

HAS WELFARE BECOME UNFAIR?

The impact of welfare changes
on disabled people

A report by the Disability Benefits Consortium
July 2019



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Executive summary

The 10-year cut – the real-life impact of welfare changes on disabled people

The welfare system is intended to provide a financial safety net for some of the most vulnerable people in our society including disabled people and people with long-term health conditions. Yet, since 2008, changes to welfare benefits have led to this safety net failing, causing people to feel abandoned by a cruel and unfair system.

These changes have had a devastating impact on disabled people. Financial security for the majority of disabled people has all but vanished. Disabled people have been left living in poverty and isolation as a result.

This has created an environment that is difficult and unforgiving for disabled people. Those with the greatest needs, who are most vulnerable and with the fewest financial and social resources, are left to navigate a complex, stressful process. It's a process that ultimately leaves them with their health worse and with less financial support.

The Disability Benefits Consortium is a national coalition of more than 80 different charities and organisations committed to working towards a fairer benefits system. Together we seek to ensure government policy reflects and meets the needs of all disabled people.

This report, generously funded by The Three Guineas Trust, combines our knowledge, experience and direct contact with millions of disabled people, their families and friends with commissioned research, to lay bare the impact of recent changes to the financial security and lived experience of disabled people over the past 10 years.

Disabled people lose more

Disabled people have lost benefit payments of around £1,200 on average each year, as a result of the changes. Non-disabled people have seen a reduction of around £300.

For anyone, a reduction of financial support can be detrimental. But for disabled people, who already face

average extra disability-related costs of £583 each month¹, the loss of money can be devastating.

Disabled people don't just lose money – they lose access to transport, their independence, and in some cases, their jobs. The support they receive through welfare benefits provides only for the basic standards of living, but not the extra costs disabled people face.

The greater the need, the bigger the loss

At the core of any social security system should be the need to protect and support the most vulnerable in society.

Our research shows that not only are disabled people worse off than people who are not disabled but, even within this group, the most vulnerable are suffering. In households with at least one disabled adult and at

least one disabled child, the total loss as a result of all the benefit changes was, on average, over £4,300 each year.

The more disabilities a person has, the more they lose out as a result of these changes. Our research shows someone who has six or more disabilities loses over £2,100 each year on average, whereas someone with one disability loses around £700 each year.

Welfare and wellbeing are not mutually exclusive

There are numerous aspects to the changing social security system that are particularly problematic for many disabled people, and which have a detrimental impact on their wellbeing. Participants told us that the process of claiming was stressful, anxiety inducing and, in many cases, made their health worse.

From beginning to end, from assessment to award, many people find the whole system a struggle. The application and assessment processes are upsetting and require people to focus on their limitations and reliance on others. Undertaking this process can often destroy people's self-esteem and confidence, which can in turn lead to wider mental health issues.

The prospect of an appeal was something many of our participants couldn't contemplate, even though they felt their final award was inaccurate or unfair. Not only do people face the risk of losing any support they have already been awarded – they also face lengthening an already stressful and demanding process.



¹ SCOPE. The disability price tag. www.scope.org.uk/campaigns/extra-costs (accessed 02/2019).



Conclusions and recommendations

This report looks at the financial impact and the lived experience of the recent changes to the social security system. It has exposed the devastating impact the changes have had on many disabled people's wellbeing and right to independent living.

The research asks if our social security system protects the most vulnerable or if it is a 'survival of the fittest' approach. But the picture that emerges in this study is that of a difficult and unforgiving environment. Disabled people who struggle to understand the system, or who have limited resources, are less able to find their way through the protracted and difficult process from application to award. And almost every change has led them further from financial security.

The research underpinning this report has shown that the cuts to benefits caused by these changes have had the biggest negative impact on those who need support the most. The families affected are, as a result, leading precarious lives characterised by financial insecurity, with worries over money, bills and what the future may hold. In these circumstances,

genuine inclusion in work, family and community life is a remote and unlikely prospect. This not only goes against what the government has said is the purpose of the changes – it is simply unjust, unfair and cruel. Many disabled people have not yet felt the full extent of the cuts made to welfare benefits, as many have not yet moved on to Universal Credit. When that happens, there will be dramatic increases in the levels of poverty among people who are already at crisis point.

It is a disaster waiting to happen.

The welfare system must be reformed so that it takes a more personal and tailored approach. We need it to provide greater support to disabled people so they can be free from poverty and despair, and live truly independent lives.



To achieve this, we urge the government to act upon the following recommendations:

Financial change

- 1. End the benefit freeze.** The freeze has been a major factor in reducing the incomes of disabled people and pushing them into poverty.
- 2. Bring back the Employment and Support Allowance (ESA)/Universal Credit work-related activity component.** There is no evidence to suggest its removal incentivises people to work. It also wrongly assumes that everyone affected can work, and that there are no extra costs for people with health conditions.
- 3. Introduce a disability element to Universal Credit to replace the disability premiums that have been cut from the system.** Disabled people face unavoidable costs as a result of their condition and cannot afford to lose substantial sums each year.

- 4. Remove the benefit cap for everyone who receives a disability-related benefit, including those in the work-related activity group or equivalent in Universal Credit.** The cost of living with a condition means they cannot afford to lose income.
- 5. Return the work allowances in Universal Credit to pre-2016 levels.** If the government's aim really is to reduce the disability employment gap, it makes sense to let people keep more of their wages, rather than punish people for having a disability.
- 6. Remove the two-child limit.** Disabled people also have children and this limit reduces their ability to ensure both they and their children do not live in poverty. The limit compounds their financial insecurity.

The application

- 7. The Department for Work and Pensions (DWP) should produce simplified claim forms.** These should be easily available in jobcentres in accessible formats such as audio described and easy-read, as well as downloadable online. There should be no need to return these within four weeks.
- 8. Increase resources so charities and other advice agencies are better able to assist people in completing all disability benefit application forms.** Completing the application form in an effective way requires significant understanding of the application and assessment processes. Without support, it is unlikely that some claimants, irrespective of need, will present their claim in an effective way.

Assessments

- 9. Introduce regulations to ensure other types of evidence are given equal legal weight to the assessment reports.** Face-to-face assessments provide only a brief window into an individual's life and often lead to inappropriate or inaccurate judgements about an individual's capability.

10. Automatically issue claimants with a copy of their assessment report, in their preferred format. Increase availability of recorded assessments, and ensure people know they have the choice to have the assessment recorded (audio or video). Assessment reports often contain errors. Many disabled people do not trust assessors to act fairly and independently.

11. A thorough review of the Personal Independence Payment (PIP) assessment criteria should be urgently conducted. There should be meaningful involvement from disabled people and those with long-term conditions to ensure criteria are fair and truly reflect the extra costs people face.

Supporting information and medical evidence

12. The DWP should commission an independent review of the evidence-gathering processes to explore ways to:

- support health and social care professionals to provide better-quality evidence eg guidance and templates
- ensure the duties and responsibilities of the assessor, the DWP and claimant are clear and observed
- make sure the DWP has a strategy to communicate to claimants and health professionals the evidence that will be most useful for their claim
- ensure evidence supplied by friends and family members is given consideration

13. From the start of the process, encourage claimants to obtain up-to-date evidence and pay or reimburse them for any costs. The DWP should also provide better guidance on what constitutes good evidence. Disabled people often need to source and present evidence to substantiate their claim but are given little support in doing so.

14. Work with medical practitioners to develop better-quality evidence for claimants. Often, medical evidence that claimants are able to obtain merely gives a diagnosis while saying little about someone's needs and day-to-day difficulties.

15. To restore confidence in the process, assessors should be obliged to review all supporting evidence provided by a claimant, with penalties if they do not. The assessor report is currently given more weight in the decision-making, which is resulting in large numbers of ill-advised decisions.

Mandatory reconsiderations and tribunals

16. Those looking at a decision again when it is challenged by the claimant should not be able to see the previous decision-maker's conclusions. This will increase impartiality. There are too many cases of mandatory reconsideration reports being copied and pasted from the original decision.

17. Those going through mandatory reconsideration should be given the opportunity to provide oral evidence of how their condition affects them in all cases. Often decisions are changed at tribunal because of new oral evidence. Giving this at an earlier stage will improve the process.

18. Increase the number of tribunal panel members so that tribunal waiting times can be brought down to more reasonable levels. The average wait is 29 weeks for a tribunal hearing, with some areas having to wait up to a year.

19. Introduce targets for the length of time cases need to wait to be heard by a tribunal. Some people have to wait up to a year to be heard at tribunal. A target will help reduce waiting times.

20. Conduct full audits of decisions that are subsequently changed at tribunals. This will help restore confidence in the system and also provide ways of improving decision-making.

21. The DWP should commission independent reviews of the Universal Credit and PIP application and decision-making processes. This should particularly but not exclusively examine the failings of the mandatory reconsideration process.

Cost of living with a disability

22. Introduce regular, independent surveys of the actual costs of living with a disability.

Then, ensure that the level of payments under PIP better reflects the actual cost of living with a disability.

About the report

With funding from the Three Guineas Trust, the Disability Benefits Consortium commissioned research into the cumulative impact of changes to the welfare benefit system on disabled people since 2008.

This report looks at the financial impact – and lived experience – of the changes on disabled people over the past 10 years.

This report examines the impact of changes to welfare benefits in the UK for disabled people. The changes followed on from the 2008 financial crash and included a range of measures first initiated by the Labour government (2005–2010). These were fully realised under the Conservative and Liberal Democrat coalition (2010–2015) and continued by the current Conservative government.

The research commissioned for this report was conducted in two parts.

The first used economic modelling to understand the macroeconomic effect of the changes to the benefit system since 2008, and how this has financially impacted disabled people. This part of the research was carried out by Howard Reed from Landman Economics, who used microsimulation modelling to highlight the effects of social security changes on various groups of disabled people.

The second part of the research examines the impact of the changes to the benefit system on the lived experience of disabled people. This offers a deeper understanding of the impact of welfare changes, particularly those to PIP, ESA and Universal Credit.

This part of the research was carried out by the University of East Anglia and the University of Glasgow and consisted of in-depth interviews with 50 disabled people living with a variety of conditions.



History of the recent benefit changes

Since 2010, there have been substantial changes to the UK's tax and benefit systems with a number of major changes to the social security system in particular. This has led to a reduction of over £30 billion in expenditure on benefits and tax credits.² These changes have occurred over a number of years and are still ongoing, with the transfer of existing claimants to Universal Credit being the most significant change still to come.

The background to some of the more significant changes that have occurred is explained below, however this list does not include all the changes dealt with in this report. These are in date order from the earliest to most recent.

Incapacity Benefit replaced with Employment and Support Allowance

In October 2008, Employment and Support Allowance (ESA) and its eligibility test – the Work Capability Assessment – were introduced for people with limited capability to work because they're disabled or have long-term health conditions. Initially

this was only for new claims but, from March 2011, the DWP started reassessing people. This was so they could be moved from incapacity benefits – Incapacity Benefit, Severe Disablement Allowance and Income Support on grounds of disability – to ESA. Before the assessments began, more than two million claimants were receiving incapacity benefits.³

ESA was introduced as the government of the day said that "as many as a million people on Incapacity Benefit want to return to employment ... but there is a 'perverse incentive' for those able to work again to stay on Incapacity Benefit".⁴ As a result, a work-related activity group was also established, on the assumption most ESA claimants would be able to work if provided with training courses, or similar, to promote their readiness to work.

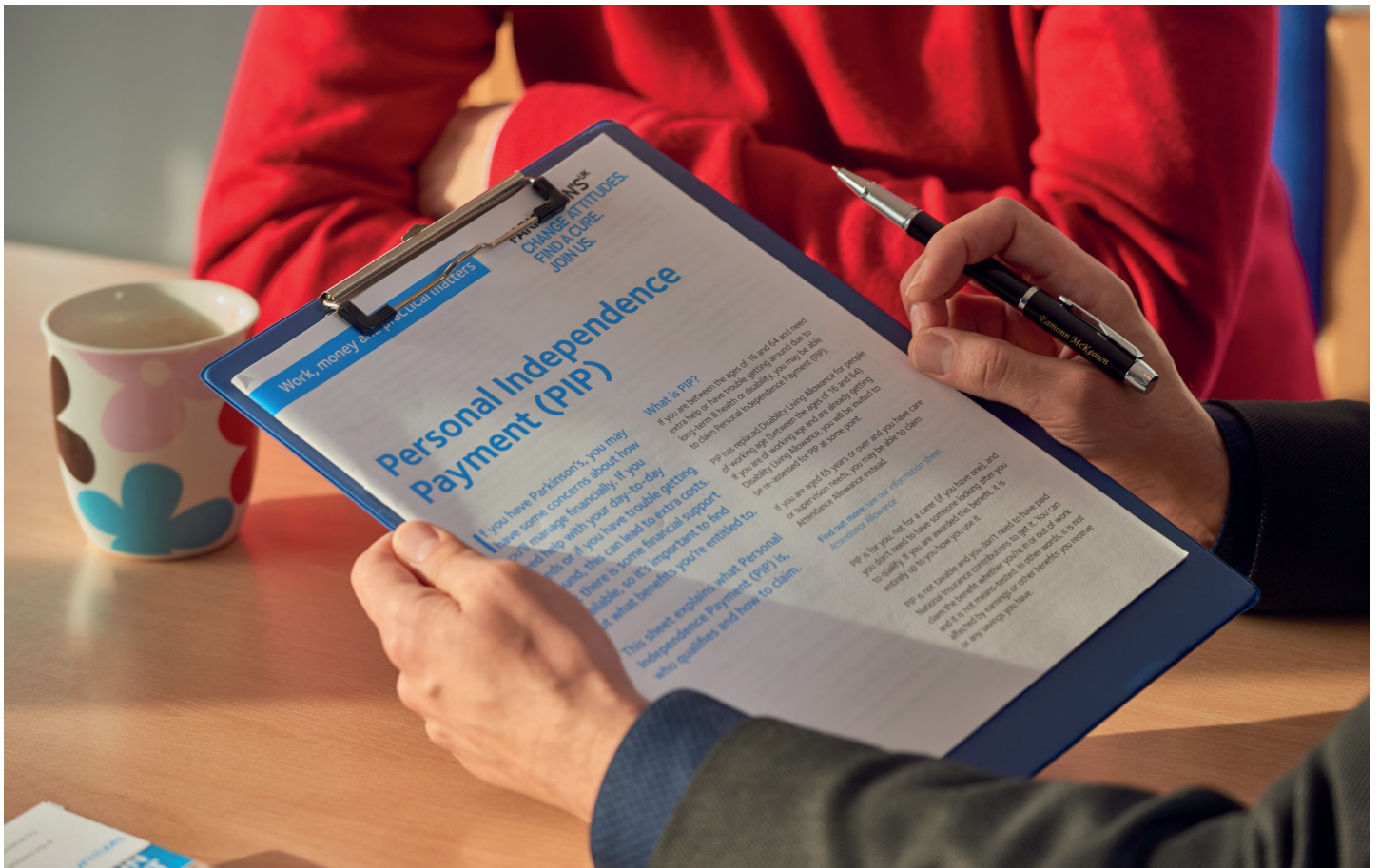
The Work Capability Assessment

People who claim ESA and Universal Credit will first complete an application form and a separate questionnaire about their health. Most will then undergo an assessment called the Work Capability

² Office for Budget Responsibility. Policy measures database. www.obr.uk/download/policy-measures-database (accessed 02/2019).

³ Department for Work and Pensions. February 2019: ESA underpayments: forecast numbers affected, forecast expenditure and progress on checking. <https://www.gov.uk/government/publications/esa-underpayments-forecast-numbers-affected-forecast-expenditure-and-progress-on-checking> (accessed 02/2019).

⁴ Incapacity Benefit to be replaced. BBC News. 2 February 2005.



Assessment. This test – which replaced the Personal Capability Assessment – is more stringent and applies a points-based system to determine what an individual is capable of. The introduction of these assessments to ESA was due to the government’s belief that the previous criteria for disability benefits were too lax.⁵

The Work Capability Assessment is currently carried out by the Centre for Health and Disability Assessments – a private provider also known as Maximus. Applicants are typically required to attend an assessment centre, where the Work Capability Assessment is overseen by an independent health professional. The Work Capability Assessment assesses which group eligible claimants are placed in.

The three possible outcomes of the Work Capability Assessment are:

1. Fit for work

Claimants ineligible for the support group in ESA, or the limited capability for work-related activity element in Universal Credit, are required to search for work as part of their claimant commitment.

2. Work-related activity group/work preparation group (Universal Credit)

Claimants in this group are recognised as being disabled, or having a long-term condition that affects their ability to work, but judged to be able to engage in work-related activity.

3. Support group/no work-related requirements group

Claimants judged unable to engage in work or work-related activity are exempt from conditionality.

Universal Credit

One of the biggest changes to the welfare system is the introduction of Universal Credit. Rollout began in 2013 starting with new claims. Initially, it was supposed to have been fully rolled out by April 2017, but a number of delays have meant it is now not expected to be fully implemented until December 2023.⁶

The purpose of Universal Credit is to replace six ‘legacy benefits’ for people of working age, with one single benefit paid monthly. It is intended to simplify the benefit system and increase incentives for people

⁵ Grover C, Piggott L. From Incapacity Benefit to Employment and Support Allowance: social sorting, sickness and impairment and social security. Policy Studies. 2010. 31: 2: 265–282.
⁶ Office for Budget Responsibility. Welfare spending: universal credit. www.obr.uk/forecasts-in-depth/tax-by-tax-spend-by-spend/welfare-spending-universal-credit (accessed 02/2019).

to work. The benefits it will be replacing are: Child Tax Credit, Housing Benefit, Income Support, income-based Job Seeker's Allowance, income-related ESA and Working Tax Credit.⁷

The rollout of Universal Credit has been plagued with difficulties and delays, with the migration of existing claimants not expected to start until 2020 (with pilots from summer 2019).⁸ The most significant for disabled people around Universal Credit are:

- the removal of the limited capability for work element
- failure to include disability-related premiums
- the cut to the work allowance for disabled people
- ongoing difficulties with the Work Capability Assessment

Under-occupancy charge (bedroom tax)

The bedroom tax was introduced in April 2013 and is aimed at social housing tenants who have more bedrooms in their homes than they're considered to need. Having one bedroom more than needed leads to a reduction of 14% in the rent eligible for Housing Benefit, while two or more 'spare' bedrooms means the rent eligible is reduced by 25%. A tenant can potentially lose all their Housing Benefit under these rules (which also apply to the rental component of Universal Credit).⁹

The reason behind the bedroom tax was said to be the growing shortage of social rented properties. There was also the need to encourage people to move to smaller properties if they no longer needed the extra bedrooms.¹⁰ However, disabled people may need an additional room for reasons related to their condition. For instance, their symptoms may mean they can't share a bedroom with other people because of violent movements in bed, or they may need an overnight carer.

Benefit cap

The benefit cap is an overall limit on how much each household of working age can receive in welfare benefit payments in any given year. The benefit cap was introduced in April 2013 and was set at £26,000

initially for families. However, this was further reduced in 2016 to £23,000 inside London and £20,000 outside London.

The benefit cap has been criticised for forcing families into hardship, poverty and homelessness when, for most, there is no way to avoid its effects.¹¹

Personal Independence Payment (PIP)

Introduced in April 2013, PIP was only first available for new claimants but later for previous Disability Living Allowance (DLA) claimants who were reassessed for the new benefit. Those already aged 65 on 9 April 2013 were exempt and continued to receive DLA. From July 2015, the DWP announced that it would be inviting long-term and indefinite DLA recipients to claim PIP. Claimants were written to via a 'random selection process'.¹² They were told their DLA was ending and they must make a new claim if they would like to receive continued financial support for their extra costs in future.

PIP applications follow a similar process as those going through the Work Capability Assessment, with applicants first completing a 'How your disability affects you' form (PIP2 form). Most applicants then undergo a face-to-face assessment with an independent health professional. These assessments involve questions which focus on how an applicant's disability affects their daily lives. Physical tests may also be carried out in claims involving physical impairments. Assessors also document informal observations of claimants during assessments.

This information forms the basis of a report, which aims to ensure the information contained in the application form is consistent with information presented in the face-to-face interview. A DWP decision-maker uses this report, alongside the initial claim form and other medical evidence, to decide whether or not, and at which rates, PIP should be awarded.

Part of the government's rationale for introducing PIP in 2013 was that DLA "no longer provides the framework for supporting disabled people that is

7 Gov.uk. Universal Credit. <https://www.gov.uk/universal-credit> (accessed 02/2019).

8 Gov.uk. Housing Benefit. What you'll get. www.gov.uk/housing-benefit/what-youll-get (accessed 02/2019).

9 Gov.uk. Amber Rudd sets out fresh approach to Universal Credit. www.gov.uk/government/news/amber-rudd-sets-out-fresh-approach-to-universal-credit (accessed 02/2019).

10 Wilson W. House of Commons Library. Under-occupying social housing: Housing Benefit entitlement. <https://researchbriefings.parliament.uk/ResearchBriefing/Summary/SN06272#fullreport> (accessed 02/2019).

11 Shelter. The benefit cap is harming struggling families. <https://blog.shelter.org.uk/2018/12/the-benefit-cap-is-harming-struggling-families/> (accessed 02/2019).

12 Department for Work and Pensions. Personal Independence Payment Toolkit. www.gov.uk/guidance/the-personal-independence-payment-pip-toolkit (accessed 02/2019).

needed in the 21st century”.¹³ In contrast, PIP would be “simpler to administer and easier to understand [while also providing support to] disabled people who face the greatest challenges to remaining independent and leading full, active lives”.¹⁴

Appeals process

The appeals process is another area where welfare changes have affected disability benefits. Following the Welfare Reform Act 2012, claimants dissatisfied with DWP decisions could no longer proceed immediately to an independent tribunal. Instead, the DWP introduced an additional stage of internal review, called mandatory reconsideration. Claimants must apply for a mandatory reconsideration before they’re allowed to appeal to Her Majesty’s Courts and Tribunals Service.

Universal Credit, ESA and PIP claimants dissatisfied with their award, or who believe the DWP have made an error, have just one calendar month to request a mandatory reconsideration. However, the decision to challenge an award is not without risks – the appeals process may result in reductions in the rate of award and/or its duration, rather than an increase or reinstatement.

After completing the mandatory reconsideration stage, claimants are entitled to appeal decisions at an independent tribunal. These tribunals are much more likely to find in favour of claimants and from July to September 2018 as many as 72% of independent tribunals’ decisions found in favour of disabled claimants for ESA and PIP cases.¹⁵

Benefit freeze

The benefit freeze was introduced from April 2016. It meant that most working-age benefits would be frozen at the 2015 level, with the intention inflation would reduce the overall spend on welfare benefits.

It was estimated that this freeze would cut the budget deficit by £3billion¹⁶, and that by 2021-22 the impact on some disabled people will leave them over £250 worse off each year.¹⁷

Two-child limit

In 2015, the then government announced changes that would make the welfare system fairer and more affordable.¹⁸ This included introducing a two-child limit from April 2017. The government argues that those receiving tax credits and some other benefits should face the same financial choices about having children as those not receiving benefits.¹⁹

It is estimated that the two-child limit will reduce spending by £2billion each year by 2020-21.²⁰ It does this by mainly limiting the amount of Child Tax Credit but can also affect the amount of Universal Credit a household can receive for the first two children in most situations.

End of the work-related activity component

Until April 2017, disabled people who received the lower rate of ESA (the work-related activity group) received an additional £29.05 a week to compensate them for the length of time they were expected to be out of work. This component, and the equivalent payment in Universal Credit, stopped for new claims from April 2017.²¹

The changes were introduced to “remove the financial incentives that could otherwise discourage claimants from taking steps back to work”. The changes have been widely criticised, especially the idea that the component incentivises people not to look for work, and the lack of evidence behind the policy.²²

13 Department for Work and Pensions. Government’s response to the consultation on Disability Living Allowance reform. 6 December 2010. <https://www.gov.uk/government/consultations/disability-living-allowance-reform> (accessed 02/2019).

14 Department for Work and Pensions. Government’s response to the consultation on Disability Living Allowance reform. 6 December 2010. <https://www.gov.uk/government/consultations/disability-living-allowance-reform> (accessed 02/2019).

15 Gov.uk. Tribunals and gender recognition certificate statistics quarterly: July to September 2018. www.gov.uk/government/statistics/tribunals-and-gender-recognition-certificate-statistics-quarterly-july-to-september-2018. (accessed 02/2019).

16 Conservatives.com. George Osborne: speech to Conservative Party. <http://press.conservatives.com/post/98719492085/george-osborne-speech-to-conservative-party> (accessed 02/2019).

17 Reed H, Landman Economics. The impact of social security reforms since 2010 on disabled people. 2019. Equality & Human Rights Commission.

18 HM Treasury. Summer Budget 2015. HC 264. July 2015.

19 HM Treasury. Summer Budget 2015. HC 264. July 2015: 1:141-150

20 Parliament.uk. The two-child limit. <https://publications.parliament.uk/pa/cm201719/cmselect/cmworpen/1540/154003.htm> (accessed 02/2019).

21 Department for Work and Pensions. Employment and Support Allowance changes from 3 April 2017. www.gov.uk/government/publications/employment-and-support-allowance-changes-from-3-april-2017 (accessed 02/2019).

22 Murphy C, et al. House of Commons Library. Abolition of the ESA Work-Related Activity Component. <https://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7649> (accessed 02/2019).



Methodology

The research commissioned for this report was conducted in two parts.

The first used economic modelling to understand the macroeconomic effect of the changes to the benefit system since 2008, and how this has financially impacted disabled people. This part of the research was carried out by Howard Reed from Landman Economics, who used microsimulation modelling to highlight the effects of social security changes on various groups of disabled people.

The modelling uses 2010 as the baseline year and any financial difference assumes the particular change had not taken place and continued at the 2010 levels.

The results presented in this report use the 2021–22 tax year to show the impact of the changes. Assuming the current parliament runs to full term, 2021–22 will be its final full year. At this point, most of the changes to the system announced since 2010 should be fully implemented.

For the purposes of this report, the term ‘household’ represents the basic family unit. This can be made up of a single adult or couple, and any dependent children or qualifying young people for whom that

adult or couple are responsible. These households are termed ‘benefit units’ but we have chosen to use the shortened term household for ease of reading. Any individuals, such as adult children or grandparents living in the same house who may claim benefits independently, are not included in the same benefit cap calculation.

The second part of the research examines the impact of the changes to the benefit system on the lived experience of disabled people. This offers a deeper understanding of the impact of welfare changes, particularly those to PIP, ESA and Universal Credit.

This part of the research was carried out by the University of East Anglia and the University of Glasgow and consisted of in-depth interviews with 50 disabled people living with a variety of conditions. The participants were sampled purposefully, meaning they all had been successful in claiming PIP, ESA or Universal Credit. The study was advertised through disabled people’s organisations, social media and the Disability Benefits Consortium partner networks. Potential participants made contact directly with a member of the research team.

The financial impact of changes to the social security system

Disabled people have seen an overall decrease in their level of income since the changes to the system began. Our research shows that, on average, disabled people will have lost £1,201 in welfare benefits each year by 2021-22 compared to 2010 levels. This decrease in income is even starker when compared with the average change for those in the general population not living with a disability, who will be £308 worse off each year.

There's a number of reasons for the difference between disabled people and people who aren't disabled.

The impact of Universal Credit has been particularly acute as it reduces the income of disabled people and provides a small increase for people who aren't disabled. In most cases, the levels of support for disabled people under Universal Credit are lower than the amounts they would have received with legacy benefits and tax credits. This is a result of the removal of disability premiums.

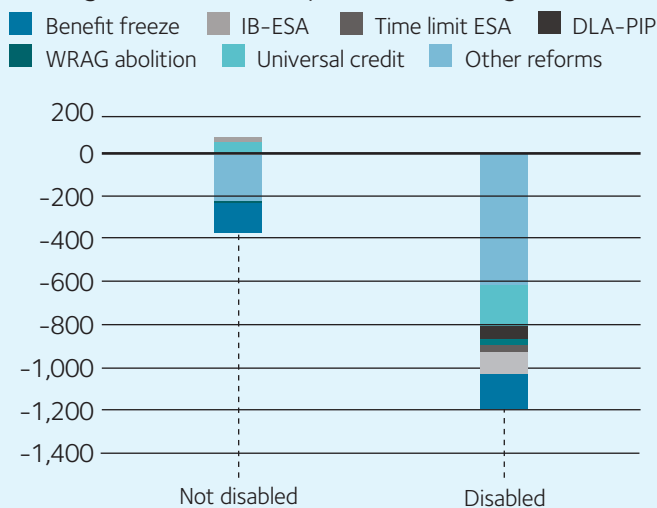
Disabled adults are also less likely to be in employment than adults who aren't disabled and, when they are in work, have lower average annual earnings.²³ As a result, the changes to income tax, National Insurance Contributions and the impact of increased minimum wages are smaller for disabled people than people who aren't disabled.

If we break down the annual cash impact of the changes into income levels for disabled people, what do we see? The research shows the burden of the welfare changes has fallen hardest on those households with the lowest income levels. Those in the poorest households saw their income levels decrease by around 8.5% between 2010 and 2021-22. Whereas those in the richest households have seen their income increase by just under 1% over the same period (see Table 1).

The changes have had a regressive impact on disabled people based on their household income, with the burden of the changes hitting those who can least afford the loss of income. Many disabled people

Table 1

Average annual cash impact of all changes



are unable to improve their incomes through paid employment. They are therefore reliant on benefits and are being forced to accept the reduction in their income levels.

Far from supporting those most in need, the changes since 2008 have reduced the welfare safety net for disabled people and left many households struggling with poverty.

Breaking down the impact of the reforms for disabled people

Within this part of the report, the impact of social security changes is broken down into seven categories:

- 1. Benefit freeze**
The impact of a 1% uprating of most benefits for working age adults and children from 2013 to 2016, plus the subsequent freeze in working-age benefits from 2016 to 2020.
- 2. Incapacity Benefit to ESA**
The impact of the Incapacity Benefit caseload being reassessed for ESA.
- 3. Time limit ESA**
The impact of the introduction of a one-year

²³ Powell, A. House of Commons Library. People with disabilities in work. <https://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7540> (accessed 02/2019).

time limit for contributory ESA claimants in the work-related activity group.

4. Work-related activity group abolition

The abolition of the work-related activity component in ESA for new claimants.

5. Disability Living Allowance to PIP

The impact of the Disability Living Allowance caseload being reassessed for PIP.

6. Universal Credit

The rollout and impact of Universal Credit.

7. Other changes

Any other changes to benefits and tax credits not included in any of the above categories.

The other changes category includes:

- changes in uprating formula for most benefits from 2011 onwards
- reductions in Council Tax support after its localisation in 2013
- reductions in Local Housing Allowance for private sector tenants
- the social sector eligible rent reduction (bedroom tax)
- the benefit cap
- reductions in the generosity of tax credits (eg increased taper rate, removal of second taper)
- limiting tax credits, Housing Benefit and Universal Credit to a maximum of two children for children born after April 2017

The research shows that the impact of the changes to the social security system on income depends on who, and how many people, in the household are disabled.

It is estimated that there will be £38billion of total cuts by 2022-23.²⁴ The underlying research for this report shows that although households with at least one disabled person make up less than a third (32.5%) of the total population, they shoulder almost two thirds of the cuts (£23.9billion, or 63%).²⁵

The benefit freeze has had a particularly large impact for households with at least one disabled child. On average, households without disabled adults and at least one disabled child will lose just under £900 each

year. Households with at least one disabled adult, and at least one disabled child, will experience a loss of just over £1,100 each year. However, households with at least one disabled adult and no disabled children will still see a substantial loss in income because of the benefit freeze. And the loss will be just over £850 each year.

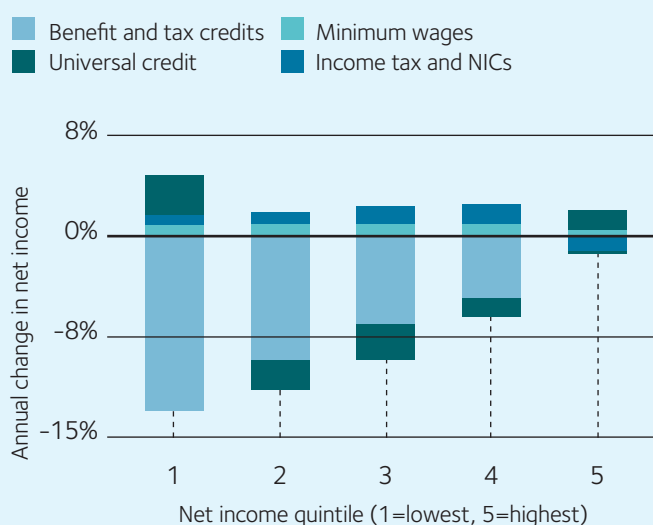
For all household types, the category with the largest impact is other changes, with very large average impacts for households with at least one disabled child. There were losses of over £2,200 where at least one adult is disabled and almost £1,950 where there are no disabled adults. Losses from other changes for childless households with at least one disabled adult are also relatively large, at just over £600.

Universal Credit also has a significant negative impact for households with at least one disabled adult and at least one disabled child – with average losses of just under £600. These households are by far the biggest overall losers from benefit changes, with losses of over £4,300 a year on average.

The reduction in income correlates to the number of disabilities a person lives with. The more disabilities a person lives with the greater the impact on their income. Someone who isn't disabled will see their income reduced by just over £300 each year as a

Table 2

Impact of all changes for disabled adults by household



²⁴ Parliament.uk. Spending of the Department for Work and Pensions. <https://researchbriefings.parliament.uk/ResearchBriefing/Summary/CDP-2019-0053#fullreport> (accessed 05/2019).
²⁵ Reed H, Landman Economics. The impact of social security reforms since 2010 on disabled people. 2019. Disability Benefit Consortium.

result of the changes. Whereas someone with six or more functional disabilities will see their income reduced by over £2,100 each year on average.

Other changes once again has the largest impact on household incomes, reaching almost £1,000 for those with six disabilities or more. For the same group, the benefit freeze, Universal Credit and the change from Disability Living Allowance to PIP have led to a combined reduction of over £1,000, on average, each year.

The group with the smallest impact of other changes is for non-disabled adults who lose less than £250 each on average. This is an important finding – benefit and tax credit changes not specifically targeted at disabled people nonetheless have bigger average impacts on disabled people than non-disabled people.

The research shows benefit changes have different levels of impact depending on the type of disability a person is living with. Those with disabilities affecting learning, mental health, memory or social interaction are the most negatively affected by the benefit changes. This confirms and reinforces the view that ‘hidden disabilities’ are treated less favourably than those that are more apparent. The benefit freeze has the biggest impact on adults with social interaction and mental health disabilities. There is an annual loss of over £300 in average losses in each case,

compared with if the benefit changes had not occurred.

We will now take a closer look at the groups of disabled people most negatively affected by the changes – adults with learning, mental health or social disabilities. It becomes clear that the move from Incapacity Benefit to ESA brings the greatest losses, leading to individuals being between £150 and £200 worse off a year in each case. The rollout of Universal Credit has the biggest negative impact on adults with learning, social and mental health disabilities, where they lose between £400 and £500 a year in each case. The impact of other changes is largest for adults with mental health and social disabilities, with a loss of over £800 a year in each case.

Overall, the findings from this economic modelling are clear – disabled people have lost out heavily because of the changes made to social security since 2010.

Changes, such as the benefit freeze, that were not specifically targeted at disabled people have generally had a bigger impact on their incomes than those changes specifically targeted at them.

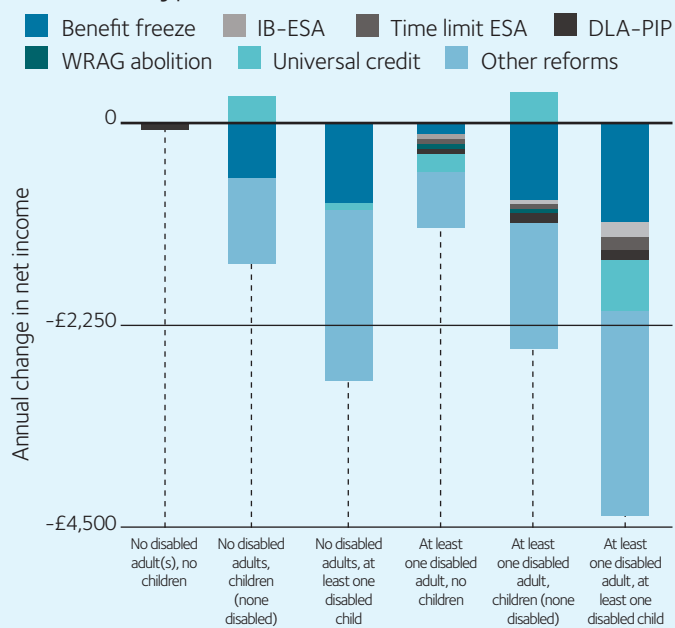
This is partly due to the fact working-age disabled people are far more likely to be receive benefits and less likely to be in employment than non-disabled adults. In addition, those who are working have lower average earnings than non-disabled adults.

The employment rate among non-disabled people stands at 81.4% compared to 51.3% for disabled people.²⁶ As a result, disabled people are less likely to benefit as much from the increases in the tax-free personal allowance for income tax since 2010. They are also less likely to have gained income from minimum wage increases.

Regarding social security cuts, the individual changes with the largest negative impacts on people with disabilities are: the limits on the uprating of benefits, the benefit freeze, the replacement of Disability Living Allowance with PIP and the rollout of Universal Credit. However, as the research has shown, the average figures don’t tell the full story of the financial impact of the changes to benefits for disabled people. This is because many disabled people are clearly much more severely affected than the average.

Table 3

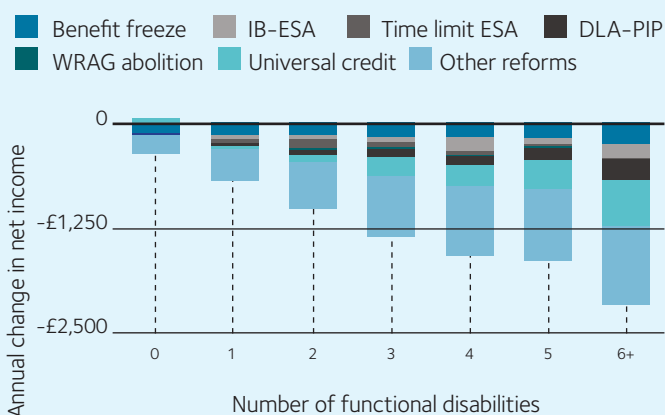
Breakdown of changes to social security by household type



²⁶ Powell, A. 2018. House of Commons Library. People with disabilities in work. <https://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7540> (accessed 02/2019).

Table 4

Breakdown of changes to social security by number of functional disabilities



The research clearly shows that the social security cuts have had the greatest impact on those most in need of support.

As this analysis has shown, the move to Universal Credit has been, and will continue to be, problematic for disabled people. Significant changes and design choices for Universal Credit have reduced the amount of income it provides to disabled people.

Chief among these changes is the reduction of the work allowance for people with limited capability for work. The work allowance is the amount of money a person is able to earn before their payment of Universal Credit begins to reduce. Prior to 2016, the higher work allowance was £647 a month but is currently £409 a month.²⁷ Furthermore, it is only due to increase by £83.33 a month from April 2019.²⁸ Using the figures from April 2019, people with disabilities will be almost £700 a year worse off than they would have been in 2015.

The data in the above economic modelling only demonstrates the average impact on a disabled person. Hidden in the average data are those at the extremes, who lose even more of their income because of the changes to the social welfare system. An example of this is with the move from legacy benefits to Universal Credit, which will cause large cuts to the extra financial support specifically designed for disabled people. Some of the most significant changes are caused by the abolition of the Limited Capability for Work Element (£29.05 a week),

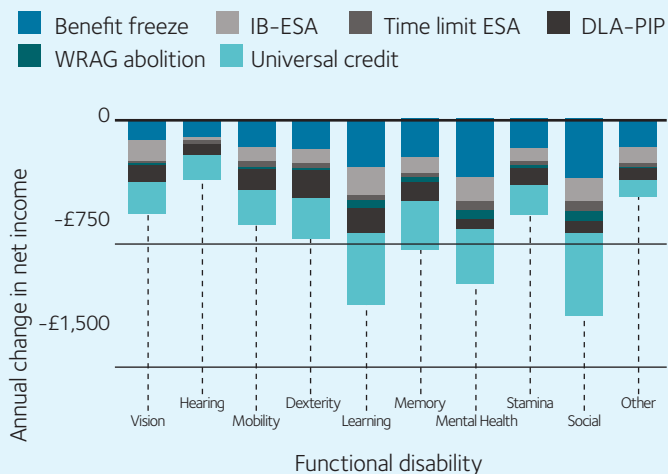
and the losses of the Enhanced Disability Premium (£16.40 a week) and Severe Disability Premium (£63.30 a week) which have been excluded from Universal Credit.

A disabled person who would have received each of the above elements if they had made a claim for legacy benefits in 2016 will lose £5,655 each year if they make a new claim for Universal Credit today. This is the same group of people who could lose out from the reduction of the work allowance in Universal Credit. It is a dramatic loss of income for someone with a disability and is not shown in the average figures of the research data. The average impact of the changes to the social security system since 2010 have, in the vast majority of situations, been negative for disabled people. In every situation, the overall impact of the changes has been negative. Far from protecting those who may be the most vulnerable in society, these changes do not protect disabled people – they penalise them for having a disability.

It's important that we remember that behind the numbers are real people. The second part of the research focuses on the lived experience of disabled people.

Table 5

Breakdown of changes to social security by functional disabilities



27 Entitled to. Work allowance for Universal Credit. www.entitledto.co.uk/help/Work-allowance-Universal-Credit (accessed 02/2019).

28 Which. How Universal Credit is calculated. www.which.co.uk/money/tax/tax-credits-and-benefits/universal-credit/how-universal-credit-is-calculated-acrr8412ckrv (accessed 02/2019).



The lived experience of benefit changes

The combined effect of the changes to the welfare system has meant that disabled people are facing increased hardship. There have been numerous reports across the media, all of which suggest that opportunities for many disabled people are significantly worse now than they were prior to the start of the changes.

The picture that emerges from this study is that of a 'survival of the fittest' welfare regime. It is one where disabled people without knowledge, and financial and social resources, are less able to weather the protracted and difficult process from application to award.

As part of the changes that have occurred to the benefit system, disabled people are regularly faced with assessment processes that did not exist previously. Assessments occur when people are transferred from Incapacity Benefit to ESA or Disability Living Allowance to PIP. Or when they are claiming these benefits or Universal Credit for the first time.

These application and assessment processes are often stressful for disabled people and can worsen their health conditions. The responses from disabled people

who participated in our research all point to what is best described as a 'hostile environment'.

Respondents say that they did not feel trusted, that they are constantly being challenged and that their word is doubted. This was the case for those experiencing the welfare system for the first time, and for those who already have some experience of the welfare system. Respondents all talked about the fear associated with assessment and the associated risk of the loss of their benefits.

The research found that there are numerous aspects to the new social security system that are particularly problematic for disabled people, and which have a detrimental impact on their wellbeing.

Lucy, 52, has rheumatoid arthritis

"I think the whole process from filling in the form and waiting for the assessment to come was like this looming thing hanging over you. Then the assessment happened and it kind of felt hard to get through and quite emotional. Then you had the stress of worrying what's going to come of it and how they see you."

Applications for disability-related benefits

Participants were particularly concerned with the application process and highlighted a number of issues. They talked a lot about how they had to emphasise just how impaired they were. They felt they had to present their lives and their abilities in a very negative way in order to receive Universal Credit, ESA and PIP. This – combined with the sense they were not to be trusted or believed – impacted their sense of self and overall wellbeing. Participants also talked about the increased bureaucratisation of the process and problems they faced with filling out the forms and completing the application process.

Another issue frequently highlighted in the application process was the importance of specialist advice and support when completing the forms. When supported, disabled people were able to present their conditions in a fair and accurate way. However, those without support were disadvantaged and less able to navigate the application process.

For many, the assessment process reflected a difficult and unforgiving environment that currently underpins the whole experience. So great has the negative portrayal of disability and disabled people become that the application process was stigmatising for some.²⁹ Applying for benefits fundamentally challenged respondents' identities, damaging their confidence and affecting how they felt about themselves.

The focus on functional ability and what an individual could or couldn't do was generally found to be very upsetting. For those applying for ESA, the process was also problematic and lengthy – with some applicants waiting up to 18 months for their payments to be confirmed.

Filling out the form

PIP, ESA and Universal Credit forms were, for many participants, difficult to complete and, for some, inaccessible. Many had to rely on others to complete the form including friends, family, disability organisations or paid support. Even for participants able to complete the form, many lacked the knowledge needed to do so effectively. For these participants, the support offered by Citizen's Advice and disabled people's organisations was vital.

Sarah, 41, has arthritis, fibromyalgia, diabetes, hypothyroidism, dyslexia, partial hearing loss and mental health issues

"Because I'm dyslexic, I couldn't complete the application form without support. Luckily, I have family who can help me but, because of the number of conditions I have, it can still take three or four hours to get everything down. It's basically a list of how bad your life is. And, if you have mental health issues, it can really impact you – telling someone else outside your family how bad your life really is. You have to talk about the worst parts because, if you don't, you won't get what you need. Often, I won't do the form in one sitting because it makes my life feel so dark. You have to take it in chunks in order to cope."

The importance of support was most apparent among participants who had some difficulties with the application process. For this group, support completing the application form and presenting their claim was essential. Many claimants, particularly those without some experience of disability and benefits, said they need specialist advice and support if they were to navigate the application stage. Without this support it is unlikely that claimants, irrespective of need, will present their claims in an effective way.

Focus on deficits and denying success

Many participants said completing the application forms required them to focus on their limitations rather than strengths. It was widely recognised that the application process needed to involve questions about illness and disability. However, many said that the current format damaged their sense of self-worth and led to wider mental health issues. This happened regardless of the outcome of claims, and even successful claimants felt the impact of the process months after the event.

This issue of distress during the application process was particularly acute for claimants encountering illness, impairment and the benefits system for the first time. For these participants, the application form's focus on deficits and limitations was especially troubling as it came at a time when they faced wider personal crises.

29 Briant E, et al. Reporting disability in the age of austerity: the changing face of media representation of disability and disabled people in the United Kingdom and the creation of new 'folk devils'. 2013. *Disability & Society*. 28(6): 874–889.

Riya, 45, has visual impairment

“In order for you to succeed with a PIP application, you have to appear to be completely dependent on somebody – for things like cooking, preparing drinks and managing day-to-day affairs. They somehow seem to think that the payment is not justified if somebody is disabled and reasonably independent, which is such a pity because then they’re not really promoting independence. If you are disabled and you say you can cook and manage the house reasonably well on your own, they would invariably say: ‘Well, you don’t need PIP’.”

Applying for benefits requires that disabled people deny their strengths and successes and focus instead on their limitations and reliance on other people. This makes the application process inherently dejecting and upsetting, causing and compounding mental health issues among claimants with disabilities.

Gathering evidence

Supporting information and medical evidence

After completing an initial application form, disabled claimants often provide additional information or medical evidence in support of their claims.

The research highlights how important providing good supporting evidence is for the success of a claim. The evidence from this study also shows that, far from being a straightforward and transparent process, collecting and providing evidence in support of benefit claims is complex and fraught with challenges, which we will discuss in the next section.

DWP guidance for PIP claims states that only existing information should be provided, and claimants are cautioned against requesting new information from their health professionals. The DWP states clearly that they will seek additional information from a GP or other professional ‘if it is needed’³⁰. Similarly, guidance from the Health Assessment Advisory Service (Maximus) about providing medical evidence for the Work Capability Assessment states: “If you have any medical evidence, such as test results, prescriptions or reports, please bring them along with you.”³¹

Hard work involved in collecting and presenting evidence

For many, the process of requesting, organising and presenting supporting information or evidence is far from easy. Often, the evidence they obtain says little about how their condition affects their capabilities. In reality, the demands the system places on claimants mean many have to expend significant time and energy, as well as financial resources, to substantiate their claims for support. William, who has cystic fibrosis and worked part-time, recalled his PIP reassessment. He described the work involved in collecting supporting information as “a very long job”.

While the DWP and independent assessment providers suggest they will source evidence if needed, participants said responsibility for providing evidence fell firmly on the disabled claimants themselves.

Disabled people often come into contact with health professionals. However, this is not always the case. For some participants, particularly those whose illness or condition was stable and did not require medical treatment, sourcing supporting information from health professionals was particularly complicated. For example, Alison, who has functional movement disorder, uses a powered wheelchair and had significant adaptations made to her home and work space. Yet she explained that she rarely sees her GP or consultant, making it difficult for them to provide information relating to her PIP claim.

Other participants said that logistical issues meant they did not have established relationships with local health professionals. This included participants whose GP practice did not offer a regular GP, and a participant who had recently moved home –

Amber, 37, has chronic pain and diabetes, experiences mental health issues and uses a wheelchair

“A friend was bringing my daughter home – at one point my daughter said: ‘Mummy, every day, when I come home from school, you’re on the phone crying.’ Every day, I would start ringing at 11am and when she got home at 3.30pm I was still on the phone.”

³⁰ Department for Work and Pensions. Personal Independence Payment – providing information to support your claim [video]. www.youtube.com/watch?v=KCMRGukO1TM&index=3&list=PLeysxjNpEPy8Y73-Yw-m7OeAGjFc1Xc-It (accessed 02/2019).

³¹ Centre for Health and Disability Assessments. The capability for work questionnaire (ESA50) and your assessment. www.chdauk.co.uk/updates/2015/08/capability-work-questionnaire-esa50-and-your-assessment (accessed 02/2019).



both situations made it harder to provide adequate supporting evidence.

Felix, 30, has cerebral palsy and dyslexia. He repeated others' concerns and highlighted a key misassumption in the assessment process. He says: "The assumption is disability equals ill health and constantly being in touch with medical professionals, naïvely assuming there is a constant paper trail. Which is often not the case."

Hard-to-evidence impairment and illness

Supporting information and medical evidence often include letters of support from health professionals or copies of medical reports, tests and treatment plans. Participants in this research indicated a broad representation of impairments and long-term conditions, and it is clear some disabilities are harder to evidence. Those with medically unexplained symptoms, mental health problems, hidden or invisible disabilities and learning disabilities reported difficulties when collecting supporting information.

Some participants said that the provision of supporting information was straightforward but this group usually comprised those with physical impairments or impairments for which there were clinical tests. However, other participants said the lack

of objective clinical tests complicated the provision of evidence and made their claim for support harder to substantiate.

Lisa, who has anxiety, depression, fibromyalgia and chronic migraines, says she found providing supporting information for mental illness "pretty impossible". She requested a letter of support from her consultant neurologist, but was unable to provide this in relation to anxiety and depression as his specialism is neurology.

Therapeutic relationships

Health professionals play a central role in providing supporting information and evidence. Yet some participants explained that, while their health

Alison, 47, has functional mobility disorder

"I don't see health professionals. Unfortunately, my condition is not medically treatable. Whilst I have a letter of diagnosis from a consultant, there's no current treatment, so I don't see the medics for my disability. I asked my nurse practitioner to write a note because she was actually the one I've seen most recently and regularly and has any degree of insight with regards to my disability."

Sarah, 41, has arthritis, fibromyalgia, diabetes, hypothyroidism, dyslexia, partial hearing loss and mental health issues.

“You give them permission to contact your doctor and I assumed they would do that, but it doesn’t look like they did. I was told if I wanted a letter from my doctor to support my own evidence it would cost £50. I wouldn’t have been able to afford that had I been on my own on disability benefits. If I had asked for my medical records there would be far too many for me to go through and work out what to send, due to my dyslexia.”

professionals were able to confirm diagnoses and prescriptions, they were not well placed to describe the implications of impairment upon everyday life. Others said that the act of requesting supporting information from health professionals held implications for their therapeutic relationships and future care arrangements.

Where participants described effective supporting information, this appeared to be the result of long-standing therapeutic relationships. Participants felt health professionals who knew their individual circumstances were able to offer more reliable evidence about how their disability affected their daily life or ability to work.

Success through personal and social resources

The process of gathering and presenting supporting evidence requires time and energy. However, it is clear from participants’ accounts that some are better placed to navigate this system than others. At one level, individuals with greater financial resources are better able to access letters of support and private assessments. For example, Rachel says that she had access to a consultant psychiatrist due to private health insurance. She says: “I had my letter from my consultant because I actually went private to have my tests done – my husband had Bupa cover.”

Other participants reported paying for private medical assessments as evidence of their impairment, while Alison says she paid for multiple freedom of information requests. She explained these requests meant she could bypass her medical team and provide documentary evidence of her care and occupational adaptations.

Alison says: “That was actually quite useful because I got a bit back from the occupational therapists and wheelchair services.” Alison was clear that this evidence came at a cost, financially and in terms of her time in submitting each request.

There is evidence to suggest there is an ‘inverse care law’ with the difficulties disabled people face



Irene, 32, has M.E.

“My biggest concern is their perception of me as a patient – I don’t want to be seen as a problematic patient because I need their support. When I see them for my appointments, I need to be able to talk to them about my condition and what I’m struggling with. I want there to be that feeling of mutual trust there. For me it matters that I’m not seen as someone that’s potentially trying to play the system or being untruthful. I’m not being untruthful, but it is something I worry about.”

when making these applications. This means those most in need of help and support are those most disadvantaged at getting that support – and often least able to make their case or to challenge and appeal decisions.

Face-to-face assessments

Following an initial application or reassessment, claimants will typically undergo a face-to-face assessment. The PIP³² and Work Capability Assessment face-to-face assessments³³ differ in aim and structure. However, disabled claimants’ experiences are largely the same. What was clear from our interviews was that face-to-face assessments demanded great energy on the part of claimants.

Claimants usually attend an assessment centre, where a qualified health professional asks questions about their impairment or illness and ability to work or carry out daily activities, and carry out clinical tests. Assessors compile a report based on this assessment, which informs the award made by a DWP decision-maker.

Assessors are required to hold a professional health qualification and often include nurses or allied health professionals such as physiotherapists or occupational therapists. These qualifications ensure some understanding of disability and illness, but assessors aren’t specialists in claimants’ long-term conditions or impairments.

Sarah, 45, has dystonia, anxiety and depression and also expressed confusion over the assessment process. She says: “I don’t know how the system

works – I really don’t.” She explains that she felt anxious because she understood how important the assessment was in deciding her future funding arrangements. She says: “Someone who has never met me will make a decision about the next year of my life.”

The stress of this assessment means Sarah has little confidence in how she presented herself. She says: “I am worried about it because I can’t tell you what answers I have given. I don’t know. I am in the lap of the gods – that is what it feels like.”

A snapshot that cannot reflect reality

A main concern with face-to-face assessments was that they gave an unrealistic window into the lives of claimants. Participants with fluctuating conditions were particularly concerned about this and said observations made during this process could lead to an inaccurate assessment of their impairment. For many participants, face-to-face assessments failed to provide a fair or accurate reflection of their situation, especially if they had a condition that fluctuated.

Maggie, 64, who lives with Parkinson’s, spoke about issues with the assessment. Describing her recent transfer from Disability Living Allowance to PIP, Maggie says that she has lost both enhanced rates of support – a decision that has seen her household budget fall by hundreds of pounds every month. Maggie says her assessor clearly mistook her fluctuating symptoms as being inconsistent with the account she gave in her PIP form. She says: “She seems to say that my comments on the day were inconsistent with what I’d written but, as I pointed out to her, Parkinson’s is a very inconsistent condition. She should have known that. No two days are the same.”

Capable assessors?

Many who had undergone face-to-face assessments expressed concerns over the capability of assessors. One prominent issue was the fact assessors were generalists and lacked knowledge about specific impairments or long-term conditions. Many of the problems described in the section above can be ascribed to a lack of knowledge about a particular condition. Without this knowledge, participants feared assessors couldn’t possibly understand the effect

32 Department for Work and Pensions. PIP assessment guide part 1: the assessment process. www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers/PIP-assessment-guide-part-1-the-assessment-process#award-review-dates (accessed 02/2019).

33 Department for Work and Pensions. PIP assessment guide part 1: the assessment process. www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers/PIP-assessment-guide-part-1-the-assessment-process#award-review-dates (accessed 02/2019).

Lisa, 48, has chronic migraine, fibromyalgia, anxiety and depression

“I spent most of the interview crying and I felt really depressed afterwards. I think that was the first time I felt really suicidal, as a direct result of the beginning of that bout of the illness. My husband came with me and he did help – the nurse was happy for him to help, but it was just so traumatic.”

of impairment on everyday life and were therefore unlikely to make a fair assessment of their capability.

Iain, 36, has a learning disability and said his PIP face-to-face assessment had been confusing and his assessor did not understand learning disabilities. Iain says: “The lady who I saw thought I was someone else – she had the notes from another patient and didn’t really seem to understand much about my disability.”

Inappropriate clinical tests

Another source of anxiety for some participants was the seemingly inappropriate tests administered by assessors. Despite DWP guidance that clinical tests must be tailored to individual applicants³⁴, participants said they had undergone clinical tests with limited relevance to their impairment. This led many to question the conclusions made by assessors.

William, 27, has cystic fibrosis and says that his latest PIP reassessment resulted in the withdrawal of support. He says: “I don’t think it was executed very well. I was asked to stand on one foot and squeeze someone’s finger, which isn’t my problem. My problem is respiratory.”

Accuracy of assessor’s reports

All of these issues combined and reinforced one other, leading to what was perhaps the most frequently occurring theme around assessments – concerns over the accuracy and veracity of the assessor’s report. Many felt their reports contained factual errors – some even included reference to clinical tests that hadn’t been carried out. Others stated that their assessor had inaccurately recorded their answers to questions. Some even claimed assessors had manipulated their answers in order to disqualify them from support.

Anna, 55, lives with rheumatoid arthritis, and was generally positive about the conduct of her assessor during the assessment. She says she was “detached but reasonable” and “seemed to listen to what I was saying”. However, when Anna received a copy of the assessor’s report she found it littered with inaccuracies and described the assessor as having made up details.

Maggie, who is living with Parkinson’s, transferred from Disability Living Allowance to PIP in 2018, described her assessor’s report as “appalling” and claimed that her assessor “told lies”. She says: “She’s written a load of physical examination results that I cannot possibly have achieved. I physically cannot have achieved the results. She’s just copied and pasted from somebody else’s report. I’m furious.”

The appeals process

Having received a decision from the DWP, claimants must decide whether or not they wish to challenge the benefits awarded. The Welfare Reform Act 2012 introduced a process called mandatory reconsideration which – as noted above – is an internal DWP review of benefit decisions. Claimants must undergo mandatory reconsideration before they are entitled to challenge DWP decisions at an independent tribunal.

Mandatory reconsiderations must be lodged within a month of the DWP’s decision and are presented as an opportunity to revisit applications, review existing evidence and request additional evidence if needed. However, for many participants in this study the decision to lodge a mandatory reconsideration was not easy, as this process also risks losing any awards already made by the DWP.

Isla, 23, has M.E. and fibromyalgia

“I told the assessor that I couldn’t do something and she decided that I could. There was no justification – the report read something like: ‘You told me that you can’t cut up hard food yourself. When we did the strength exercises, I didn’t observe any weakness, so I’ve decided that you can cut up your own food.’ But how she could possibly know what my tremor is like from looking at my grip, especially because it’s an intermittent tremor. It just didn’t make any sense.”

34 Department for Work and Pensions. PIP assessment guide. <https://www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers> (accessed 02/2019).



Participants who had experienced tribunals said they were stressful and demanded great energy and resilience. Yet those who had seen their claims reviewed by a tribunal panel often reported the tribunal itself to be fair, transparent and accessible when compared to the benefits system more generally. However, this is an expensive way to ensure that benefit decisions are fair.

Deciding to challenge – risk and resilience

The decision to challenge DWP decisions is not without risks, as mandatory reconsiderations may return revised decisions where claimants lose existing awards. For many claimants, this was not an empty risk, as often these benefits make up the majority of their income. Several participants said that this risk meant they did not challenge DWP decisions, despite their deep conviction these decisions were inaccurate or unfair.

Isla decided not to appeal her PIP decision, which awarded her standard rates of PIP, despite her claim that the assessment report was “laughable”. Her decision not to appeal was because of her financial vulnerability and immediate need for financial support.

Other participants said that an appeal represented too much of a challenge at a time when they had already spent so much time and energy on lengthy

initial claims. Often this means stopping after their mandatory reconsideration decision, despite there being a much greater chance of success at a tribunal hearing.

Another difficulty is that where claimants are challenging ESA decisions they sometimes make a claim for Universal Credit. Once they have made a claim for Universal Credit, they cannot go back to ESA, even if their appeal is successful.

Mandatory reconsiderations – genuine review or unnecessary barrier?

In 2018, 81% of mandatory reconsiderations for new PIP claims and 77% of mandatory reconsiderations for reassessments resulted in no change to the awards under review³⁵. For the ESA Work Capability Assessment in the same year, 85% of mandatory reconsiderations resulted in no change of award³⁶. These figures are reflected in our study, as all but

William, 27, has cystic fibrosis

“Without the support of my mum, I think it would have been very difficult. I don’t think I’d have got as far as I did. My confidence isn’t 100% with that sort of thing, so I think trying to keep on top of my health as well would have been very difficult.”

35 Department for Work and Pensions. Employment and Support Allowance: Work Capability Assessments, mandatory reconsiderations and appeals. Quarterly release. <https://www.gov.uk/government/statistics/esa-out-comes-of-work-capability-assessments-including-mandatory-reconsiderations-and-appeals-march-2019> (accessed 02/2019).

36 Department for Work and Pensions. Personal Independence Payment: official statistics. Quarterly release. <https://www.gov.uk/government/collections/personal-independence-payment-statistics> (accessed 02/2019).

one participant reported mandatory reconsiderations returning no change of award.

For some participants, mandatory reconsideration was a demanding process, requiring letters to be written and further evidence to be obtained. In these cases, the apparent lack of genuine reconsideration made the process seem futile and senseless. However, the great majority of claimants succeed if they go on to appeal (see below).

The stress and hard work in appealing to tribunals

Following mandatory reconsideration, claimants are entitled to appeal their decisions to Her Majesty's Courts and Tribunals Service. The decision to lodge a tribunal appeal must be made within a month of the mandatory reconsideration decision. ESA and Universal Credit appeals are usually heard by a judge and medical doctor, while PIP appeals include a disability expert in the panel. From July to September 2018, 72% of PIP and ESA tribunals found in favour of the claimant against the DWP³⁷, a proportion mirrored in our sample.

Unsurprisingly for many participants, the prospect of a formal legal tribunal was intimidating, and the decision to pursue their claim in this way not easily taken.

Andy, 48, experiences nerve damage and chronic pain and described his experience of his PIP tribunal as "horrendous, absolutely horrendous". For Andy, the presence of a DWP presenting officer at the hearing was particularly troubling. Andy says: "I didn't know the DWP was actually going to have somebody there counter-arguing my points and making me feel like I was stupid, belittling me."

Describing the moments before the tribunal's decision was announced, Andy says: "I couldn't stop shaking and I couldn't actually go back in to hear their decision." The tribunal found in Andy's favour, awarding him enhanced rates of daily living and mobility.

Strengths of independent tribunals

Despite the stress and personal costs involved, most

Linda, 61, has osteoarthritis, fibromyalgia and Sjögren's syndrome

"At my PIP original assessment, I got 11 points and, although I was advised to appeal in the hope of being awarded the enhanced rate, I chose not to. By the time it came around to my second assessment in 2016, my health had worsened. The assessor was totally lacking in empathy and made incorrect statements in her report. I got 8 points for my second assessment. Although I disagreed with the assessment, I couldn't face challenging the veracity of the report. I was scared of losing the PIP I had been given if I appealed."

participants reflected positively on tribunals. For these participants, independent tribunals provided a transparent and evidence-based decision, which contrasted starkly with their initial assessments. Lisa's PIP assessment in 2017 initially returned a decision of 'zero points' and, after her mandatory reconsideration returned no change in award, Lisa decided to go to tribunal.

As was the experience for all participants, the process was far from easy. Despite this, Lisa says the tribunal was accessible and the panel supportive. She adds: "I don't think I could have asked more from the panel in terms of how they dealt with me. They were extremely helpful and patient."

The tribunal panel decided to award Lisa standard rates of daily living and no mobility support. This was a significant victory for her. She says: "I was very happy with that – I thought it was fair, exactly on par with the descriptors I'd matched myself to. I felt that they understood me the same way as I understood that I fit into the criteria."

All participants found the months preceding the tribunals to be stressful and some had distressing experiences on the day itself. However, most stated clearly that tribunals offered a fairer and more transparent process of decision-making.

37 Gov.uk. Tribunals and gender recognition certificate statistics quarterly: July to September 2018. <https://www.gov.uk/government/statistics/tribunals-and-gender-recognition-certificate-statistics-quarterly-july-to-september-2018> (accessed 02/2019).



Independent lives?

The term 'independent living' refers to all disabled people having the same choices, control and freedom as any other citizen – at home, at work and as members of the community. More recently, the drive towards independent living has been underpinned globally by a legal framework. The adoption of the Convention on the Rights of Persons with Disabilities in 2008 was a turning point in the international recognition of disability rights. A key focus of the Convention was the inclusion of Article 19, which focused on the right to independent living.

Although this offers the potential to transform how we think about independence, for it to be used in any meaningful way it must be reinforced by social and financial security. This includes appropriate housing, accessibility and support, alongside the right to exercise choice as to where and with whom one lives³⁸. It is in this context that the changes to disability benefits need to be assessed.

The extra costs of disability

Disabled people often face additional costs incurred by purchasing specialist aids and adaptations, but also through paying over the odds for basic goods

Maggie, 64, lives with Parkinson's

"We're struggling. Massively struggling. My husband gets his state pension at the end of September, but we have to survive until then – it really isn't sustainable. When I lost the higher rates of PIP it cost us over £600 in lost benefits, plus it means I feel as though perhaps they think I've lied all the time. I know I have these problems but the DWP don't seem to think I do."

and services. Additional transport costs can also be very significant (see further on). Scope, in their recent report *The disability price tag*³⁹, found that disabled people face extra costs of £583 a month on average. Most participants in this study spoke of extra disability-related extra costs and those who received PIP said their benefits went some way to covering these costs. For those without PIP, however, the extra costs were met, if at all, through private sources of income.

Even among participants who received PIP, these extra costs could be a significant drain on private

38 Kanter A. The development of disability rights under international law: from charity to human rights. 2015. Routledge, Abingdon.
39 SCOPE. The disability price tag. www.scope.org.uk/campaigns/extra-costs (accessed 02/2019).

resources. Paul, 52, has cerebral palsy. He challenged the idea that benefits afford a comfortable lifestyle and said that he relied on privately earned income. Paul received enhanced rates of PIP, but he stated clearly that PIP did not meet the costs of disability. He says: "PIP doesn't cover the cost of being disabled. Although I have good rates of PIP, it doesn't cover all of the costs. I worked out that, over the course of the year, I reckon I was spending about £2,500 more on impairment-related stuff than I was getting in PIP."

Just about managing – as good as it gets?

Far from affording secure and comfortable lives, participants in this study revealed a picture of life on benefits as insecure and providing only the basic standards of living. Indeed, among the small proportion of respondents who said they felt financially secure, it was only through employment or private sources of income that a good standard of living was achieved.

A minority of participants said they were financially secure, if only precariously. However, the majority of participants said that life on benefits was a constant struggle, marked by continuing worries over present and future finances.

In many cases, PIP mobility payments made the difference between social interaction or isolation. John, 43, who has endogenous depression and receives Universal Credit, described his financial issues in stark detail. John receives Universal Credit and the enhanced rate of daily living PIP, yet he described his everyday life in impoverished terms.

John, 43, lives with endogenous depression

"I wake up in the morning and I've no gas, no electric, no food. And it just upsets me that I've got no food to cook. It's not a life you'd want to wake up to and think – have I got to live the next 40 years of my life like this? You can't depend on the benefits system because they don't give you enough money to live off. You're constantly going to be struggling with debt and finance, for the rest of your life. If my life is going to be like this for the rest of it, I don't want to be here. I would rather commit suicide than live like this – it's not a life."



Conclusion and recommendations

This report, generously supported by the Three Guineas Trust, has looked at the financial impact and the lived experience of the recent changes to the social security system. It has exposed the devastating impact the changes have had, since 2010, on disabled people's wellbeing and right to independent living.

The research asks if our social security system protects the most vulnerable or if it is a 'survival of the fittest' approach. But the picture that emerges in this study is that of a difficult and unforgiving environment. Disabled people who struggle to understand the system, or who have limited resources, are less able to find their way through the protracted and difficult process from application to award. And almost every change has led them further from the financial security they deserve.

The research underpinning this report has shown the cuts to benefits caused by these changes have had the biggest negative impact on those who need support most. They are those in the poorest households, those with disabled children and those who have more disabilities than others. This not only goes against what the government has said is the purpose of the changes – it is simply unjust, unfair and cruel.

This report highlights the everyday concerns faced by people claiming disability benefits – and shows the benefits system far from providing them with comfortable, secure lifestyles. They are leading precarious lives characterised by financial insecurity, with immediate and enduring worries over money, bills and what the future may hold. In these circumstances, genuine inclusion in work, family and community life is a remote and unlikely prospect.

Many disabled people have not yet felt the full extent of the cuts made to welfare benefits, as many have not yet moved on to Universal Credit. When that happens, there will be dramatic increases in the levels of poverty among people who are already at a crisis point.

It is a disaster waiting to happen.

We urge the government to take immediate action to stop this happening by acting on the recommendations in this report.

The welfare system must be reformed so that it takes a more personal and tailored approach. We want it to provide greater support to disabled people so they



can be free from poverty and despair, and live truly independent lives.

The welfare safety net is not only failing those who need it most – it is making the situation even worse.

Recommendations

Financial change

- 1. End the benefit freeze.** The freeze has been a major factor in reducing the incomes of disabled people and pushing them into poverty.
- 2. Bring back the Employment and Support Allowance (ESA)/Universal Credit work-related activity component.** There is no evidence to suggest its removal incentivises people to work. It also wrongly assumes that everyone affected can work, and that there are no extra costs for people with health conditions.

- 3. Introduce a disability element to Universal Credit to replace the disability premiums that have been cut from the system.** Disabled people face unavoidable costs as a result of their condition and cannot afford to lose substantial sums each year.
- 4. Remove the benefit cap for everyone who receives a disability-related benefit, including those in the work-related activity group or equivalent in Universal Credit.** The cost of living with a condition means they cannot afford to lose income.
- 5. Return the work allowances in Universal Credit to pre-2016 levels.** If the government's aim really is to reduce the disability employment gap, it makes sense to let people keep more of their wages, rather than punish people for having a disability.
- 6. Remove the two-child limit.** Disabled people also have children and this limit reduces their ability to ensure both they and their children do not live in poverty. The limit compounds their financial insecurity.

The application

- 7. The Department for Work and Pensions (DWP) should produce simplified claim forms.** These should be easily available in jobcentres in accessible formats such as audio described and easy-read, as well as downloadable online. There should be no need to return these within four weeks.
- 8. Increase resources so charities and other advice agencies are better able to assist people in completing all disability benefit application forms.** Completing the application form in an effective way requires significant understanding of the application and assessment processes. Without support, it is unlikely that some claimants, irrespective of need, will present their claim in an effective way.

Assessments

- 9. Introduce regulations to ensure other types of evidence are given equal legal weight to the assessment reports.** Face-to-face

assessments provide only a brief window into an individual's life and often lead to inappropriate or inaccurate judgements about an individual's capability.

10. Automatically issue claimants with a copy of their assessment report, in their preferred format. Increase availability of recorded assessments, and ensure people know they have the choice to have the assessment recorded (audio or video). Assessment reports often contain errors. Many disabled people do not trust assessors to act fairly and independently.

11. A thorough review of the Personal Independence Payment (PIP) assessment criteria should be urgently conducted. There should be meaningful involvement from disabled people and those with long-term conditions to ensure criteria are fair and truly reflect the extra costs people face.

Supporting information and medical evidence

12. The DWP should commission an independent review of the evidence-gathering processes to explore ways to:

- support health and social care professionals to provide better-quality evidence eg guidance and templates

- ensure the duties and responsibilities of the assessor, the DWP and claimant are clear and observed
- make sure the DWP has a strategy to communicate to claimants and health professionals the evidence that will be most useful for their claim
- ensure evidence supplied by friends and family members is given consideration

13. From the start of the process, encourage claimants to obtain up-to-date evidence and pay or reimburse them for any costs. The DWP should also provide better guidance on what constitutes good evidence. Disabled people often need to source and present evidence to substantiate their claim but are given little support in doing so.

14. Work with medical practitioners to develop better-quality evidence for claimants. Often, medical evidence that claimants are able to obtain merely gives a diagnosis while saying little about someone's needs and day-to-day difficulties.

15. To restore confidence in the process, assessors should be obliged to review all supporting evidence provided by a claimant, with penalties if they do not. The assessor





report is currently given more weight in the decision-making, which is resulting in large numbers of ill-advised decisions.

Mandatory reconsiderations and tribunals

- 16. Those looking at a decision again when it is challenged by the claimant should not be able to see the previous decision-maker's conclusions.** This will increase impartiality. There are too many cases of mandatory reconsideration reports being copied and pasted from the original decision.
- 17. Those going through mandatory reconsideration should be given the opportunity to provide oral evidence of how their condition affects them in all cases.** Often decisions are changed at tribunal because of new oral evidence. Giving this at an earlier stage will improve the process.
- 18. Increase the number of tribunal panel members so that tribunal waiting times can be brought down to more reasonable levels.** The average wait is 29 weeks for a tribunal hearing, with some areas having to wait up to a year.

19. Introduce targets for the length of time cases need to wait to be heard by a tribunal. Some people have to wait up to a year to be heard at tribunal. A target will help reduce waiting times.

20. Conduct full audits of decisions that are subsequently changed at tribunals. This will help restore confidence in the system and also provide ways of improving decision-making.

21. The DWP should commission independent reviews of the Universal Credit and PIP application and decision-making processes. This should particularly but not exclusively examine the failings of the mandatory reconsideration process.

Cost of living with a disability

22. Introduce regular, independent surveys of the actual costs of living with a disability. Then, ensure that the level of payments under PIP better reflects the actual cost of living with a disability.

Notes

Notes

Notes

Disability Benefits Consortium members

Action Duchenne

Action for M.E.

Action on Hearing Loss

Advice UK

Advocard

Age UK

Ambitious about Autism

Association of Pensions and Benefits Claimants

Aspire

Autism Anglia

The Brain Charity

Breast Cancer Care

British Lung Foundation

Capability Scotland

Carers UK

Child Poverty Action Group

The Children's Society

Citizens Advice

CLIC Sargent

Contact a Family

The Council for Disabled Children

Crohn's and Colitis UK

Cystic Fibrosis Trust

Deafblind UK

Dimensions UK

Disability Agenda Scotland

Disability Law Service

Disability Rights UK

Down's Syndrome Association

DrugScope

ENABLE Scotland

Epilepsy Society

Epilepsy Action

Equalities National Council

Guide Dogs for the Blind Association

Haemophilia Society

Hafal

Health and Social Care Alliance Scotland

Inclusion London

Inspire Wellbeing

Institute of Revenues, Rating and Valuation

Kidney Care UK

LASA

Leonard Cheshire Disability

Livability

Low Incomes Tax Reform Group

Marie Curie

Meningitis Research Foundation

Mind

Motor Neurone Disease Association

MS Society

Muscular Dystrophy UK

Multiple System Atrophy Trust

Myeloma UK

National Ankylosing Spondylitis Society

National AIDS Trust

National Association of Welfare Rights Advisors

National Autistic Society

National Children's Bureau

National Deaf Children's Society

National Rheumatoid Arthritis Society

National Union of Students

Papworth Trust

Parkinson's UK

Rethink Mental Illness

Royal British Legion

Royal College of Psychiatrists

Royal Mencap Society

Royal National Institute of Blind People

RSI Action

Scope

Scottish Association for Mental Health

Shine

Sense

Sense Scotland

The Somerville Foundation

St Joseph's Hospice

The Stroke Association

Sue Ryder

Terrence Higgins Trust

Thomas Pocklington Trust

Together for Short Lives

Transport for All

The Trussell Trust

TUC

United Response

Versus Arthritis

Revitalise

Welsh Association of ME & CFS Support

Zacchaeus 2000 Trust
