budgetary cuts have impacted on their lives. Many of these have been difficult to calculate or predict – including the closure of services and changes to non-disability benefits.

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

In this report, we have noticed another emerging theme – the financial and emotional problems brought about by administrative oversight or the complexities of the social care and benefits systems. The households in our study are reporting having to ‘battle’ to secure support; delays and missed payments may prove an inconvenience for households with some financial cushion, but for disabled households with no financial safety net and no means of remedying this, even small administrative discrepancies disrupting regular payments can have significant and long-term negative effects on their financial, emotional and physical wellbeing. We are also witnessing how the complexity of the systems that deliver financial and other support has led to disabled people being ill-informed of the changes taking place, what they will mean for them, and how they can ensure they receive everything to which they are entitled. In one case, this confusion led to one of the people in our study – Steve – using up his small amount of savings as he mistakenly thought he would not be eligible for social care support if he had any savings whatsoever.

A third important theme which is emerging is that the households in our study are finding it difficult to secure alternative means of support in order to be able to cope with the

effect of the cuts. When asked, most reported speaking to advisers about alternative sources of financial support, to be told they were claiming everything to which they were entitled from the state. Most were seeking out alternative sources of support from charitable schemes, their community or families – suggesting non-state support may be the only viable option for disabled people in times of financial crisis. However, it is clear that all of these options are one-off emergency measures, rather than sustainable solutions. In the light of reduced funding for voluntary organisations in the face of increased demands for help, it is unsurprising that disabled people are finding it difficult now to secure any alternative means of support. At least one of the couples in our study – Albert and his wife – is not coping well, has exhausted help from charitable sources, and has accumulated large amounts of debt since the Government reduced Support for Mortgage Interest (SMI) and other benefits payments.

In the following case studies, we therefore consider:

- the predictable impact of the Government's welfare reform – including but not exclusively the transfer to CPI uprating, reassessment of IB and so on
- the less predictable impact of the Government's budgetary cuts and the wider economic climate on local services
- the events that demonstrate the precarious situation disabled people face, including administrative errors
- how well the household is coping and the sources of alternative support being used

Aisha: a disabled child, cared for by her parents

Everything is going up and our income is going down... We are getting to the point where there is nothing else to cut back on.

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

The predicted losses of welfare reforms

The primary impact we predicted for this family in *Destination Unknown: Spring 2011* was the lower than expected increases to a range of benefits in April 2011, as a result of increasing benefits by September 2010's CPI (3.1 per cent) instead of RPI (4.6 per cent) or Rossi (4.8 per cent) inflation rates. As Aisha's parents also receive Child Benefit for their other children – which the Government has now frozen at 2010 rates for the next three years – their overall reduction in benefit income is more substantial than other households in our study. As the cost of living (reflected in record levels of RPI and CPI inflation this year, as mentioned above) is currently so high, this is likely to have a significant impact on the family's disposable income. Between our first update in April 2011 and the time of writing, Aisha's family is £199.52 worse off as a result of these measures. Table 2 gives details of how the benefit reforms since April 2011 are affecting Aisha's family.

Table 2 **How the reforms to benefits from April 2011 affect Aisha's family**

Family benefits	Reforms to benefits from April 2011	Worse off between April 2011 and October 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, £22.22 worse off from April to October 2011
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, £32.40 worse off from April to October 2011
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, £120.30 worse off from April to October 2011
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, £24.60 worse off from April to October 2011

Aisha's family has lost £199.52 in the last six months.

What didn't we account for?

For every one of the households in our study, we are able to model the potential losses to benefit income driven as a result of announced welfare reforms. However, the impact of other cuts (to public services) is something of an unknown quantity – even after the local government settlement was announced in the spending review and local authorities set their budgets in April

2011, the impact of the proposed measures on front-line services and how they will affect individual households is impossible to predict.

The bedroom

In Aisha's case, fortunes have been mixed. First, there has been good news about her bedroom. In April, Aisha's mother described a situation whereby her daughter's bedroom had been designed incorrectly by an occupational therapist: the door was obstructed by the bed, there was not enough room to get around the bed to give Aisha chest therapy (which she needs four times a day), and not enough room for her hoist. Their local authority's Children with Disabilities team admitted liability for these mistakes but told Aisha's family they did not have the budget to fix the room properly. Aisha's mother was considering splitting up the family to move to more suitable accommodation.

Since then, the local authority signed off a plan that would increase the width of Aisha's room to allow a carer to move around the bed – a positive step – however, this would not adjust the length of the room, which was still too short to house Aisha's wardrobe and would impede her ability to get up and ready for school in the morning. Fortunately, her father's company has a scheme that helps employees' families who are in financial difficulty and the scheme manager offered to match the funds allocated by social services in order to increase the length of the room. Initially, the local authority was reluctant to work in cooperation with the scheme, but the family has finally received formal planning permission to change the room.

Starting school

Aisha started reception class at a local school a few months ago, and this has not been without its problems. Lunchtimes are difficult as she needs one-to-one supervision; she is at risk of choking, and food needs to be prepared for her. Yet Aisha's special educational needs statement outlines this need in 'part 2', which describes her educational needs as well as some of her requirements to get through the school day. The local authority is unwilling to incorporate this need into 'part 3' of the SEN

statement, as this would make it legally obliged to provide this service.

In light of these developments, Aisha's mother told us: 'we have another battle on our hands' – referring to the 'fight' she described to us back in April 2011 to receive an hour of support for Aisha from the local authority to help her get to school in the morning. In the meantime, the school – which her mother describes as 'wonderful' – is providing a supervisor to look after Aisha at lunch time.

Equipment

Aisha's family tell us they are noticing cuts affecting physiotherapy services, and the securing of equipment for their daughter. Another 'battle' for the family has been to access the equipment Aisha is entitled to and separately needs. In May, Aisha went for a fitting for a standing frame, supplied by the NHS. Yet when we interviewed the family recently, nearly six months later, Aisha still hadn't received the frame. The family is waiting for it to be signed off for approval by their local healthcare authority. Aisha's mother thinks they will probably receive it next year, and tells us: 'I just don't have the energy [to fight for it]'. She thinks in this unsteady financial climate, parents of disabled children have to find the money for their own equipment, and that charities that could have helped before are now overburdened with demand.

It is for this reason that Aisha's family gave up another 'fight' – to get a motorised wheelchair for Aisha. She is now old enough for a motorised wheelchair but her family told us in April that the local authority refused to pay for it. They would only provide an indoor wheelchair, but Aisha – now age four – needed an outdoor one so she could get out to school and to play in nearby parks. Outdoor powerchairs are extremely expensive – they can cost around £8,000. Rather than continue to argue with the local authority, Aisha's parents' engaged in a massive fundraising effort in their local community from June and managed to raise enough, by October, to afford Aisha's chair themselves.

The local community's show of support for Aisha has been fantastic and is much appreciated by her family. But, it clearly hasn't been easy to go out among the public and ask for support. Aisha's mother is clearly exasperated by the lengths she has had to go to and told us: 'We shouldn't have been forced to go out in public like that. We had to beg... that was very hard on my husband.'

No safety net – coping with financial shocks

In April we reported how Aisha's father had resorted to taking unpaid leave in order to help care for Aisha. This has now become a permanent arrangement, with her father taking unpaid leave for four weeks per year. Reducing his working hours in this way has had a significant impact on the family's finances: they haven't been able to have a holiday, and the children have had to stop participating in some of the afterschool clubs they used to go to (Aisha's sister has had to give up playing the flute because they cannot afford the lessons any more).

Aisha's mother reports they have to make trade-offs between essentials like food and heating. When we last spoke to the family in April 2011, we discovered that Aisha's parents were spending £150 per month on diesel to take Aisha to frequent appointments at three different hospitals, demonstrating that the financial downturn is not just about budget cuts, but also about increased food and fuel prices. Aisha's family relies heavily on their car to take Aisha to a variety of outpatient appointments to manage her condition – and their experience is by no means atypical of a disabled person for whom public transport is inaccessible. The details of their journeys and associated costs, which we originally presented in our April report, illustrates how higher fuel prices have a disproportionate impact on those most reliant on their cars – not through choice, but through necessity.

The costs of transport

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

- *The first is 12 miles away; Aisha has three appointments a month there. Aisha's father drives or they have to pay £20 for the return trip for a taxi. There are no direct buses and buses do not allow Aisha's wheelchair on board if they are already carrying buggies.*
- *The second hospital is 40 miles away, which Aisha must attend once a week. It costs about £90 for the return trip by taxi if Aisha's father is not free to drive them (about half the time).*
- *The third is 70 miles away, which Aisha 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 so that the other children are looked after.*

The family explained in April 2011 how the cost of attending these appointments (in fuel, taxi fares and childcare) had an enormous impact on the family's income. Aisha's mother now reports: 'We have got to a point where we have to cancel the appointments as we cannot afford to get the cabs.' They have already had to cancel two appointments in the last six months.

How is Aisha's family coping?

When we last spoke to her, Aisha's mother said the struggle over her daughter's bedroom had left her 'less in control' over her anxiety and depression; she worried she might have to go back onto medication. Six months later, she now has to have weekly counselling, which is provided by the NHS, and needs antidepressants three times a day. Although these have been bought on a prepaid certificate, costing £100 a year, it is yet another drain on the family's finances. Speaking about how she has managed over the last six months she said, 'I shouldn't have been pushed so hard. It really pushed me beyond what I can cope with.'

Aisha's family has done well in securing community support through fundraisers, her father's employer and even Aisha's school. We ask if Aisha's mother has sought further help from the state. She tells us that they sought advice from a

benefits adviser who told them they were already receiving everything to which they were entitled. Only if her husband cut his working hours further would they be eligible for other benefits, but he does not want to do this, as he has worked all his life and does not want to depend on state benefits. Already he has had to take unpaid leave from work to help care for the children. When her youngest child starts school next September, Aisha's mother says she may have to take up a position working a night shift to bring in more income.

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

They got very heavy. Bully boy tactics. They were really, really ferocious. It got to a point where it was madness.

- *Albert was self-employed businessman who 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 is due for more surgery soon. He also now suffers from regular memory loss.*
- *Albert's wife is his carer, who was made redundant three years ago. She has arthritis.*
- *They have a £137,000 mortgage, mortgage arrears of £13,000 and £54,000 in other debts.*
- *They receive:*
 - *Disability Living Allowance (DLA) for Albert (high mobility, middle care)*
 - *DLA for Albert's wife (low care)*
 - *Incapacity Benefit (IB)*
 - *Support for Mortgage Interest (SMI)*
- *They lost Income Support and Carer's Allowance in return for Pension Credit.*

The predicted losses of welfare reforms

As with our other case study participants, Albert and his wife received lower than expected increases to their benefits in April as a result of the switch from rating them according to the CPI rather than RPI. Albert's IB 'age addition' of £15 (given to him as he became disabled before he turned 45) was also cut to £13.80 this year, creating a larger than expected drop in income. Over the last six months, Albert and his wife have £300 less in income because of this one reform.

In addition, as Albert receives IB, he will also be due for a reassessment and moved onto Employment and Support Allowance (ESA) or, if found fit to work, Jobseeker's Allowance (JSA). The national roll out of IB reassessments using the work capability assessment began in April 2011, though Albert has not yet received his reassessment notice. Table 3 gives details of how the benefit reforms since April 2011 are affecting Albert and his wife.

Although the loss of £781.55 in six months is very large indeed, the reduction in SMI has led to the most significant hardship for Albert and his wife. Since October 2010, SMI has been paid at the level of the Bank of England's average mortgage rate (3.63 per cent), which is significantly lower than the previous SMI rate of 6.08 per cent, set in December 2008.

Albert's mortgage is around £137,000, and until October 2010, the couple was receiving £426 per month in SMI – though they told us when we spoke to them in September 2010 that this did not cover the total mortgage cost. When the Government's reform came into effect, Albert and his wife only received £226 per month in SMI. By April 2011; they were £7,000 in arrears and were receiving letters threatening them with charges. When we spoke to them again six months later in October 2011, they told us their SMI had been increased to £302.07 per month, no doubt because of the increased amount they now owed – but they are now £13,000 in arrears, having accumulated an additional £6,000 in debt since we last spoke to them. Their lender had threatened to repossess their home. They had received daily letters and phone calls. The lender asked Albert to get a job (he has been unable to work since his stroke), to ask his neighbours for money, or to sell his (Motability) car. The lender even suggested

Table 3 **How the reforms to benefits from April 2011 affect Albert and his wife**

Family benefits	Reforms to benefits	Worse off between April 2011 and October 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, £22.22 worse off over six months
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, £20.70 worse off over six months
Disability Living Allowance – low care for Albert's wife	Benefit increased by CPI instead of RPI – from £18.95 to £19.55 per week (CPI), instead of £19.82 (RPI)	27p per week, £8.10 worse off over six months
Incapacity Benefit	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, £81.90 worse off over six months; 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, until 6 July (3 months 1 week) and then total loss of £110.60 from 6 July to end October
Carer's Allowance for Albert'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 until 6 July (3 months 1 week) and then total loss of £55.55 from 6 July to end October

Table 3 **How the reforms to benefits from April 2011 affect Albert and his wife - *continued***

Family benefits	Reforms to benefits	Worse off between April 2011 and October 2011?
Albert's wife's pension	Receives £102.15 per week plus £31 carer's premium since 6 July	Total pension income so far is £2,263.55; total loss of Income Support and Carer's Allowance is £2,859.26 since April

Albert and his wife have lost £300.55 in income between April and October 2011 in lower benefits, plus £2,744.55 in Income Support and Carer's Allowance, totalling £3,045.10 loss, but gained £2,263.55 in pension income. Overall Albert and his wife have lost £781.55 over a six month period in total.

he used his pension to pay off the debts, even though Albert is legally unable to do anything with his pension until he reaches the age of 55. Albert told us: 'They got very heavy. Bully boy tactics. They were really, really ferocious. It got to a point where it was madness.'

The latest news is that, a few days after we spoke to Albert, he and his wife were told they are to be evicted from their home of 10 years in February 2012. An estate agent has visited and Albert hopes he will be able to sell, pay off the mortgage and 'move to a nice area'. It is concerning that within a year of the first cuts being made (in this case SMI being drastically reduced), one couple in our study is losing their home.

What didn't we account for?

In April 2011, we found that Albert's wife fell foul of the Government's gradual increase of the pension age from 65 to 66. She was supposed to have received her state pension of £97 per week from 6 November 2010, but the date was changed to 6 July 2011. This eight-month delay has resulted in her losing out on £3,186 in pension income (based on four months loss of the basic state pension rate of £97 in financial year 2010 and £102.15 in

financial year 2011). On speaking to Albert in October 2011, we found out that Albert's wife did indeed receive her pension in July – one would think this was a welcome increase in income for the couple. However, in reality, they have made a loss – something which we were unable to predict.

As Albert and his wife's household income is above the minimum income guarantee, Albert's wife was not eligible for any Pension Credit to top up her basic state pension of £102.15 per week, but as a carer she is entitled to an extra £31 per week carer's premium. She started receiving this additional £133.15 per week from July 2011.

However, as Albert's wife is getting some element of Pension Credit, Albert is no longer eligible for Income Support, and Albert's wife is no longer eligible for Carer's Allowance as she receives the carer's element of Pension Credit. So the couple were told in July that £166.15 per week would be removed from their benefit income as a result of Albert's wife receiving her pension. In short, the move from benefit income to pension income has led to the couple's household income falling by a further £33 per week. Taking the lower uprating of Income Support and Carer's Allowance from April until July, followed by losing these benefits completely from July until October, we see that Albert and his wife have lost £3,045.10 in income in six months. As Albert's wife has only received £2,263.55 in pension payments in the same period, this means this couple is £781.55 worse off between April and October as a result of changes to these particular benefits.

But this is not the end of Albert's story. When his wife's Pension Credit began being paid into the couple's account in July 2011, the SMI addition – payable on top of this allowance – was delayed over the summer and not paid until October. The delay caused them to slip deeper into arrears and exacerbated the situation with their mortgage lender; although the missing SMI was backdated and the lender received a lump sum, this has not prevented the eviction scheduled for early next year. It is clear from this incident how vulnerable disabled people, who have no financial safety net, can be to seemingly small administrative errors.

No safety net – coping with financial shocks

In recent months, Albert's wife's condition has deteriorated and she is having heat treatment on her spine. Albert's own health is worse, and he now has spondylitis – the inflammation of his vertebra. He is seeing a neurologist but is still waiting for reports since January 2011, when he had to have treatment in London after it was thought that he had had another stroke. Albert recently asked for help from a community psychiatric nurse but his local primary care trust told him that they no longer had such nurses available because of the cuts to their budget, and suggested he approach a charity instead. This is an important point – the state is advising Albert to seek support from the charitable sector because they cannot afford to help him (despite the NHS being a state service free at the point of use). The assumption is being made that there is a local charity with adequate funding to step in and provide a nurse – as we have already mentioned, the reduction in grants provided to charities by local government is leading to widespread closures and reductions in the amount of support available. As explained below, this year a charity has already refused to help Albert pay his water bill.

Because of their conditions, Albert and his wife require a well-heated house. Over the particularly cold winter in 2010 and early 2011, and as a result of increases in electricity and gas prices, Albert and his wife told us in April that they faced the significant financial shock of three large utilities bills: a £465 gas bill, a £300 electricity bill and a £643 water bill. Albert estimates their monthly bills have increased by £30 (electric) and £15 (gas). Albert had no savings to use to pay these bills, so had the money taken directly from the couple's benefit income. Albert's IB was automatically reduced as part of the third party payment scheme, at a rate of £140 per month. As a result, Albert tells us he has just managed to pay off his gas and electricity bills this month, but is now dreading this winter and the prospect of another large bill.

There has been some good news on this front – the couple has been moved onto a social tariff by their gas provider; so in January 2012, they will have £120 cut from their bill. Also, as Albert's wife now has her pension, the couple will be entitled to

winter fuel allowance, which will provide them with a £200 lump sum to help them cover their bills over the winter period.

However, more than six months on from when we last spoke to him about the disrepair in his house, Albert tells us his windows still have not been repaired. The broken windows in their house let in the cold and the rain, and he and his wife have had to stop the gaps with towels. This is likely to be increasing their utility bills as they have to turn the heating up to counteract the cold coming in. Albert told us: ‘This is the worst part of the year. I feel the cold. Unbelievably. It’s like your head goes cold.’

A greater concern is that one of the biggest financial shocks for the couple in our last report had been the £643 water bill – something which will not be reduced by the couple’s new ‘social tariff’. Albert had received help from a charitable trust set up by the water provider to cover that cost, but when Albert tried to apply for the same scheme this year he was told that he would not be eligible for help as he and his wife had benefited from the scheme the year before, and this year the provider had been ‘inundated with claims’ and would target those households which had not previously received help. This shows how charitable sources of support as alternatives to the state – part of the Government’s vision of the Big Society – are not sustainable when third sector funding is also being reduced.

Carla: a single disabled woman

It’s an awful situation to be beholden to people, but I don’t have a choice.

- *Carla is a single woman who lives in London. Aged almost 60, she worked throughout the 1980s and 1990s (although she was made redundant twice).*
- *In 2000, she suffered a mental breakdown, and was initially sectioned and diagnosed with recurring depressive disorder.*
- *She applied for Disability Living Allowance (DLA), and was turned down, appealing the decision and losing twice before attempting suicide.*

- *Her case was taken on by a local law centre, which pursued the decision to tribunal at which point she was awarded DLA. She now receives:*
 - *DLA (higher rate care and lower rate mobility)*
 - *Incapacity Benefit (IB)*
 - *Income Support and Severe Disability Premium*
 - *the housing element of income support*
 - *Council Tax Benefit*
- *As she lives alone, receives higher rate DLA care but has no one to help care for her, Carla is entitled to the Severe Disability Premium (currently set at £55.30 a week). She lives in her own flat and receives the housing element of Income Support to cover her mortgage payments – at about £57 per week.*

The predicted losses of welfare reforms

All Carla's benefits have been increased by a lower than expected amount in April 2011, with the result that she has lost £140 over the past six months, and there are additional changes which are likely to affect her shortly. As Carla is currently receiving IB, she could at any point be reassessed as part of the Government's plans to move IB claimants onto Employment and Support Allowance (ESA). Although Carla is well aware of the forthcoming replacement of DLA with Personal Independence Payment (PIP), she was unaware of the introduction of ESA to replace IB three years ago, and was upset when we told her, exclaiming 'oh God'. The idea that she may have to undergo another medical assessment shocked her – following her assessment for IB in 2003, her doctor told her she would not have to undergo such an assessment again. 'If you're going to reassess everyone, then people are going to jump off a cliff,' she told us.

Carla told us that she is hoping she will be old enough to avoid some of the Government's reforms to working age benefits, though in fact she will not have reached 65 by the time PIP is

rolled out nationally nor at pensionable age before she is moved onto ESA (or found fit to work). Reflecting on the months ahead and the public spending cuts, she said: ‘I think its upside-down... they hit the most disadvantaged hardest.’ Table 4 gives details of how the benefit reforms since April 2011 are affecting Carla.

Table 4 **How the reforms to benefits from April 2011 affect Carla**

Family benefits	Reforms to benefits	Worse off between April 2011 and October 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, £8.10 worse off over six months
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, £32.40 worse off over six months
Incapacity Benefit	Benefit increased by CPI instead of Rossi - from £91.40 to £94.25 per week (CPI), instead of £95.70 (Rossi)	£1.55 per week, £46.50 worse off over six months; due for reassessment from April 2011
Income Support (plus £57 towards housing costs)	Benefit increased by CPI instead of Rossi - from £65.45 to £67.50 per week (CPI), instead of £68.46 (Rossi)	96p per week, £28.80 worse off over six months
Severe Disablement Premium	Benefit increased by CPI instead of RPI - £53.65 to £55.30 instead of £56.11 (RPI)	81p per week, £24.30 worse off over six months

Carla has lost £140.10 in the last six months.

What didn't we account for?

After her breakdown, social workers and local support agencies recommended Carla should get out into the community more. As a mental health service user, she is eligible for a discretionary freedom pass to use London transport for free. Using this to pay for public transport has been of great help in improving her wellbeing and combating her agoraphobia. 'It's wonderful for people who are agoraphobic.' However, her local council is now consulting on the possible abolition of discretionary freedom passes for people with mental health conditions, reserving them for those with physical impairments only. As Carla is not yet eligible for an older person's freedom pass (as the age limit has been increased from April 2010), she faces the prospect of not being able to travel so freely (whether to attend medical appointments, or to improve her mental wellbeing).

No safety net – coping with financial shocks

Over the past year, cuts to local services have had a significant but unexpected impact on Carla's life. She receives help with service charges for the property; she pays 10 per cent of insurance and repair bills while the rest is covered by her Income Support. She submits her paperwork and receipts and the benefits agency covers the costs, reimbursing her via payments into her own account, which she then uses to pay back the management company.

However, Carla recently discovered that her benefits agency – to which she was submitting her paperwork – had closed without informing her. Because of this, building insurance and repair costs for this year and the last had not been paid. She had to resubmit her paperwork, which she did six times, to other agencies further afield before she could have her 2010 costs (of around £282) paid. As Carla is reimbursed in instalments – paid over the course of a year – this has led to long delays in her paying back the management company. She has costs of about £250 this year and has had to wait for the reimbursements to come into her account before she can set up a standing order to pay them back. Again, we can see how administrative oversight can wholly disrupt the lives of those who have no financial cushion to absorb a delayed or missed payment.

Carla believes that the closure of the benefits agency that managed her housing costs payments and created the financial mess she is now in was caused by the Government's spending cuts. More importantly, she reports that her local law agency, which took up her DLA case and then helped her claim for the other benefits she was entitled to following her breakdown, is now struggling for money and has to put on regular fundraising events. She is very distressed by this and told us: 'I credit the agency with saving my life.' It is clear that the wider economic environment is slowly but surely removing the support structures – not just financial but also advice and information – that disabled people rely on to ensure they receive what they are entitled to.

Philip: a single disabled man

I've always felt very guilty about being on benefits, but I don't know how I'd hold a job down.

- *Philip is in his late 40s and lives alone. He has lifelong epilepsy, which deteriorated in 2008 and left him unable to work and separated from his wife.*
- *He has a mortgage of £73,000, a £5,800 credit card debt, £1,500–2,500 overdraft and owes his brother £6,500.*

He receives:

- *Disability Living Allowance (DLA; low mobility; middle rate care)*
- *Employment and Support Allowance (ESA), Work Related Activity Group (WRAG)*
- *Council Tax Benefit*

The predicted losses of welfare reforms

Like other disabled people, Philip received a smaller increase in his DLA than he would have done if it had continued to be

uprated by the CPI rather than the RPI, but the most significant development for Philip will be the new time limit for claiming the contributory WRAG rate of ESA. As he had been claiming this for longer than a year when the policy was applied in April 2011, he only had 12 months left to claim ESA from that point. He now has less than six months before he will be automatically transferred to either income-based ESA, or Jobseeker's Allowance (JSA). When we spoke to Philip about this in October 2011, he was not aware of this change – he told us he had seen his benefits adviser in June, who told him that he could expect to remain in the WRAG unless he heard otherwise. Table 5 gives details of how the benefit reforms since April 2011 are affecting Philip.

Table 5 **How the reforms to benefits from April 2011 affect Philip**

Family benefits	Reforms to benefits from April 2011	Worse off between April 2011 and October 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, £8.10 worse off over six months
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, £20.70 worse off over six months
Employment and Support Allowance, work related activity group 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, £45.90 worse off over six months and only eligible for this benefit for six more months

Philip has lost £74.70 in the past six months.

No safety net – coping with financial shocks

Philip tells us that he is ‘exceptionally frugal’ and spends a lot of time finding deals and discounts. Perhaps as a result, he has been able to pay off some of his debt in the past six months – a positive development. However, in recent months his health has deteriorated. His sleep pattern has worsened and so has his mental health. The anti-convulsive medication he takes for his epilepsy affects his sleep and a month before we spoke to him in October 2011 he had undergone a two day sleep study in hospital. During the week we had interviewed him, he had slept from Tuesday morning straight through to Thursday afternoon.

The results of the study are imminent, and he is anxious about what they might find. It is possible, he says, that he will be diagnosed with a combination of catalepsy and narcoplexy – sleep disorders. At the same time, his unusual sleeping pattern could just be because of the anti-convulsive medication he takes, in which case, he believes he may well be found fit to work when reassessed. He told us: ‘I don’t know how I’d hold a job down... If you looked at me you would think I was normal.’

In addition, shortly after we spoke to him in April, Philip was diagnosed with bipolar disorder. He is still waiting for his medication because cross-communication between the three different hospitals he attends has caused unexpected delays: his medication needs to be checked as there is a worry that it may clash with the medication he takes for his epilepsy.

Anticipating the imminent results of the sleep study is causing Philip ‘a great deal of anxiety’ about the next few months and the changes to his condition make him worry about how he could sustain employment. But at the same time he is uncomfortable with not being able to work and having to rely on benefits: ‘I’ve always felt very guilty about being on benefits. Does it cause me a guilt problem? Absolutely. Yes, it does.’

Steve: a social care user

They have to cut the deficit somehow but I don't see why they have to take it out on disabled people.

- *Steve is in his late 40s. He has secondary progressive multiple sclerosis, which has worsened over the last five years. He used to work, but retired because of his poor health and was given an early pension, worth £12,000 per year, in 2005.*
- *He lives with his wife, who works full time as a nurse.*
- *They have a mortgage but no other substantial debts.*

Steve receives:

- *Disability Living Allowance (DLA; high mobility, high care)*
- *Incapacity Benefit (IB)*
- *Direct payments for social care, which he uses to purchase 21 hours of home care per week*

The predicted losses of welfare reforms

Steve's benefits will be increased by a smaller amount than predicted this year – but the bigger impact of the cuts on Steve may be the reassessment of IB claimants, which began in April 2011. Jobcentre Plus told Steve about the impending reassessment last year, though in April Steve told us he was not concerned as he believed he will be moved into the Support Group, which is reserved for those who are not expected to find a job. Fortunately, and to Steve's massive relief, his reassessment has gone through this month and he has been placed in the Support Group in recognition of the complexity of his condition. Before he received this news, we asked him about the prospect of finding a job. He said: 'If they want to find me a job [I'll do it]. I don't think any employer is going to want someone who can't do anything.'

Steve has not yet received his new Support Group payments, but these will be slightly higher than his current rate of IB – he will be better off by £5.60 a week. In the meantime, Steve has received £101 less in income over the past six months as a result of the Government's less generous uprating system, in addition to the contributions he has to make to his care (which amount to more than £500).

Table 6 gives details of how the benefit reforms since April 2011 are affecting Steve and his wife.

Table 6 How the reforms to benefits from April 2011 affect Steve and his wife

Family benefits	Reforms to benefits from April 2011	Worse off between April 2011 and October 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, £22.22 worse off over six months
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)	£1.08 per week, £32.40 worse off over six months
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, £46.50 worse off over six months

Steve has lost £101.12 because of lower benefits and £517.65 in DLA payments towards his care since April 2011 – a total of £618.77 lost in six months.

What didn't we account for?

When we last spoke to Steve in April 2011, his local authority had just been in touch to inform him that he may have to contribute to the social care services he had been receiving. He would have to declare any savings he had, and how much income he received from his DLA. In *Coping with the Cuts*, we found around half of all local authorities were taking DLA into account as part of their care contribution rules, with varying levels of rigour. Some, like Steve's local authority, take a set amount automatically from a person's DLA income – others are more lenient and have a case by case approach, with each person contributing a different level

based on their income and disability related expenditure. Six months later, Steve now has to contribute £24.65 from his DLA care component in order to keep receiving his direct payments.⁶⁴ Steve's benefit income is set to be reduced substantially as a result of local authority budget cuts – he has already lost £517.65 of income since he began contributing his DLA in June 2011.

This has had a significant effect on Steve's life. He told us: 'That money [DLA care component] was in *addition* to the direct payments.' Like many disabled people who receive DLA, he uses it to help cover the extra costs he incurs from living with his impairment – costs like physiotherapy and maintaining specialist equipment. His powered wheelchair, which cost him around £8,000 and is provided privately, needs to be maintained – often at significant cost. The tyres need replacing, but they cost £71 each. Such items are often perceived to be provided by only a few suppliers and come at great expense: '£71 for a tyre for a power chair? I don't know how they [the supplier] can justify it!' As well as wheelchair-related costs, he also used to use his DLA to fund adaptations in his home and pay for a stairlift and specially adapted toilet. Now that his DLA care component has been reduced, he tells us he tends not to buy anything: 'I have to wait to get more money.'

No safety net – coping with financial shocks

Steve incurs significant extra costs as a result of living with his condition. He recently received an electricity bill for over £100, despite it being summer, which came as shock to him. Being disabled means he has higher utility bills than many non-disabled people: his electric wheelchair battery needs to be charged every 48 hours; his hoist, which he uses daily, needs plugging in frequently; even his television has to be left on standby, as once he is helped into bed by his carers he is unable to get up to turn it off.

Steve has recently spent the small amount of savings he had on home adaptations, including a ramp so that he can get out into the garden. Although he admits the work needed doing, he was prompted to make these changes because he (mistakenly)

thought he would not be eligible for social care support if he had any savings whatsoever. Steve's actions are a direct result of the lack of clarity and widespread confusion over the support systems that disabled people rely on. Lack of clarity, poor communication by the Government and lack of access to information and advice on benefits reforms and social care systems have a negative effect on disabled people, causing uncertainty and distress about the future, not least their financial implications.

Now that he has used up most of his savings, Steve has little in the way of any financial safety net: 'If anything does happen [in an emergency], I'll have to get a bank loan.'

When we asked Steve if he has tried getting other forms of support, he said he had been told that he is already receiving all the benefits he is eligible for. Thinking about the months ahead he is worried about further cuts to benefits: 'I suppose it's [the cuts are] inevitable... they have to cut the deficit somehow but I don't see why they have to take it out on disabled people.'

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

It has to be that you're at breaking point to actually get any help.

In our earlier research, reported in *Destination Unknown* and *Destination Unknown: Spring 2011* we interviewed Helen not as a 'typical' disabled person but as an illustration of how difficult life can be for some disabled people when relying on benefits and public services.⁶⁵ In 2010, Helen, who lives in Wales with her son, was concerned that her disability, and social services' limited support for her own and her son's disability, would lead to her son being taken into residential care. In April 2011, she was having difficulties with securing respite for her son, and trying to move from her poorly adapted house. When we revisited her in October, her housing problems had led her to take a drastic decision, which will have significant implications on her financial wellbeing.

- *Helen is a disabled woman who suffers from neuralgia, epilepsy, migraines and rheumatoid arthritis.*
- *She has a 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.*
- *Helen bears the burden of most of her son's care as her husband left the family a few years ago, unable to cope with his son's disability. Helen worked in the past but is now classified as long-term unemployed because she has to look after her son. They live in a council house and receive:*
 - *Disability Living Allowance (DLA; low mobility, middle care)*
 - *Incapacity Benefit (IB)*
 - *Child Benefit*
 - *Housing Benefit*
 - *Carer's Premium*

The predicted losses of welfare reforms

Like others in our case studies, all of Helen's benefits have been increased by a lower amount than before the Government's reforms. Helen also suffers a substantial loss because her Child Benefit has been frozen from April 2011 and her IB age addition has been cut from £15 to £13.80 per week. As of April 2011, she has been liable for reassessment and transfer to Employment and Support Allowance (ESA). Like Steve, it is possible she will be placed in the Support Group and receive a small increase in income, but she may well be moved into the Work Related Activity Group (WRAG) or indeed found ineligible for ESA. In April 2012, when we next report, we may have a better idea of Helen's reassessment status. Table 7 gives details of how the benefit reforms since April 2011 are affecting Helen and her son.

What didn't we account for?

When we spoke to Helen in the spring, she was in the midst of a 'continuous battle' for housing adaptations. She and her son live

Table 7 **How the reforms to benefits from April 2011 affect Helen and her son**

Family benefits	Reforms to benefits from April 2011	Worse off between April 2011 and October 2011?
Disability Living Allowance (Helen) – low mobility	Benefit increased by CPI instead of RPI – from £18.95 in 2010 to £19.55 per week (CPI), instead of £19.82 (RPI)	27p per week, £8.10 worse off over six months
Disability Living Allowance (Helen) – 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, £20.70 worse off over six months
Disability Living Allowance (Helen's son) – high mobility	Benefit increased by CPI instead of RPI – from £49.85 to £51.40 per week (CPI), instead of £52.14 (RPI)	74p per week, £22.22 worse off over six months
Disability Living Allowance (Helen's son) – high care	Benefit increased by CPI instead of RPI – from £71.40 to £73.60 per week (CPI), instead of £74.68 (RPI)	£1.08 per week, £32.40 worse off over six months
Incapacity Benefit (plus £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, £81.90 worse off over six months; 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, £32.70 worse off over six months

Table 7 **How the reforms to benefits from April 2011 affect Helen and her son – *continued***

Family benefits	Reforms to benefits from April 2011	Worse off between April 2011 and October 2011?
Carer's Premium	Benefit increased by CPI instead of RPI – from £30.05 in 2010 to £31 per week (CPI), instead of £31.43 (RPI)	43p per week, £12.90 worse off over six months
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, £27.90 worse off over six months

Helen and her son have lost £238.82 over the past six months.

in a council house, which she says has been identified by the local authority as being unsuitable for her and her son's needs. She had long been on the waiting list for an adapted bungalow. Six months since we last spoke to her, she is still waiting, but her son's needs have become more complex following recent operations, so the house has become even more unsuitable.

Helen told us that she recently discovered that suitable properties had become available in the nearby area. These were managed by a private housing provider, which works with the local authority to provide adapted homes. On enquiring about whether she and her son would be able to move into one of the newly available bungalows, Helen was told that they would not be considered eligible as her son was not in a wheelchair. But although he is able to walk, he is a danger to himself and at risk of falling downstairs, or pushing someone down them. Helen has decided to take matters into her own hands and move into a different property, and rent privately.

This change will have a big impact on the family's income. Had they been able to move into the adapted bungalow, the rent would have been covered by their Housing Benefit. But renting

the property into which they are about to move will cost £400 a week *more* than the amount her Housing Benefit will cover, as the amount she receives is set at the two bedroom rate (as Helen is a resident carer for her son, she is not entitled to an additional amount to pay for a third bedroom, which the Government has introduced for non-resident carers). Nonetheless, as Helen's son needs two-to-one care, Helen has decided to rent a bungalow with an additional (third) bedroom for a carer. The additional rent is a significant sum of money for her, and Helen says she will have to use her son's trust fund, which was established with the money from her ex-husband following their divorce.

On top of the extra rent, Helen will also have to use her son's trust fund to pay for adaptations to the new property. She told us that local occupational therapy services would be able to carry out the adaptations, but would need four to five months' notice to do so. As her son has multiple, complex needs, the property needs urgent attention; she cannot afford to stay in the council house and pay rent for two properties as they wait for the adaptations to be made to their new home.

Moreover, if she moves to the private property, she will be moved down to the bottom of the waiting list for an adapted bungalow, despite having waited for one for seven years already. She told us: 'I feel I'm being threatened to stay in this house... This is a very awkward situation I have been placed in.'

The family's housing problems are compounded by continuing problems arising with her son's care needs. When we first interviewed Helen in 2010, she told us that although social services had told her he needed two-to-one care, she had had no legal statement in writing to say that the social services would meet this need. Staff insisted on naming her as one of the carers, saying that if she cannot cope he will have to be taken into care. When we last spoke to her earlier this year, she was resorting to using her own direct payments to purchase care for her son to give her some respite. She had received an apology from social services, but was pressing ahead with a court case to secure more care for her son. Six months later, and still there is no care plan in place, though court proceedings are well under way. She told us, 'I feel I have no other option... to ensure my son's [care]

needs are met.’ The family has ‘an extremely difficult relationship with social services’, which, she says, does not care about her son’s needs or future, only about the budget.

As documented in our last report, Helen used to receive four hours of respite care from a children’s charity but these had been withdrawn after her son had had a tantrum and the carers were unable to manage him. Helen has pursued this with the charity but says that this still hasn’t been resolved.

The months ahead will almost certainly be turbulent times for Helen and her son. The outcome of the court case with social services is due soon; the move to a new property will have a dramatic impact on the family’s income and wellbeing. Helen describes the foreseeable future as ‘an absolute nightmare... It has to be that you’re at breaking point... to actually get any help.’

What have we seen? An overview

In our first update report in April this year, we felt we could categorise the information the disabled people in our case study shared with us in four ways:

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

In this report, six months on, two new important themes are beginning to emerge. In addition to the financial vulnerability of the households in our study, we have seen the unexpected negative effect of bureaucracy, leading to administrative errors and delays, and the complexity of the health and care and benefits systems causing financial hardship and emotional distress.

We are also starting to see how some disabled households are resorting to charity and family support in the absence of state

help – and how these sources are proving unsustainable and quickly being exhausted, leaving them with nowhere left to turn.

How increasing benefits by CPI have affected some disabled households over the past six months

Table 8 shows the amount the households in this study have lost as a result of the lower than expected increases in their benefit income from April 2011 to October 2011.

Table 8 **The financial loss to households in our case studies following the change to their benefit income from April to October 2011**

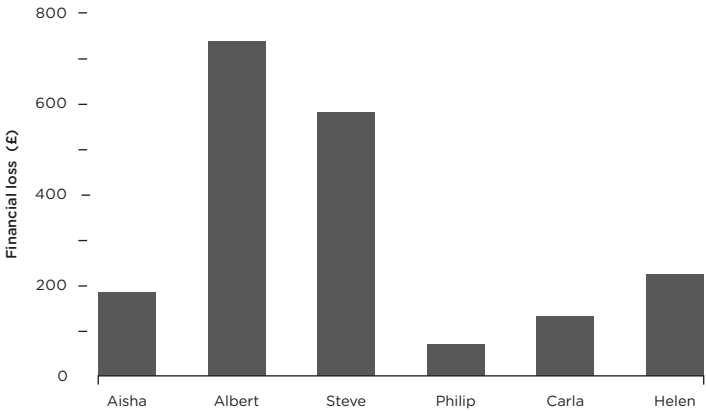
Household	Financial loss	Proportion of benefit income
Aisha and her parents	£199.52	2.5%
Albert and his wife	£300.45 (of £781.55 total)	2.8% (7.19%)
Steve	£101.12 (of £618.77 total)	1.54% (9.4%)
Philip	£74.70	1.52%
Carla	£140.10	1.5%
Helen and her son	£238.82	2.68%

To this we must add other reductions in income brought about by ad hoc reforms. For example, because Albert and his wife's benefits were reduced as a result of her new pension income, the couple has lost more than 7 per cent of their income in six months. And this does not even include the reduction of nearly £200 per month in Support for Mortgage Interest (SMI) payments made to them.

As Steve now has to contribute to his care he has lost almost 10 per cent of his income. These are highly significant amounts – the equivalent would be someone on an average wage of £24,000 per year being docked £1,128 from their paycheck every six months – £2,256 in a year or £188 per month.

It is also interesting to note that the Government's decision to uprate benefits according to CPI instead of RPI should have

Figure 1 Financial loss in benefit income for households surveyed from April to October 2011



led to an overall reduction in benefits of 1.5 percentage points. It is clear that the impact on disabled households is larger, and far more varied, as a result of different rules applying to some benefits (for example, benefit freezes).

Figure 1 shows the total financial loss in benefit income to the households in our study over a six-month period.

Additional reforms with a larger impact and unpredictable effects of cuts

Albert and his wife rely on 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 nearly £200 less support per month. Clearly Albert and his wife have a mortgage which is not at today's 'average' interest rate of 3.63 per cent – they are now facing eviction because of this SMI shortfall.

Albert, Carla, Steve and Helen are claiming Incapacity Benefit, and are all now due for reassessment and will be transferred onto Employment and Support Allowance (ESA) – Steve has already been reassessed and placed in the Support Group. Philip is currently claiming ESA, but has just six months left before he is moved onto income-based ESA (if he passes the means test).

All the disabled people in our study claim Disability Living Allowance (DLA). Assuming the Disability Alliance's estimations are correct and those claiming a low-rate of DLA may be ineligible for the new two-level Personal Independence Payment (PIP) benefit as part of the Government's plan to reduce DLA costs by 20 per cent, some of them may be at risk of losing this benefit when PIP is rolled out in 2013 – they include Carla, Philip and Helen, who all claim the low rate of the mobility element of DLA.⁶⁶

Perhaps the most significant changes to two of our case study households have been caused by cuts we were unable to predict. The first is Albert and his wife's imminent eviction from their home of ten years, a direct result of the Government's reduction in SMI payments, and their significant £33 weekly loss in benefits as a result of Albert's wife's pension income; the second is Steve's substantial £24.65 per week loss in income after his local authority's care contribution rules became less generous and required Steve to contribute almost half of his DLA towards his care costs.

Difficulty in dealing with financial shocks

As in our April report, we were struck by how precarious the financial situations of the households in our study were – they had little or no protection against unexpected costs, such as the need for repairs or payment of unexpectedly large bills. This theme continues in this latest report, as we see Steve's savings wiped out and other households accumulating more debt. Albert and his wife are dreading winter and the utility bills that will come about because they need to keep warm, made worse by their broken window frames, which they do not have the money

to repair. Steve does not know how he will pay for the replacement tyres on his electric wheelchair. This financial insecurity is compounded by fluctuations and deteriorations in health conditions: Albert and his wife, Aisha's mother, Philip and Helen's son all report worsening health since we spoke to them in April, demonstrating how vulnerable disabled people can be to changes in their circumstances and ability to work.

But the effects of budget cuts in the wider environment are also making themselves felt – Carla is facing the prospect of losing her freedom pass, and believes her benefits agency closed through lack of funding. Her local law office looks set to close for the same reason. A charitable trust has told Albert it cannot help with his water bill two years in a row because it is inundated with new claims for financial assistance, while his local NHS trust has refused to provide him with a community psychiatric nurse through lack of funds, and told him to go to a charity instead. Aisha's family is facing increased delays and difficulty in securing physiotherapy services and equipment. All these wider events are serving to make life more difficult and stressful for disabled people.

The impact of bureaucracy, administrative error and lack of understanding of benefits and care systems

As we follow the households in our study it is becoming increasingly clear that the complexity of the benefits and care and support systems they must navigate is causing emotional distress and financial hardship. Both Aisha's mother and Helen describe the 'fights' and 'battles' they have in securing support they need for themselves and their children, and this is proving to be frustrating and draining.

Aisha's parents are fighting on several fronts: they have fought to have her room adapted properly, and are still fighting to have her lunchtime supervision need made a duty on her SEN statement, and to receive her standing frame, which is six months late. This follows from their 'fight' last year to receive an extra hour of care in the mornings to help Aisha get to school. Helen, too, has had an 'ongoing battle' to be moved to a more suitable

property, only to have recently given up and opted for the considerably more expensive route of renting privately. Yet her legal case – another battle – to secure more care for her son still goes on.

Other households have been penalised through no fault of their own. Albert and his wife's SMI was suspended between June and October following an administrative error – no doubt exacerbating the situation and will result in them being evicted in February 2012. This is reminiscent of Helen's difficulties earlier this year when, through administrative error, her direct payments were stopped and she became overdrawn without spotting the error. Carla found that her benefits agency closed down, without her being informed – leaving her with unpaid maintenance and insurance charges. Philip has still not received the correct medication for his mental health condition because of the poor communication between hospitals.

These events might be inconvenient for any household, but such disruptions and delays can have a disproportionate impact on the finances and health of those with no savings as a financial cushion, or with physical and mental conditions which require consistent support. Aisha's mother's mental health has deteriorated since we last spoke to her, because of the stress of fighting for the right support for Aisha. Carla and Philip are both very anxious about the prospect of medical reassessment. We are concerned that in the months ahead – as all of the disabled people in our study face a reassessment of some sort – the risk of administrative disruption (not to mention the added stress and uncertainty) may prove too much for some of them, who each have to deal with unpredictable health conditions already. Moreover, in the next two years, the largest change to the benefits system since its inception will be ushered in – the Universal Credit. This is likely to cause significant disruption during the transition phase, but we are more concerned by the lack of communication the Government has engaged in to help those most affected by these changes understand what is going to happen and prepare accordingly.

No doubt as a direct result of the complexity of the systems they have to navigate, many of the disabled people in our study

are unaware of the ongoing benefits changes and how they will be affected. Carla had never heard of ESA and was shocked at the prospect of reassessment – despite this replacing Incapacity Benefit back in 2008. She will soon be transferred onto this benefit from Incapacity Benefit but she did not know about it at all. Philip, too, did not know about the time limitation of the ESA Work Related Activity Group (WRAG) he is claiming, while Steve believed he had to spend his savings in order to remain eligible for the social care package he is receiving. The Government clearly needs to do more to reach disabled people and provide information and advice so that such misunderstandings do not occur, and to ease the sense of uncertainty and confusion about the future, as this was a consistent theme in the conversations we had with disabled people in our study.

Other ways of coping

The final development we are now witnessing is that several of the households in our study have sought different sources of financial assistance when faced with a reduction in state support. In itself this could be a positive development – indeed, it is at the heart of the Government’s vision of the Big Society that people should be able to support themselves within their communities with the help of the voluntary and community sectors. However, such a development poses its own risks, if it were to be used to justify the removal of the fundamental safety net provided by the welfare state. The findings in this report suggest that supplementing welfare support with non-state alternatives is neither adequate nor sustainable in the current financial climate, and that the Big Society in practice falls short of the Government’s vision of it.

Aisha’s family has turned to a support scheme run by Aisha’s father’s employer, and held a fundraising event in their community to raise funds for Aisha’s new wheelchair, while Albert and his wife managed to secure a charitable grant to pay their water bill.

But it is clear these are one-off emergency measures, which are not sustainable and do not constitute an ongoing source of

support. Albert and his wife attempted to reapply for the charitable grant this year and were refused, as the charity is ‘inundated’ with requests for help. As funding for voluntary and charitable organisations is cut alongside budgets for state services, so the theory of the Big Society rings hollow – community support can never be an adequate replacement of the welfare state, and even as a supplement it is only viable if community support organisations are adequately funded. Albert’s health trust told him to ask a charity to provide a community nurse as the local NHS could not afford to provide him with one. But what if there are no local charities able to help Albert, because of cuts to their grants leading to their closure or cutting back on who they support? Carla’s local law agency faces closure – the same agency which she credits with ‘saving her life’ by securing her the benefits she was entitled to. What happens if, when Carla is reassessed and moved onto ESA in the coming months, she needs further vital legal advice? Where will she turn? Scope’s own recent research suggests the Government’s cuts to legal aid will lead to around 78,000 disabled people each year being unable to afford to appeal benefits eligibility decisions.⁶⁷ As around 40 per cent of appeals against ESA decisions are upheld and ESA is awarded, this would suggest that a large number of disabled people will be denied funding that is rightfully theirs as a result of this change.

Others in our study – Helen, Philip and Steve – have taken different routes. Philip has borrowed a substantial sum from his brother, and is being ‘exceptionally frugal’ in order to pay off his debts. Steve, who has now used up his savings, says he will simply not buy things until he has more money, or gets a loan. Helen has decided to use her son’s trust fund in order to rent a suitable house for them. None of these options seems sustainable in the longer term without significant negative effects on Helen, Philip and Steve’s physical and mental wellbeing.

We are concerned that, as the disabled people in our study exhaust their non-state options for financial support, and as these options are becoming scarcer or over-stretched, they will soon be left with nowhere to turn. Albert’s benefits do not cover his water bill. The charity cannot afford to help him meet this

payment. Where will Albert turn next? Aisha's family has already resorted to fundraising from their community to buy a wheelchair – they cannot expect their friends and neighbours to continue to maintain the family when another large unexpected cost arises. And Helen's son's trust fund is a finite amount of money – what happens when this is used up and Helen can no longer afford to rent privately? We expect to see some of the households facing extremely difficult situations by April 2012.

Table 9 summarises the financial effects and unexpected impacts of the changes in benefit income on the households in our study.

Table 9 **The effects on the households in our study of the change to their benefit income from April to October 2011**

Case study	Lost income between April 2011 and October 2011 update reports	Unexpected impacts from service cuts and reforms we had not taken into account	Financial shocks and administrative complexity	How are they coping?
Aisha and her parents	£199.52	Delay in receiving standing frame; council refusal to pay for wheelchair	Disagreement over Aisha's SEN statement; unpaid leave annual occurrence	Help from employer and community fundraising, cutting back on travel (missing medical appointments)
Albert and his wife	£300.45 due to lower benefits; £781.55 in total	Pension led to drop in benefit income of £33 per week; no community nurse available	House repairs still outstanding; SMI payments delayed for three months; now £13,000 in arrears; eviction in Feb 2012	Charitable grant to cover water bill – one-off measure

Table 9 **The effects on the households in our study of the change to their benefit income from April to October 2011 – *continued***

Philip – single man	£74.70; only six months to claim ESA WRAG benefit		Bipolar disorder and sleep study results shortly after delay in receiving correct medication	Borrowing from family and cutting costs to a minimum
Carla – single woman	£140.10; Incapacity Benefit due for reassessment	Possible loss of freedom pass (free travel)	Closure of benefits agency left bills unpaid	
Steve – a social care user	£101.12 due to lower benefits; £618.77 total; transferring to ESA	Contribution of DLA to care costs from June – £517.65 worse off so far	Replacement of wheelchair tyres, £71 each; £4,500 on adaptations	Used up savings; will resort to a loan if necessary.
Helen and her son – in extremis	£238.82 Incapacity Benefit due for reassessment	Inability to access suitable council housing – seven-year waiting list	Legal challenge to secure more care for her son	Using her son's trust fund to rent privately

3 Conclusions, recommendations and a look ahead

First and foremost, we have a clear impression from speaking to the people in our study that uncertainty and confusion about the benefits and care and support systems are rife, particularly in the midst of the introduction of so many new reforms and changes. When carrying out this study we found that Carla had never heard of Employment Support Allowance (ESA), though it has been in place for three years; Philip had no idea his benefit was now time limited; and Steve assumed he had to have no savings in order to be eligible for care funding. This lack of awareness of the ongoing reform process, combined with the ‘battles’ disabled people report in securing the benefits and support they are entitled to, all suggest that the Government needs to think seriously about how it is communicating the reform agenda to ensure those most affected by it – disabled people and in particular those disabled people who are unemployed – are fully aware of the implications of these changes.

The Universal Credit is the most significant change to the welfare system since it was created 60 years ago, and is being brought in partly in response to the Government recognising how complex the benefits system has become. But this does not mean the transition to this new system will be simple – far from it. It is vital that people are prepared for this change with proper levels of information and hands-on support so they receive everything to which they are entitled.

More fundamentally, the Government must engage in a more open and frank discussion on what people should expect from the welfare state. The Coalition Government and the opposition both talk about ‘something for something’ when discussing welfare payments, suggesting there is a growing

consensus across the political spectrum that welfare is a conditional privilege, rather than a right for those – such as disabled people – who are vulnerable and unable to support themselves adequately. This is concerning, as such a view undermines the original purpose of the welfare state when it was founded 60 years ago. Moreover, while this has been expressed at senior government level, it has yet to be articulated in a way that makes sense to those most affected by this political shift – disabled people. The confusion and uncertainty among the disabled households in our study – generated by the public pronouncements of senior government and opposition spokespeople without any detail provided to those with the most at stake – is clearly causing emotional distress.

Mitigating the worst effects of the cuts on disabled households

The findings from this second update report are starting to create a more varied picture of the lives of disabled people through a period of welfare and local service cuts. In the original *Destination Unknown*, we made several recommendations designed to mitigate the worst effects of welfare reform for disabled people over the long term. In our first update report, we made specific recommendations relating to the challenges disabled people were facing in April 2011, which pointed to new issues emerging which required attention if the Government hoped to avoid driving disabled households further into untenable financial situations and critically undermine their quality of life. These were some of our recommendations in April:

- Scrap the proposal to limit ESA Work Related Activity Group (WRAG) claims to one year.
- Maintain the local authority duty to provide community care grants and crisis loans, and ringfence this funding.
- End the inclusion of Disability Living Allowance (DLA) as a contribution to social care funding.
- Review the single rate of Support for Mortgage Interest (SMI) payments and consider the claims of each case.

- Ensure assessment for the new Personal Independent Payment (PIP) reflects costs, not just a determinant of ‘need’.
- Carry out a proper review of local level cuts.⁶⁸

A bleak outlook

In light of our latest findings, we believe the case for each of these recommendations is stronger than ever. For example, the one size fits all approach to SMI payments was seen as overly generous by the Government when set at 6.08 per cent (it meant that when this rate was higher than the rate charged by a homeowner’s lender, people receiving these payments were able to cover their mortgage interest payments and put a small amount towards their arrears or capital repayments.) But now, setting SMI universally at such a low alternative (3.63 per cent) is a highly damaging approach – this rate is recorded as historically extremely low,⁶⁹ a direct result of the credit crunch and the Bank of England base rate being set at an unprecedented 0.5 per cent in an attempt to boost the economy. Only once in the ten years before the recession did the base rate fall below 4 per cent, in 2003.⁷⁰ This would suggest that, for the majority of people with mortgages receiving SMI, 3.63 per cent is far below their actual lending rate. We are gravely concerned that many other disabled people across the country are in a similar predicament to Albert and his wife who, within a year of the SMI rate being cut, have been served with an eviction notice.

All the disabled people in our study receive DLA, and the range of living costs they report which are related to their disability (from transport and childcare to utilities and equipment) illustrates very well how living with a disability can be very expensive. It is clear from this handful of households that the costs of living with a disability are extremely varied and do not always coincide with the complexity of a condition or level of care required. We doubt the PIP assessment, as currently configured, is nuanced enough to recognise this. We are concerned that people like Steve may find the new PIP assessment will not recognise that although he is mobile thanks to his powered wheelchair, maintaining it costs £71 every time he

needs a new tyre, not to mention recharging the battery every 48 hours.

Unfortunately, we have seen little if any progress on these six fronts: our research suggests increasing numbers of local authorities are including DLA income into their care contribution calculations in order to cope with the significant budgetary reductions imposed on them by central government. We remain hopeful that next year's social care white paper may introduce a more coherent and fairer social care funding system, whereby working age adults will not have to contribute to their care at all.⁷¹ Nonetheless it is likely that the reduction of DLA for social care users will become standard practice in the intervening years of budgetary restriction before a new system is implemented.

In light of the ongoing financial shocks the households in our study are suffering and the limited alternative sources of support that are available, it is vital to maintain nationally guaranteed access to community care grants and crisis loans rather than devolving them to locally discretionary (and non-ringfenced) pots and removing the local duty to provide this support, but nonetheless, the Government is pressing on with this plan. Similarly, the Government has not reconsidered its reform of SMI, and no doubt many thousands of people who happened to have secured their mortgage during a time of high interest rates will find themselves accumulating significant arrears.

But perhaps most importantly, the section of the Welfare Reform Bill related to the time limitation of contributory ESA WRAG to a year has passed the Grand Committee stage without amendment, after Lord McKenzie's proposed amendment to make the time limit at least two years was rejected by the Lords in early November.⁷² It is now highly likely this section of the Welfare Reform Bill will be implemented, in spite of widespread concerns voiced by MPs and Lords alongside disability charities and commentators on the arbitrary and unnecessarily punitive natures of this measure.⁷³ People like Philip may soon find themselves unable to claim a contributory sickness benefit in spite of having worked and contributed throughout their working lives.

This will take into account longer-term inflationary trends and avoid the arbitrary nature of setting the uprating rate according to some other measure. We do not believe setting benefits according to average wage increases is a helpful approach. We must remember those on benefits are on lower – often far lower – incomes than those in work, and so are more sensitive to increases in costs of living, which CPI reflects more accurately than average wage increases. Moreover, working adults have the opportunity to increase their income relatively easily by changing jobs or indeed working longer hours, whereas the income of a person on benefits is fixed, if they are unable to work. This lack of opportunity to increase one's income in the face of rising living costs is why benefits must meet the costs of living, rather than wages. Several of the people in our study are keen to work – Philip is extremely frustrated by his benefits dependency; Aisha's father refuses to give up work even though he might be able to access more support if he was unemployed; and even Steve, who has now been assessed by the Government as unable to work and placed in the ESA Support Group, is open to the prospect of work if an employer would accept him and find something he could do.

A longer-term view

In the face of extremely worrying developments among the disabled people we spoke to it is tempting to be drawn into the most pressing reform issues, which are having a devastating impact on their financial, physical and emotional wellbeing – DLA reform, the time limitation of ESA, blanket reductions of SMI payments, and so forth.

However, we should take a step back and consider the underlying problems which have prompted the Government to embark on such a radical reform and deficit reduction agenda. The Government is seeking to reduce benefits dependency and 'incentivise work' by reducing benefits. However, a lack of willingness to work is not the problem for those we covered in our case studies. Rather, their problems stem from difficult to manage and unpredictable conditions, which means suitable jobs

are harder to come by, and lacking the skills and confidence to rejoin the labour market. We remain highly doubtful that reductions in benefit payments, without a commensurate increase in welfare to work support, will lead to an increase in disabled people finding work – particularly in this unhealthy labour market.

We therefore repeat our call, first made in *Destination Unknown* in 2010, for an expansion of access to Work Choice, the tailored and modular work support programme for disabled people with a strong track record for securing sustained employment.⁷⁴ Current access to Work Choice is extremely limited, reserved for those with ‘most difficulties’ – estimated to be around 13,000 people per year,⁷⁵ while the rest rely on the mainstream Work Programme. We are not convinced the Work Programme will provide adequate specialist support for all disabled people, reliant as it is on large prime providers 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 (particularly those with mental health problems), and also identified a lack of local specialist groups to assist them with this task.⁷⁶ Recent reports suggest that prime providers are indeed not meeting the needs of vulnerable job seekers, and instead are placing increased burden and transferring risk to their voluntary sector sub-contracted partners, with reports that many are being expected to assist job seekers in return for no payment.⁷⁷ Increasing access to the specialist and highly effective support Work Choice can provide is even more critical now that ESA WRAG payments are time limited – those able to work, given only one year to secure employment, should be given all the specialist support they can get.

A look ahead to spring 2012

In the six months between *Destination Unknown*, published in October 2010, and our first update report, *Destination Unknown: Spring 2011*,⁷⁸ several new policies have been announced. 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 DLA and the introduction of the PIP
- time-limiting contributions-based 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, in April 2011 disabled people had yet to feel the effects of many of these reforms – benefits were uprated by the lower inflation rate (CPI) for the first time in April, and the Incapacity Benefit reassessments, time limitation of WRAG ESA and housing benefit caps had only just begun. Moreover, local authority budgets were only set in April 2011. With all this taken into account, we viewed our April 2011 report as ‘the calm before the storm’ – with only small initial losses and hardship reported. Even then, some of the households in our case studies had already experienced dramatic changes to their lives.

In this report, we have seen local budget cuts taking effect – disabled people are struggling to get equipment, being refused community health services, and having to contribute a proportion of their benefits to services which had hitherto been free. Moreover – and unlike in our April report where we could only predict losses over 2011 – we now have concrete figures on how much worse off the households in our study are in the six months since benefit reforms started to be implemented. These losses range from £74.70 to a highly significant £781.55, and some disabled people are now reporting they have to choose between fuel and food, cancelling appointments as they are unable to afford transport costs, and leaving their houses to fall into disrepair. It is clear that with each passing month, the financial resilience of disabled people decreases – savings are wiped out, debts accumulate, one-off emergency grants are used up.

In six months’ time, April 2012, we will revisit the households in our case studies. We expect to see some significant – life changing – events occurring to the households in our study:

- Incapacity Benefit reassessments are being rolled out across the country, with Albert, Carla, Steve and Helen all liable for reassessment and being moved onto ESA or Jobseeker's Allowance (JSA). We would expect Steve to have been reassessed by next April – he has already received his form.
- Albert and his wife will have moved out of their home of ten years, after accumulating £13,000 in mortgage arrears.
- Philip will have his contributory ESA stopped, and will be no doubt be facing reassessment for eligibility for the means-tested income-based ESA.

However, while these are all 'predictable' negative outcomes, the more significant risks the households in our study face are those we are unable to foresee.

Time and again, we have found that the losses we predict are only the tip of the iceberg. For example, we feared Albert and his wife might lose their home as they fell further into arrears, but we could not predict their loss of income resulting from Albert's wife receiving her pension. We had no way of knowing that Steve would live in a local authority that decided, in order to cope with budgetary reductions to social care services, to ask him and other DLA claimants to contribute £24.65 per week to their care costs. And we did not expect that after seven years of being on a waiting list for a suitable property, Helen would take the drastic step of renting privately, with significant implications for her and her son's financial security.

If these unexpected and life changing events occurred in the last six-month period, we dread to think what new developments may await us in April 2012.

Notes

- 1 C Wood and E Grant, *Destination Unknown*, London: Demos, 2010.
- 2 C Wood, P Cheetham and T Gregory, *Coping with the Cuts*, London: Demos, 2011.
- 3 C Wood and E Grant, *Destination Unknown: Spring 2011*, London: Demos, 2011.
- 4 Ibid.
- 5 Opening remarks by Carl Emmerson at IFS briefing on the October 2010 spending review, Institute for Fiscal Studies, 21 Oct 2010, www.ifs.org.uk/budgets/sr2010/opening_remarks.pdf (accessed March 2011).
- 6 Richard Hawkes, quoted in 'The social policies we want from a new government', *Guardian*, 7 Apr 2010, www.guardian.co.uk/society/2010/apr/07/election-2010-social-policy-government (accessed 21 Nov 2010).
- 7 Wood and Grant, *Destination Unknown*.
- 8 Wood et al, *Coping with the Cuts*.
- 9 Employment and Support Allowance (ESA) claimants are assessed via the Work Capability Assessment (WCA) and, depending on the result of this assessment, are allocated to either the Work Related Activity Group (for those thought able to work in the near future, but not immediately) or the Support Group (for those believed unable to work and who do not have to undertake any mandatory work related activity).

- 10 P Curtis, R Ramesh and S Bowers, 'George Osborne facing budget backlash', *Guardian*, 21 Jun 2010, www.guardian.co.uk/uk/2010/jun/20/george-osborne-facing-budget-backlash (accessed Mar 2011).
- 11 George Osborne, quoted in T Onanuga, 'Emergency budget: George Osborne's speech in full', *Guardian*, 22 Jun 2010, www.guardian.co.uk/uk/2010/jun/22/emergency-budget-full-speech-text (accessed March 2010).
- 12 R Chote, 'Opening remarks', presentation from IFS lunchtime briefing, 23 Jun 2010, <http://ifs.org.uk/projects/330> (accessed Aug 2010).
- 13 R Ramesh and A Butler, 'Budget 2010 losers: women, disabled and families bear the brunt', *Guardian*, 23 Jun 2010, www.guardian.co.uk/politics/2010/jun/23/budget-2010-losers-women-disabled (accessed Aug 2010); N Watt, 'Benefits: families and disabled people will be hit by "Thatcherite" cuts', *Guardian*, 23 Jun 2010, www.guardian.co.uk/society/2010/jun/23/benefits-disabled-families-thatcher (accessed Aug 2010); Theresa May, quoted in A Jamieson, 'Theresa May warned Chancellor his budget could hit women hardest', 5 Aug 2010, *Telegraph*, www.telegraph.co.uk/news/newstoppers/politics/conservative/georgeosborne/7927623/Theresa-May-warned-Chancellor-his-Budget-could-hit-women-hardest.html (accessed Aug 2010).
- 14 Opening remarks by Carl Emmerson at IFS briefing on the October 2010 spending review.
- 15 Ibid.
- 16 Ibid.
- 17 Dept for Work and Pensions, 'Time limiting contributory Employment and Support Allowance to one year for those in the Work Related Activity Group: equality impact assessment', Oct 2011, www.dwp.gov.uk/docs/eia-esa-time-limit-wr2011.pdf (accessed Nov 2011).

- 18 HM Treasury, *Spending Review 2010*, Cm 7942, Norwich: The Stationery Office, 2010, http://cdn.hm-treasury.gov.uk/sr2010_completereport.pdf (accessed 6 Apr 2011).
- 19 Mencap, 'Charities fight cut to DLA mobility component', 20 Jan 2011, www.mencap.org.uk/news.asp?id=20623 (accessed 6 Apr 2011).
- 20 A Barker, 'Welfare bill ditches housing benefit cut', *Financial Times*, 17 Feb 2011, www.ft.com/cms/s/0/3047362e-3a26-11e0-a441-00144feabdco.html#axzz1HPQfSPFt (accessed 6 Apr 2011).
- 21 Dept for Work and Pensions, 'Disability Living Allowance reform: equality impact assessment', Oct 2011, www.dwp.gov.uk/docs/eia-dla-reform-wr2011.pdf (accessed Nov 2011).
- 22 House of Commons, *Welfare Reform Bill: Explanatory notes*, Bill 154-EN, London: The Stationery Office, 2011, www.publications.parliament.uk/pa/cm201011/cmbills/154/en/11154en.pdf (accessed 6 Apr 2011).
- 23 Ibid.
- 24 Ibid.
- 25 Wood and Grant, *Destination Unknown: Spring 2011*.
- 26 Dept for Work and Pensions, 'Household Benefit Cap: equality impact assessment', Oct 2011, www.dwp.gov.uk/docs/eia-universal-credit-wr2011.pdf (accessed Nov 2011).
- 27 Ibid.
- 28 P Kenway et al, *Working-age 'Welfare': Who gets it, why, and what it costs*, York: Joseph Rowntree Foundation, 2010, www.jrf.org.uk/sites/files/jrf/working-age-welfare-summary.pdf (accessed 6 Apr 2011).

- 29 Dept for Work and Pensions, 'Time limiting contributory Employment and Support Allowance to one year for those in the work-related activity group'.
- 30 A Gentleman, 'Mobility allowance glee is premature', *Guardian*, 22 Feb 2011, www.guardian.co.uk/society/joepublic/2011/feb/22/mobility-allowance-u-turn-glee-premature (accessed Feb 2011).
- 31 Dept for Work and Pensions, 'Abolition of concessionary Employment and Support Allowance (ESA) 'youth' National Insurance qualification conditions: equality impact assessment', Oct 2011, www.dwp.gov.uk/docs/eia-esa-youth-provisions-wr2011.pdf (accessed Nov 2011).
- 32 National Housing Federation, 'New rules could price thousands of disabled people out of their homes, Federation warns', 23 Mar 2011, www.housing.org.uk/news/up_to_108,000_disabled_people.aspx (accessed 6 Apr 2011).
- 33 Ibid.
- 34 Dept for Work and Pensions, *Personal Independence Payment: Initial draft of assessment criteria*, 2011, www.dwp.gov.uk/docs/pip-draft-assessment-criteria-note.pdf (accessed 22 Nov 2011).
- 35 DWP, *Personal Independence Payment: Second draft of assessment regulations*, Dept for Work and Pensions, 2011, www.dwp.gov.uk/docs/pip-second-draft-assessment-regulations.pdf (accessed 22 Nov 2011).
- 36 Work and Pensions Committee, Written Evidence, Proposal to replace Disability Living Allowance with Personal Independence Payment, Sep 2011, www.publications.parliament.uk/pa/cm201012/cmselect/cmworpen/writtev/1493/contents.htm (accessed Oct 2011).

- 37 Disability Rights Partnership, *End of a Lifeline: Ending Disability Living Allowance to introduce Personal Independence Payment, DLA reform consultation response*, London: Disability Rights Partnership, 2011, www.disabilityalliance.org/r68.doc (accessed Oct 2011).
- 38 E Grant, *The Future of PIP: A social model-based approach*, London: Scope, 2011, www.scope.org.uk/sites/default/files/The%20Future%20of%20PIP%20-%20A%20Social%20Model%20Based%20Approach.pdf (accessed Oct 2011).
- 39 C Wood and E Grant, *Counting the Cost*, London: Demos, 2010.
- 40 Work and Pensions Select Committee, *Hansard*, Oral evidence, 19 Oct 2011.
- 41 Liberal Democrats Autumn Conference, Conference Daily, Saturday 17 September 2011, www.libdems.org.uk/siteFiles/resources/docs/conference/CD%20Saturday.pdf (accessed 15 Nov 2011).
- 42 P Butler and S Bates, 'Terminally ill patients told their benefits may be cut', *Guardian*, 21 Sep 2011, www.guardian.co.uk/politics/2011/sep/21/terminally-ill-told-benefits-cut?CMP=twt_gu (accessed Oct 2011).
- 43 House of Lords, Grand Committee, Welfare Reform Bill, *Hansard*, Debates, 8 Nov 2011, www.publications.parliament.uk/pa/ld201011/ldhansrd/text/111108-gc0001.htm (accessed Nov 2011).
- 44 Dept for Work and Pensions, 'Conditionality under Universal Credit: the work search and work availability requirements', Universal Credit policy briefing note 12, Oct 2011, www.dwp.gov.uk/docs/ucpbn-12-work-search.pdf (accessed 21 Nov 2011).
- 45 *Ibid.*

- 46 'Lord Low's review urges Government to save mobility payments for disabled people living in residential care', press release, <http://mobilityreview.files.wordpress.com/2011/07/press-release.doc> (accessed Nov 2011).
- 47 'Spending review: council cuts to be "front loaded"', BBC News, 21 Oct 2010, www.bbc.co.uk/news/uk-england-derbyshire-11602938 (accessed 6 Apr 2011); 'Round-up: spending review', *Money Observer*, 20 Oct 2010, www.moneyobserver.com/news/10-10-20/round-spending-review (accessed 6 Apr 2011).
- 48 Wood and Grant, *Destination Unknown: Spring 2011*.
- 49 'Spending review: care cuts "may hit hospital beds"', BBC News website, 23 Oct 2010, www.bbc.co.uk/news/uk-politics-11611423 (accessed 6 Apr 2011).
- 50 T Ross and R Winnett, 'Misery for millions as elderly care funds cut', *Telegraph*, 27 Oct 2011, www.telegraph.co.uk/health/elderhealth/8854308/Misery-for-millions-as-elderly-care-funds-cut.html (accessed Oct 2011).
- 51 Wood et al, *Coping with the Cuts*.
- 52 J Carr-West and L Lucas, *Promoting Independence: The future of housing-related support*, London: Local Government Information Unit, Oct 2011, <https://member.lgiu.org.uk/whatwedo/Publications/Documents/Promoting%20Independence.pdf> (accessed Oct 2011).
- 53 M Samuel, 'Supporting people cuts "put vulnerable people at risk and shunt costs"', *Community Care*, 26 Oct 2011, www.communitycare.co.uk/Articles/26/10/2011/117667/supporting-people-cuts-put-people-at-risk-and-shunt-costs.htm (accessed Nov 2011).

- 54 LVSC, *The Big Squeeze 2011: The squeeze tightens*, London: London Voluntary Service Council, 2011, www.lvsc.org.uk/media/52270/big%20squeeze%20exec%20summary%202011.pdf (accessed Nov 2011).
- 55 KIDS and Mencap, *Are Cuts to Local Authority Budgets Denying Families the Right to Childcare? A report by KIDS in partnership with MENCAP*, London: KIDS, 2011, www.kids.org.uk/files/106393/FileName/mencapreportdraft_f.pdf (accessed Nov 2011).
- 56 Wood and Grant, *Destination Unknown*.
- 57 RNIB, 'The Hardest Hit Campaign', Royal National Institute for the Blind, www.rnib.org.uk/getinvolved/campaign/yourmoney/welfarereform/Pages/hardest_hit.aspx (accessed Oct 2011).
- 58 'Adult social care £51m cut plans in Birmingham', *BBC News*, 4 Mar 2011, www.bbc.co.uk/news/uk-england-birmingham-12653063 (accessed 6 Apr 2011).
- 59 Justice Walker, quoted in N Timmins, 'Curb on disabled care ruled unlawful', *Financial Times*, 19 May 2011 (accessed Oct 2011).
- 60 P Walker, 'Council's social care cuts unlawful, judge rules', *Society Guardian*, 11 Nov 2011, www.guardian.co.uk/society/2011/nov/11/social-care-cuts-unlawful?CMP=tw_t_fd (accessed Nov 2011).
- 61 'Sefton council care home fee freeze ruled unlawful', *BBC News Liverpool*, 9 Nov 2011, www.bbc.co.uk/news/uk-england-merseyside-15665980 (accessed Nov 2011).
- 62 Wood et al, *Coping with the Cuts*.
- 63 G Parker and S O'Connor, 'Duncan Smith braced for benefits battle', *Financial Times*, 2 Nov 2011, www.ft.com/cms/s/o/69628844-057f-11e1-8eaa-00144feabdco.html#axzz1cmBsyMbo (accessed Nov 2011).

- 64 'Cabinet agrees adult care budget savings', Derbyshire County Council, 26 Jan 2011, www.derbyshire.gov.uk/council/news_events/news-updates/2010/january/news_items/cabinet_agrees_adult_care_budget_savings.asp (accessed 6 Apr 2011).
- 65 Wood and Grant, *Destination Unknown*; Wood and Grant, *Destination Unknown: Spring 2011*
- 66 With the exception of Aisha and Helen's son who, as children, will not be immediately affected by the PIP reform and will remain on DLA.
- 67 Scope, 'Scope report uncovers impact of legal aid cuts on disabled people', 14 Nov 2011, www.scope.org.uk/news/legal-aid-cuts-on-disabled-people (accessed 21 Nov 2011).
- 68 Wood and Grant, *Destination Unknown: Spring 2011*.
- 69 Y Phoon, 'Mortgage rates at all time low', 27 Jun 2011, www.mortgageintroducer.com/ccstory/240583/5/Mortgage_rates_at_all_time_low.htm (accessed Oct 2011).
- 70 Mortgages, 'Bank of England', interest rate tracker – current rate and historical data, 2011, www.mortgages.co.uk/interest-rates/interest-rate-history.html (accessed 21 Nov 2011).
- 71 Commission on Funding of Care and Support, *Fairer Care Funding: The report of the Commission on Funding of Care and Support*, 4 Jul 2011, www.dilnotcommission.dh.gov.uk/files/2011/07/Fairer-Care-Funding-Report.pdf (accessed 25 Nov 2011).
- 72 House of Lords, Grand Committee, Welfare Reform Bill, *Hansard*, Debates, 8 Nov 2011.

- 73 They Work For You, Employment Support Services, Oral answers to questions – Work and Pensions, 28 Mar 2011, www.theyworkforyou.com/debates/?id=2011-03-28b.3.6#g4.2 (accessed April 2011).
- 74 Wood and Grant, *Destination Unknown*.
- 75 Ibid.
- 76 M Hudson et al, *The Influence of Outcome Based Contracting on Provider Led Pathways to Work*, London: Dept for Work and Pensions, 2010.
- 77 P Butler, ‘The “big society” Work Programme (and other myths)’, *Guardian*, 12 Oct 2011, www.guardian.co.uk/society/patrick-butler-cuts-blog/2011/oct/12/big-society-work-programme-a-myth-say-charities (accessed 21 Nov 2011).
- 78 Wood and Grant, *Destination Unknown*; Wood and Grant, *Destination Unknown: Spring 2011*.

References

- 'Adult social care £51m cut plans in Birmingham', *BBC News*, 4 Mar 2011, www.bbc.co.uk/news/uk-england-birmingham-12653063 (accessed 6 Apr 2011).
- 'Cabinet agrees adult care budget savings', Derbyshire County Council, 26 Jan 2011, www.derbyshire.gov.uk/council/news_events/news-updates/2010/january/news_items/cabinet_agrees_adult_care_budget_savings.asp (accessed 6 Apr 2011).
- 'Lord Low's review urges Government to save mobility payments for disabled people living in residential care', press release, <http://mobilityreview.files.wordpress.com/2011/07/press-release.doc> (accessed Nov 2011).
- 'Round-up: spending review', *Money Observer*, 20 Oct 2010, www.moneyobserver.com/news/10-10-20/round-spending-review (accessed 6 Apr 2011).
- 'Sefton council care home fee freeze ruled unlawful', *BBC News Liverpool*, 9 Nov 2011, www.bbc.co.uk/news/uk-england-merseyside-15665980 (accessed Nov 2011).
- 'Spending review: care cuts "may hit hospital beds"', BBC News website, 23 Oct 2010, www.bbc.co.uk/news/uk-politics-11611423 (accessed 6 Apr 2011).
- 'Spending review: council cuts to be "front loaded"', BBC News, 21 Oct 2010, www.bbc.co.uk/news/uk-england-derbyshire-11602938 (accessed 6 Apr 2011).

References

'UK CPI inflation rate rises to 5.2% in September', *BBC Business News*, 18 Oct 2011, www.bbc.co.uk/news/business-15344297 (accessed Oct 2011).

Barker A, 'Welfare bill ditches housing benefit cut', *Financial Times*, 17 Feb 2011, www.ft.com/cms/s/0/3047362e-3a26-11e0-a441-00144feabdco.html#axzz1HPQfSPFt (accessed 6 Apr 2011).

Butler P, 'The "big society" Work Programme (and other myths)', *Guardian*, 12 Oct 2011, www.guardian.co.uk/society/patrick-butler-cuts-blog/2011/oct/12/big-society-work-programme-a-myth-say-charities (accessed 21 Nov 2011).

Butler P and Bates S, 'Terminally ill patients told their benefits may be cut', *Guardian*, 21 Sep 2011, www.guardian.co.uk/politics/2011/sep/21/terminally-ill-told-benefits-cut?CMP=twt_gu (accessed Oct 2011).

Carr-West J and Lucas L, *Promoting Independence: The future of housing-related support*, London: Local Government Information Unit, Oct 2011, <https://member.lgiu.org.uk/whatwedo/Publications/Documents/Promoting%20Independence.pdf> (accessed Oct 2011).

Commission on Funding of Care and Support, *Fairer Care Funding: The report of the Commission on Funding of Care and Support*, 4 Jul 2011, www.dilnotcommission.dh.gov.uk/files/2011/07/Fairer-Care-Funding-Report.pdf (accessed 25 Nov 2011).

Curtis P, Ramesh R and Bowers S, 'George Osborne facing budget backlash', *Guardian*, 21 Jun 2010, www.guardian.co.uk/uk/2010/jun/20/george-osborne-facing-budget-backlash (accessed Mar 2011).

Dept for Work and Pensions, 'Abolition of concessionary Employment and Support Allowance (ESA) 'youth' National Insurance qualification conditions: equality impact assessment',

Oct 2011, www.dwp.gov.uk/docs/eia-esa-youth-provisions-wr2011.pdf (accessed Nov 2011).

Dept for Work and Pensions, 'Conditionality under Universal Credit: the work search and work availability requirements', Universal Credit policy briefing note 12, Oct 2011, www.dwp.gov.uk/docs/ucpbn-12-work-search.pdf (accessed 21 Nov 2011).

Dept for Work and Pensions, 'Disability Living Allowance reform: equality impact assessment', Oct 2011, www.dwp.gov.uk/docs/eia-dla-reform-wr2011.pdf (accessed Nov 2011).

Dept for Work and Pensions, 'Household Benefit Cap: equality impact assessment', Oct 2011, www.dwp.gov.uk/docs/eia-universal-credit-wr2011.pdf (accessed Nov 2011).

Dept for Work and Pensions, 'Time limiting contributory Employment and Support Allowance to one year for those in the Work Related Activity Group: equality impact assessment', Oct 2011, www.dwp.gov.uk/docs/eia-esa-time-limit-wr2011.pdf (accessed Nov 2011).

Dept for Work and Pensions, *Personal Independence Payment: Initial draft of assessment criteria*, Dept for Work and Pensions, 2011, www.dwp.gov.uk/docs/pip-draft-assessment-criteria-note.pdf (accessed 22 Nov 2011).

Dept for Work and Pensions, *Personal Independence Payment: Second draft of assessment regulations*, Dept for Work and Pensions, 2011, www.dwp.gov.uk/docs/pip-second-draft-assessment-regulations.pdf (accessed 22 Nov 2011).

Disability Rights Partnership, *End of a Lifeline: Ending Disability Living Allowance to introduce Personal Independence Payment, DLA reform consultation response*, London: Disability Rights Partnership, 2011, www.disabilityalliance.org/r68.doc (accessed Oct 2011).

References

Gentleman A, 'Mobility allowance glee is premature', *Guardian*, 22 Feb 2011, www.guardian.co.uk/society/joepublic/2011/feb/22/mobility-allowance-u-turn-glee-premature (accessed Feb 2011).

Grant E, *The Future of PIP: A social model-based approach*, London: Scope, 2011, www.scope.org.uk/sites/default/files/The%20Future%20of%20PIP%20-%20A%20Social%20Model%20Based%20Approach.pdf (accessed Oct 2011).

HM Treasury, *Spending Review 2010*, Cm 7942, Norwich: The Stationery Office, 2010, http://cdn.hm-treasury.gov.uk/sr2010_completereport.pdf (accessed 6 Apr 2011).

House of Commons, *Welfare Reform Bill: Explanatory notes*, Bill 154-EN, London: The Stationery Office, 2011, www.publications.parliament.uk/pa/cm201011/cmbills/154/en/11154en.pdf (accessed 6 Apr 2011).

House of Lords, Grand Committee, Welfare Reform Bill, *Hansard*, Debates, 8 Nov 2011, www.publications.parliament.uk/pa/ld201011/ldhansrd/text/111108-gc0001.htm (accessed Nov 2011).

Hudson M et al, *The Influence of Outcome Based Contracting on Provider Led Pathways to Work*, London: Dept for Work and Pensions, 2010.

Kenway P et al, *Working-age 'Welfare': Who gets it, why, and what it costs*, York: Joseph Rowntree Foundation, 2010, www.jrf.org.uk/sites/files/jrf/working-age-welfare-summary.pdf (accessed 6 Apr 2011).

KIDS and Mencap, *Are Cuts to Local Authority Budgets Denying Families the Right to Childcare? A report by KIDS in partnership with MENCAP*, London: KIDS, 2011, www.kids.org.uk/files/106393/FileName/mencapreportdraft_f.pdf (accessed Nov 2011).

LVSC, *The Big Squeeze 2011: The squeeze tightens*, London: London Voluntary Service Council, 2011, www.lvsc.org.uk/media/52270/big%20squeeze%20exec%20summary%202011.pdf (accessed Nov 2011).

Mencap, 'Charities fight cut to DLA mobility component', 20 Jan 2011, www.mencap.org.uk/news.asp?id=20623 (accessed 6 Apr 2011).

National Housing Federation, 'New rules could price thousands of disabled people out of their homes, Federation warns', 23 Mar 2011, www.housing.org.uk/news/up_to_108,000_disabled_people.aspx (accessed 6 Apr 2011).

Parker G and O'Connor S, 'Duncan Smith braced for benefits battle', *Financial Times*, 2 Nov 2011, www.ft.com/cms/s/o/69628844-057f-11e1-8eaa-00144feabdco.html#axzz1cmBsyMbo (accessed Nov 2011).

Phoon Y, 'Mortgage rates at all time low', 27 Jun 2011, www.mortgageintroducer.com/ccstory/240583/5/Mortgage_rates_at_all_time_low.htm (accessed Oct 2011).

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

RNIB, 'The Hardest Hit Campaign', Royal National Institute for the Blind, www.rnib.org.uk/getinvolved/campaign/yourmoney/welfarereform/Pages/hardest_hit.aspx (accessed Oct 2011).

Ross T and Winnett R, 'Misery for millions as elderly care funds cut', *Telegraph*, 27 Oct 2011, www.telegraph.co.uk/health/elderhealth/8854308/Misery-for-millions-as-elderly-care-funds-cut.html (accessed Oct 2011).

References

Samuel M, 'Supporting people cuts "put vulnerable people at risk and shunt costs"', *Community Care*, 26 Oct 2011, www.communitycare.co.uk/Articles/26/10/2011/117667/supporting-people-cuts-put-people-at-risk-and-shunt-costs.htm (accessed Nov 2011).

Scope, 'Scope report uncovers impact of legal aid cuts on disabled people', 14 Nov 2011, www.scope.org.uk/news/legal-aid-cuts-on-disabled-people (accessed 21 Nov 2011).

Walker P, 'Council's social care cuts unlawful, judge rules', *Society Guardian*, 11 Nov 2011, www.guardian.co.uk/society/2011/nov/11/social-care-cuts-unlawful?CMP=tw_tfd (accessed Nov 2011).

Watt N, 'Benefits: families and disabled people will be hit by "Thatcherite" cuts', *Guardian*, 23 Jun 2010, www.guardian.co.uk/society/2010/jun/23/benefits-disabled-families-thatcher (accessed Aug 2010).

Wood C and Grant E, *Counting the Cost*, London: Demos, 2010.

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

Wood C and Grant E, *Destination Unknown: Spring 2011*, London: Demos, 2011.

Wood C, Cheetham P and Gregory T, *Coping with the Cuts*, London: Demos, 2011.

Work and Pensions Committee, Written Evidence, Proposal to replace Disability Living Allowance with Personal Independence Payment, Sep 2011, www.publications.parliament.uk/pa/cm201012/cmselect/cmworpen/writew/1493/contents.htm (accessed Oct 2011).

Demos - Licence to Publish

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

1 Definitions

- A **'Collective Work'** means a work, such as a periodical issue, anthology or encyclopedia, in which the Work in its entirety in unmodified form, along with a number of other contributions, constituting separate and independent works in themselves, are assembled into a collective whole. A work that constitutes a Collective Work will not be considered a Derivative Work (as defined below) for the purposes of this Licence.
- B **'Derivative Work'** means a work based upon the Work or upon the Work and other pre-existing works, such as a musical arrangement, dramatisation, fictionalisation, motion picture version, sound recording, art reproduction, abridgment, condensation, or any other form in which the Work may be recast, transformed, or adapted, except that a work that constitutes a Collective Work or a translation from English into another language will not be considered a Derivative Work for the purpose of this Licence.
- C **'Licensor'** means the individual or entity that offers the Work under the terms of this Licence.
- D **'Original Author'** means the individual or entity who created the Work.
- E **'Work'** means the copyrightable work of authorship offered under the terms of this Licence.
- F **'You'** means an individual or entity exercising rights under this Licence who has not previously violated the terms of this Licence with respect to the Work, or who has received express permission from Demos to exercise rights under this Licence despite a previous violation.

2 Fair Use Rights

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

3 Licence Grant

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

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

4 Restrictions

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

- A You may distribute, publicly display, publicly perform, or publicly digitally perform the Work only under the terms of this Licence, and You must include a copy of, or the Uniform Resource Identifier for, this Licence with every copy or phonorecord of the Work You distribute, publicly display, publicly perform, or publicly digitally perform. You may not offer or impose any terms on the Work that alter or restrict the terms of this Licence or the recipients' exercise of the rights granted here under. You may not sublicense the Work. You must keep intact all notices that refer to this Licence and to the disclaimer of warranties. You may not distribute, publicly display, publicly perform, or publicly digitally perform the Work with any technological measures that control access or use of the Work in a manner inconsistent with the terms of this Licence Agreement. The above applies to the Work as incorporated in a Collective Work, but this does not require the Collective Work apart from the Work itself to be made subject to the terms of this Licence. If You create a Collective Work, upon notice from any Licensor You must, to the extent practicable, remove from the Collective Work any reference to such Licensor or the Original Author, as requested.
- B You may not exercise any of the rights granted to You in Section 3 above in any manner that is primarily intended for or directed towards commercial advantage or private monetary

compensation. The exchange of the Work for other copyrighted works by means of digital filesharing or otherwise shall not be considered to be intended for or directed towards commercial advantage or private monetary compensation, provided there is no payment of any monetary compensation in connection with the exchange of copyrighted works.

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

5 Representations, Warranties and Disclaimer

- A By offering the Work for public release under this Licence, Licensor represents and warrants that, to the best of Licensor's knowledge after reasonable inquiry:
 - i Licensor has secured all rights in the Work necessary to grant the licence rights hereunder and to permit the lawful exercise of the rights granted hereunder without You having any obligation to pay any royalties, compulsory licence fees, residuals or any other payments;
 - ii The Work does not infringe the copyright, trademark, publicity rights, common law rights or any other right of any third party or constitute defamation, invasion of privacy or other tortious injury to any third party.
- B except as expressly stated in this licence or otherwise agreed in writing or required by applicable law, the work is licenced on an 'as is' basis, without warranties of any kind, either express or implied including, without limitation, any warranties regarding the contents or accuracy of the work.

6 Limitation on Liability

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

7 Termination

- A This Licence and the rights granted hereunder will terminate automatically upon any breach by You of the terms of this Licence. Individuals or entities who have received Collective Works from You under this Licence, however, will not have their licences terminated provided such individuals or entities remain in full compliance with those licences. Sections 1, 2, 5, 6, 7, and 8 will survive any termination of this Licence.
- B Subject to the above terms and conditions, the licence granted here is perpetual (for the duration of the applicable copyright in the Work). Notwithstanding the above, Licensor reserves the right to release the Work under different licence terms or to stop distributing the Work at any time; provided, however that any such election will not serve to withdraw this Licence (or any other licence that has been, or is required to be, granted under the terms of this Licence), and this Licence will continue in full force and effect unless terminated as stated above.

8 Miscellaneous

- A Each time You distribute or publicly digitally perform the Work or a Collective Work, Demos offers to the recipient a licence to the Work on the same terms and conditions as the licence granted to You under this Licence.
- B If any provision of this Licence is invalid or unenforceable under applicable law, it shall not affect the validity or enforceability of the remainder of the terms of this Licence, and without further action by the parties to this agreement, such provision shall be reformed to the minimum extent necessary to make such provision valid and enforceable.
- C No term or provision of this Licence shall be deemed waived and no breach consented to unless such waiver or consent shall be in writing and signed by the party to be charged with such waiver or consent.
- D This Licence constitutes the entire agreement between the parties with respect to the Work licenced here. There are no understandings, agreements or representations with respect to the Work not specified here. Licensor shall not be bound by any additional provisions that may appear in any communication from You. This Licence may not be modified without the mutual written agreement of Demos and You.

This project was supported by:

scope

About cerebral palsy.
For disabled people achieving equality.

Just over a year 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, totalling £9 billion.

However, this initial research only told half of the picture – it was only possible to model the impact of welfare cuts on disabled people and not the implications of cuts to public services and local authority budgets. To understand more fully the effects of these changes, we began the Disability in Austerity Study, following five typical disabled families through the course of this Parliament and tracking the impact of fiscal tightening on their lives.

This pamphlet is the second report in the ongoing longitudinal study and is the first since new local authority budgets and a range of welfare reforms took effect. It provides detail on the real consequences the cuts have for the everyday lives of disabled people, revealing 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.

ISBN 978-1-906693-89-3 £10

© Demos 2011

