



Inclusion Scotland

Disabled People's Organisation

Our voices ■ Our choices

“They got him on a good day, they didn't see him on a day when he was in bed crying and couldn't get up. He pulled himself together as best he could for the medical and was told his benefits were stopping.... three months later he was gone.”

**Second class citizens?
How welfare reform
marginalises
disabled people.**

March 2015

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Key Findings

- Disabled people find the process of applying for benefits difficult and distressing. A combination of past experience and the stories of their peers mean that they hold little faith in their benefits applications being successful. Application forms are difficult to complete and participants nearly always required support from third sector organisations, council offices or advice agencies. Participants also found it difficult to explain impairments or conditions satisfactorily on application forms and during face-to-face assessment.
- Women who are survivors of sexual violence are being failed by the benefits system. Their experiences of applying and being assessed for benefits can re-ignite feelings of trauma, particularly when confronted with male assessors or male dominated panels.
- There has been a lack of consistent and reliable information about the benefits changes, and this has led to confusion for disabled people who wish to apply for benefits. Further, the onus has been on disabled people to go out and find sources of information and support which can help. While some organisations have been working to keep people informed and supported, disabled people feel that the benefits system is a technical world they are largely shut out of.
- More support is needed for disabled people who rely on the benefits system. Staff at Job Centre Plus offices have little time for individual claimants, and may not use the time they do have positively. Some participants reported Job Centre staff openly using derogatory language to describe benefits claimants.
- The political and media rhetoric around the benefits changes is deeply stigmatising and has left disabled people feeling isolated in their communities, and increasingly vulnerable.
- Disabled people feel a great deal of fear around losing their benefits, particularly since impairments and health conditions create extra costs. Those who have long-term reliance on benefits have such low incomes already that any cuts pose a huge threat. The rhetoric around the changes also perpetuates fear about losing benefits.
- The majority of research participants feel negative about finding and staying in work, and about their future prospects generally. Benefits changes are identified as a cause of increasingly negative feelings.

1. Introduction

1.1. Background

When the Welfare Reform Act (2012) replaced some existing benefits and introduced new charges and a tougher sanctions regime, Inclusion Scotland were immediately concerned about the potential impact this would have on disabled people. We were particularly concerned about:

- Tougher assessment for those claiming sickness and disability benefits;
- More stringent conditionality for those on out-of-work benefits;
- A disproportionate number of disabled households being hit by the Bedroom Tax;
- A harsher political and media rhetoric about benefits claimants, including disabled people.

We estimated that at least half of the benefits cuts (+ £1 billion) would fall on Scottish disabled people and their families.¹ And we were not alone on our concerns about the disproportionate burden disabled people would bear. The Centre for Welfare Reform argued that the cuts have been ‘targeted’ - disabled people have been targeted 9 times more than non-disabled people; and those requiring social care have been targeted 19 times more than other citizens.² We anticipated that tough times lay ahead for disabled people - not only financially, but also in terms of health and well-being and participation in society and work.

Yet, according to the Department for Work and Pensions (DWP), the changes aim to ensure that it ‘pays to work’ and that public spending is put on a more sustainable footing. They also look towards ‘protecting the most vulnerable’ - including disabled people - by supporting them to lead independent lives.³

¹ Inclusion Scotland Welfare Reform Briefing: September 2011

² Dr Simon Duffy, Briefing on How Cuts are Targeted (2013):
<http://www.centreforwelfarereform.org/library/by-date/briefing-on-how-cuts-are-targeted.html>

³ DWP April 2014:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/312874/dwp-reform-agenda-explained-apr-2014-1.pdf

Our research however suggests that the so-called 'reforms' do little to support disabled people.⁴ Instead, they impact negatively on the well-being and personal resilience of disabled people, and on their ability to live independently.⁵

Further, these reforms seem oblivious to some of the difficulties disabled people have finding and staying in work. Even if it 'pays to work', in order to get work it does not pay to be disabled.

Inclusion Scotland is the lead disabled people's organisations in Scotland to take up the issue of welfare reform. We have voiced the concerns of our members about the changes through:

- Submitting evidence to the DWP and the Scottish and UK Parliaments' Committees;
- Briefing MPs and MSPs about the impacts on disabled people;
- Providing evidence and supporting disabled people to speak directly to Raquel Rolnick, the UN's Special Rapporteur on Housing, about the impact of the Bedroom Tax;
- Providing written and oral evidence to the United Nations Universal Periodic Review in Geneva and reporting to the United Nations committee monitoring implementation of the UN Convention on the Rights of Disabled People.⁶

We have highlighted some specific areas of impact, including: housing, mobility, the accessibility of benefits applications, and disabled people's human rights.

Housing

The Bedroom Tax (formally known in the Welfare Reform Act as the 'under occupation penalty') resulted in disproportionately high levels of rent arrears being incurred by Registered Social Landlords (RSLs) and Scottish Local Authorities. It also resulted in some disabled people having to move out of specially adapted properties and into new accommodation, which then had to be adapted at some expense to meet their needs.

⁴ We use the word 'reform' tentatively. According to the Oxford English Dictionary, to reform is 'to make changes (to something, such as a system) in order to improve it'. We reject the idea that things are improving, given the ways in which disabled people are being affected.

⁵ Inclusion Scotland understand Independent Living to mean disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. This includes rights to practical assistance and support to participate in society and live an ordinary life. It does not mean being left to fend for ourselves.

⁶ <http://www.un.org/disabilities/default.asp?id=150>

By the end of May 2013, 82,500 households in Scotland had already been affected by the Bedroom Tax - and 80% of those households contained a disabled person.⁷ Disabled people had experienced anxiety, financial difficulty and relocation as a result of the policy. After the UK Government transferred the power to cap Discretionary Housing Payments (DHPs) in the run-up to the referendum on independence, the Scottish Government pledged £50 million in extra funding for DHPs for this financial year to help Local Authorities mitigate the impact of the Bedroom Tax. However these are only a temporary measure, and we are concerned that the Bedroom Tax is likely to affect disabled people in the future unless it is scrapped.

Mobility

The replacement of Disability Living Allowance (DLA) with Personal Independence Payment (PIP) brings more stringent eligibility criteria for the higher mobility component, now called the 'Enhanced Mobility' element under PIP. 47,000 disabled people who currently receive DLA high rate mobility are expected to fail to meet this new criteria. This will impact on access to concessionary travel and Motability vehicles as entitlement to higher rate mobility also brings entitlement to other benefits. The new costs associated with travel are likely to reduce disabled people's access to family, social, and community life, as well as to work. Overall, this will negatively impact on their human right to independent living.⁸

Accessibility of Benefits Applications

UK Government's new 'Digital by Default' strategy encourages the majority of benefit claims to be made online. However, Inclusion Scotland has noted that this creates additional barriers for disabled people, given that only 44% of disabled people in Scotland have home internet access, compared to 74% of non-disabled people.⁹ Further, lengthy online forms can be difficult to complete without support; or within the restricted usage times allowed on public library computers. These issues are particularly pertinent for people with learning difficulties, but a lack of access to the computers needed to complete benefit applications also impacts on already impoverished disabled people who cannot afford home computing or travel to internet access points.

⁷Inclusion Scotland submission: Impact of the Under Occupation Penalty or 'Bedroom Tax' on Disabled People in Scotland

⁸See 2011 report by Joint Committee on Human Rights:
<http://www.parliament.uk/business/committees/committees-a-z/joint-select/human-rights-committee/inquiries/parliament-2010/protecting-the-right-of-disabled-people-to-independent-living/>

⁹<http://www.scotland.gov.uk/Publications/2011/12/22155754/5>

It also impacts on blind or visually impaired people who cannot afford additional software to allow them to access online documents.

Human Rights

The cumulative impact of the reforms breaches disabled people's right to independent living, to an adequate income, and to inclusion in the community.¹⁰ Further, the UK Government announced the cuts before any Equality Impact Assessments (EIAs) were undertaken. We believe that this shows a blatant disregard for the Equality Act, which promotes the use of EIAs. In addition to this, our shadow report to the committee of the United Nations Disabled People's Convention (UNCRPD) explains the way in which the changes to the welfare system challenge disabled people's right to family life and equality of employment under the UNCRPD.¹¹ This has involved discussion of the constraints placed on disabled people and their living arrangements by the Bedroom Tax, and the discriminatory nature of the Work Programme, respectively.

The Smith Commission on Further Devolution

This research was being completed around the time of the Scottish referendum on independence and the subsequent Smith Commission on further devolution. Although this report does not include our reflections on the devolution process, it is nonetheless worth mentioning how it relates to some of our concerns.¹² The Westminster Parliament is to retain powers which prevent any reform to the Work Capability Assessment (WCA), Mandatory Reconsiderations and Sanctions.¹³ However disability benefits, including Personal Independence Payment (PIP), have now been recommended for devolution to Scotland. Unfortunately, it is realistic to expect that the Scottish Parliament will not receive them for some time. We hope that disability benefits will subsequently be revised within a fairer system in which disabled people have some say, but this will take even longer still.

¹⁰ See, for example, Inclusion Scotland Welfare Reform briefing, September 2011

¹¹ See Inclusion Scotland's List of Issue for UNCRPD committee, drafted October 2014.

¹² You can read our submission to the Smith Commission here: <http://www.inclusionscotland.org/>

¹³ Mandatory Reconsideration was introduced in October 2014 after our interviews had taken place. It is therefore not mentioned in this report. The Child Poverty Action Group (CPAG) provide a useful explanation of Mandatory Reconsideration: <http://www.cpag.org.uk/content/new-appeals-rules-and-procedures>

1.2. Aims

This research was undertaken to:

- A. Capture the views and experiences of disabled people in Scotland who are, or expect to be, affected by the current fleet of benefits changes.** Given our concerns about the impact of the changes on disabled people, it is important that opportunities exist for disabled people to share their experiences and reveal what the changes mean in the context of real lives.
- B. Highlight key issues around the welfare changes as currently experienced by Scotland's disabled citizens.** Case studies illustrate some of those issues.
- C. Make recommendations about the future of Scotland's welfare system based on the findings of the research.**

1.3. Methodology

We wanted to know how disabled people in Scotland are experiencing the changes being made to the welfare system. We did not set out to find out about specific changes, but asked our research participants to inform us about the changes they had encountered - or expected to encounter - and to tell us about their experiences of this.

The research proceeded in four stages. To help us gain an understanding of the pertinent issues we undertook a review of recent literature on the impact of the welfare changes in relation to disabled people. This included reports written by third sector organisations, government departments and parliamentary committees throughout Scotland and the UK. As our focus is on disabled people, we refer only to the literature which makes specific reference to welfare change and disabled people.

Secondly, we conducted an online survey to find out how disabled people in Scotland feel the welfare changes have affected them. The survey asked respondents about the benefits they received, and requested that they rate the impact of benefits changes on specific areas of their lives using a simple three-point Likert scale.¹⁴

¹⁴ <https://www.surveymonkey.com/mp/likert-scale/>

We asked about financial security, mobility, affordability of housing, sense of community, well-being of family and friends, attitude to work, social life, well-being of carers and feelings about the future. The survey returned 315 responses, plus more than 60 'free text' comments.

Thirdly, we conducted semi-structured qualitative interviews with disabled people we contacted through our networks. We again asked about the benefits changes people had experienced and how this affected different areas of their lives. In cases where no benefits changes had yet been experienced, we asked about how participants expected to be impacted. In all of the interviews, we also asked participants to reflect on the current climate for disabled people and how they experience participation in society and politics. This helped us to collect rich, detailed information on welfare reform as a lived experience for disabled people.

Fourthly, we contacted some of our survey respondents to find out about their experiences. Having noted that we had not heard about disabled people's experiences of the Bedroom Tax or sanctions, we contacted survey respondents who had indicated that they had experience of these issues.

This led to several further interviews, bringing our interview total to 24 people overall.

All interviewees were thus self-selected, and most of those who came forward identified as White British or Scottish. We regret that despite our best efforts groups - for example, by working with partner BME organisations - we were unable to recruit interviewees from minority ethnic. We were also unable to gather the views of LGBTQI disabled people - again, despite our best efforts. We do however remain committed to the importance of building in strategies to include those with multiple protected characteristics in our research.

In addition to the primary research strategy, we have also utilised evidence gathered through our on-going consultation and engagement work with disabled people.

An important point to make is that this research has been conducted at an early stage in the roll-out of the welfare reforms in Scotland. This means that not all benefits are covered and the experiences interview participants have of the changes are limited. Universal Credit (UC) has yet to be rolled out in Scotland, but we do touch on some of the concerns participants have around this.

Personal Independence Payment (PIP) underwent a phased introduction in

Scotland from 13th January 2014, and currently only affects new claimants, claimants whose existing DLA has expired, terminally ill claimants and claimants who note a change of circumstance.¹⁵ Further, administration faults have meant that the time between an initial application and receipt of the benefit can take 6 - 8 months or more. This further reduces the numbers who have full experience of the outcome of the application process. However, it has allowed us to highlight the frustrations people feel around these long delays. Finally, the Bedroom Tax was introduced on 1st April 2014 and, although people were affected in the early period, the Scottish Government was given new powers to offset the charge in May 2014.

¹⁵ To qualify as terminally ill, the claimant must be expected to die within 6 months.

2. LITERATURE REVIEW: THE IMPACT OF WELFARE REFORM ON DISABLED PEOPLE IN SCOTLAND

Reports by third sector organisations, university departments and academics, and government departments, record the impact of welfare changes to date and project future impact. However, only a small proportion addresses the impact on disabled people. Not only have many of the benefits received by disabled people changed, but it has been predicted that disabled individuals will 'experience these changes cumulatively', and this will have a 'disproportionate impact' (Joint Parliamentary Committee on Human Rights 2012:10-18) on their lives. In what follows, we review the literature to date, focussing specifically on what it reveals about the impact on disabled people.

There are estimates about the number of individuals and households affected by the changes, and the financial losses they face. While different figures are reported by different organisations, there is agreement that disabled people face the sharp end of the cuts.¹⁶ This is because the largest welfare cuts in cash terms are to those benefits,¹⁷ which sick and disabled people are most likely to rely on.

The Scottish Government estimates that when the reforms come into full effect in Scotland - in most cases, during the 2014/15 financial year - 55,000 households will be affected by the changes to Disability Living Allowance;¹⁸ 144,000 by changes to Incapacity Benefit; 80,000¹⁹ by changes to local housing allowance; the same again by the new size criteria for council/RSL rented properties; and 2,600 by the household benefit cap. Additionally, a New Statesman article²⁰ estimates that 3.7 million disabled people across the UK stand to be affected by 2018, losing an alarming £28.3 billion worth of financial support.

The financial impact of the cuts of course brings a host of related, non-financial impacts along with it. For example, when 105,000 disabled people stand to lose their disability benefits by 2018 in the change-over from DLA to PIP, there

¹⁶ See CLES 2012; Duffy 2013

¹⁷ Duffy 2013 a

¹⁸ Lister et al 2014

¹⁹ The figure 80,000 refers to households containing one or more disabled person.

²⁰ "Where do disabled people fit into George Osborne's aspiration nation?", Richard Hawke, New Statesman, 28th March, 2013

will be negative consequences for mobility and the affordability of care. Further, Carer's Allowance only applies where a claimant is caring for somebody who receives disability benefit. This means that for households where disability benefit is lost, there may be another financial loss in the form of Carer's Allowance.

Many reports have questioned the sincerity of the UK government's stated intention to ensure that the most vulnerable are protected and that disabled people are able to live independent lives. Cross argues that:

“the intention of this government is not to improve the lives of disabled people; not to find them jobs; not to increase their independence... (but) to destroy the welfare state.”²¹

Similarly, Simon Duffy reflects that:

“Never before have we seen such a direct attack on the rights and interests of disabled people. Never before have we seen such radical cuts to social care. Never before have we seen such an increase in central government power . Never before have we seen such direct efforts to undermine human rights, the duties of citizens and the role of government in guaranteeing our basic securities.”²²

Both Cross and Duffy argue the cuts increase the vulnerability of disabled people and negatively impact on rights, interests, and independence. Much of the literature supports this assessment, drawing attention to the impact on disabled people in the areas of housing, mobility, health and well-being, work, and human rights. We cover each of these concerns in what follows.

In housing, disabled people have been impacted by the ‘bedroom tax’, one of the most controversial changes. Scottish Government reports that over 70,000 households were affected, losing on average £11.25 per week; and a massive 80% of those households contained a disabled person.²³ Scottish Government have now mitigated this charge in Scotland²⁴ for the time being.

²¹ 2013:722

²² Duffy 2014:3

²³ <http://www.scotland.gov.uk/Publications/2014/06/4507/1>

²⁴ See introduction

At a UK level, Carers UK (2013) has found that only 1 in 10 carers²⁵ have been receiving discretionary housing payments on an on-going basis. Worryingly, three quarters are now being forced to cut back on essentials such as food and heating; and 1 in 6 are falling into rent arrears and facing eviction.

The literature shows that the health and well-being of disabled people is already suffering as a result of welfare cuts. There are 'increases in anxiety, fear and distress' as people contemplate the compulsory²⁶ health assessments which the new benefits require.²⁷ This can in turn exacerbate existing mental health issues and hinder recovery. Further, some disabled people's fear of losing entitlement is intensified by a system which appears unequipped to deal with mental health conditions.²⁸ Jackson and Nixon note that -

“the impact of the Work Capability Assessment (for Employment Support Allowance) is likely to be highest on people with mental health problems who may not comply with the reassessment process or whose conditions are difficult to assess by generalists.”²⁹

Additionally, Hilary Wainwright asks

“what kind of society is it where people are called in for crude tick box tests to prove that they are ‘really’ disabled, then found fit to work only to die a few months later?”³⁰

The difficulty of applying for benefits in the first place only adds to all of this. Clifton et al. found that the language used in DWP communications is difficult to decipher, and application forms arrive with no guidance on how to complete them, demanding a lot of time and attention.³¹

²⁵ While there is often a distinction made between carers and disabled people, impacts on one affect the other. Further, many carers are also disabled people.

²⁶ A face-to face assessment may not be carried out when the claimant's condition is evident without it, or they are not well enough to attend.

²⁷ Clifton et al (2013)

²⁸ CLASS 2013

²⁹ 2012:5

³⁰ Wainwright cites a minimal number of cases, which nonetheless highlight the mistakes being made by assessors

³¹ 2013

They also revealed a feeling that ‘the system is designed to stop people applying’ and is ‘financially driven’, not people centred.³² Incorrect assessment and the high level of successful appeals (Clifton et al 2013:13) perhaps present initial evidence that there is a ‘quota’ system set by the DWP, aimed at getting people off benefits and thereby denying sick and disabled people the financial support they need.³³

A significant feature of the whole process has been a feeling amongst service users that they are ‘under scrutiny’ and classed as ‘criminals’ or work-shy ‘scroungers’.³⁴ Indeed, focus groups conducted by Clifton and his colleagues revealed misguided attitudes about disabled people amongst the general public.³⁵

For example, people over-estimate the instance and severity of benefit fraud. Unsurprisingly, disabled people have reported feeling threatened by a climate where they are subject to the withdrawal of financial support and a national discourse which paints them as ‘underserving’ ‘scroungers’.

Indeed, Aditya Chakraborty has written recently in the Guardian newspaper that to be disabled in modern day Britain is

“to be constantly monitored on whether you really are disabled, because the Department for Work and Pensions is animated by only one idea: that someone, somewhere, is claiming something to which they're not entitled.”

This has not been helped by the media. Inclusion London, for example, notes a shift in media discourse between 2004/5 and 2010/11 towards discrediting disabled people.³⁶ Stories about disability benefits fraud or stories which frame disabled people as a ‘burden’ on society increased, as did the use of pejorative language to describe disabled people.

Articles describing disabled people in sympathetic and deserving terms decreased; as did articles documenting real life experiences of living as a disabled person, and ‘contextualising’ issues such as how the cuts will impact on disabled people.

³² Clifton et al 2013:11-2

³³ See Kayila Franklin 2013

³⁴ Clifton et al 2013:15

³⁵ Organised as part of the research by Clifton et al 2013

³⁶ Briant et al 2011, commissioned by Inclusion London

A survey by Disability Rights UK in 2012 found that while 77% of the public could cite a negative media article about disabled people, only 35% could think of a positive story. 76% felt that the volume of negativity was increasing and 94% said that coverage of disability equality issues was 'unfair'.³⁷

Since the Labour Government reformed Incapacity Benefit in 2006, there has been 'a requirement for all but the most severely ill or disabled [people] to engage in work-related activity' (Beatty and Fothergill 2011).

However, it has been asked 'whether suitable jobs exist and whether disabled people are able to get them' (CLASS 2013:10). Research commissioned by Sheffield Hallam university suggests for instance, that 'IB claimants ... often stand little realistic chance of finding work' (Beatty and Fothergill 2011:23).

Often, jobs simply do not accommodate impairments and health conditions; and although employers are legally bound to make 'reasonable adjustments', continuing very high levels of worklessness amongst disabled people show that this often dissuades employers from appointing disabled people. Although illegal, it can be very difficult to prove that this discrimination happens during recruitment processes. Furthermore, a disproportionate number of people claiming disability benefits live in the weakest local economies, have lower educational attainment and poorer health - all of which negatively impact on employability (CLASS 2013:10).

While the demands of the labour market make it more difficult for disabled people to find employment, general living costs tend to be higher for a disabled person than for a non-disabled person. A recent study by the disability charity, Scope found that disabled people spend an average £550 a month in disability related expenses. This includes costs such as taxis, increased use of heating and electrical amenities, maintaining equipment and paying for care.³⁸ The study also says that disabled people:

- Are twice as likely to have unsecured debt totalling more than half of their income;
- Are three times more likely to use doorstep loans;
- Have on average £108,000 less in savings and assets than non-disabled people;
- In the 55-64 age group, have on average £125,000 less in private pension savings.

³⁷ <http://www.disabilityrightsuk.org/press-portrayal-disabled-people-rise-hostility-fuelled-austerity>

³⁸ See Scope report here:
<http://www.scope.org.uk/sites/default/files/Credit%20and%20Debt.pdf>

The Government has been widely criticised for its failure to properly evaluate the impact of welfare cuts on disabled people. The Westminster Parliament's Joint Committee on Human Rights is 'not satisfied that the government has demonstrated reasonable justification for the negative impact of the introduction of PIPs on the rights of disabled people to independent living',³⁹ while many organisations have called repeatedly for a cumulative impact assessment of all the different cuts to benefits on disabled people from the UK Government.⁴⁰

³⁹JCHR (2012:22)

⁴⁰For example, see the WOW petition campaign

3. FINDINGS

3.1. The process of applying and being assessed for benefits is distressing for disabled people.

Research participants told us that DWP letters and application forms are complex, intimidating and can be misleading. On receipt of the invitation letter to apply for PIP, people with learning difficulties or autistic spectrum disorder did not always understand what they were required to do.

Several research participants noticed that letters from the DWP tended to arrive on a Friday. This means that applicants are often unable to speak to someone about their application for a further 2 days, which accentuates worry and causes additional stress. Further, letters are frequently not delivered in accessible formats. One interview participant said **“They [the DWP] never do large print... it's like getting blood out of a stone... I asked again and again and again”**.

Participants often found it difficult to capture their conditions or impairments on application forms - although **“(the forms) say attach an additional sheet if necessary, it's making what you've got fit the boxes”**.

Participants tended to feel great **“worry [around] how to explain things. ...They make you feel as though you have to justify breathing”**.

Application forms require information to be written in specific, often non-intuitive, ways; and most participants required professional support in completing them. This included help in understanding the questions, advice about the best way to frame how an impairment or condition is managed, and guidance around using the correct language.

Some of the explanations offered by participants included: **“I looked at [the form] and I didn't know what they were asking”** and **“I would be guilty of answering 'yes I can do that' - but actually on further reflection I can only do it because of the help I can get”**.

It was notable that participants with further or higher education qualifications opted for support just as frequently as those without. One person felt that **“you shouldn't need to get professional advice (because) there shouldn't be trick questions!”** while **“for the ordinary lay person [the application] is difficult”** regardless of their background.

Others reflected on the difficulties which some disabled people may face if they do not have knowledge of, or access to, appropriate services and resources. This echoes some of the findings in Clifton et al's research.⁴¹

Participants received support from Local Authority offices, citizen's advice bureaux, housing associations, individual support workers and third sector organisations, including advocacy and support groups.

For example, Grapevine (the information service of Lothian Centre for Inclusive Living) has been helping claimants to complete PIP application forms, and participants gave very positive feedback about this service.⁴² However it was notable that not all participants were initially aware of the help available and often had to seek this out for themselves. While all participants had managed to find help, levels of understanding and satisfaction differed considerably.

Further, despite help being available the application process is over-shadowed by UK Government estimates about withdrawal of support from people on disability benefits, as well as wider political rhetoric which highlights the need to reduce the benefits bill alongside the number of people falsely claiming benefits.⁴³ This has resulted in people who have applied for benefits feeling that it was **“completely stigmatising”**; and people awaiting assessment or review for a benefit experiencing a **“constant insecurity”** which affected **“health, well-being and outlook on life”**.

Applicants felt **“completely powerless in the whole scheme of things”** and understood the aim of those assessing their application to be discovering reasons to doubt the legitimacy of the claim. In some cases, identity as a disabled person had been undermined as it was felt that **“you have to work hard to convince people that you are a genuine claimant”** and this can create self-doubt about that status.

Participants were frustrated by lengthy processing times for applications; and experienced difficulty establishing whether information had been received by the DWP and what its status was.

For example, one participant applying for PIP waited 8 months for a decision. It was difficult to get started with the process since she relied on her mother, also her carer, finding time around her job and carer role to access support.

⁴¹ See Clifton et al 2013

⁴² see Inclusion Scotland PIP consultation on 19th August 2014

⁴³ For example, that 6000,000 disabled people will lose support under the new PIP criteria: <http://www.bbc.co.uk/news/uk-22058059>

She then received no information about her application after it was logged. Her mother made several attempts to call the DWP. However lengthy waiting times and caring responsibilities meant that she had to abandon her attempts repeatedly or neglect her family's needs while she waited and spoke to someone.

Due to the PIP implementation timetable and problems with its administration,⁴⁴ no interviewee had experienced a face-to-face assessment.⁴⁵ There was however a strong belief amongst all participants that ATOS are not equipped to carry out assessments; and that assessments are completed by **“faceless bureaucrats”** who are ill-informed about life as a disabled person.

One survey respondent said: **“I feel very insecure in my financial situation as I know I can be re-assessed at any time and I do not feel confident in the assessor's ability to give a fair assessment”**. Word-of-mouth and media reporting of people's experiences at assessment - particularly the Work Capability Assessment (WCA) - helped to shape opinion here, entrenching dissatisfaction and low expectations about the outcomes of assessment.

However, during consultation workshops we conducted later in the research process we did meet some disabled people who had attended a face-to-face assessment for PIP. They were bemused that assessors would only allow brief answers and did not provide scope to explain conditions, particularly fluctuating and mental health conditions.

The application and assessment process is particularly ill-suited to those living with mental health or other 'hidden' conditions. Delays in applications can aggravate conditions.

For example, one interviewee explained: **“I was having terrible anxiety attacks (while waiting to hear about an application). Suffering depression is part of my MS, but I was having anxiety like I had never experienced”**. Anxiety can also come from fear of wrongfully being found fit for work - and therefore not a legitimate claimant.

Regardless of impairment or health condition, interviewees expected that they would have to return to work; and worried about how they would cope. One interviewee reached the conclusion that **“they're saying if I can flick a switch I can work”**, while others thought that simply being able to walk would mean being found fit for work.

⁴⁴ This has been widely reported in the media. See, for example: <http://www.mirror.co.uk/news/uk-news/atos-tests-failed-75-disabled-4126386>

⁴⁵ see Inclusion Scotland PIP consultation on 19th August 2014

If health conditions are overlooked the results can be devastating. Suicide affects a tragic minority of claimants who lose their benefits, but those incidents shape the views others hold about the assessment process and what life will be like afterwards.

One interviewee spoke about a friend who took his own life after losing Employment Support Allowance (ESA):

“He wasn’t able to work but he was one of those unfortunate people who presented very well when he was asked a question. He was eloquent and he could compose himself very well... He was found fit to work, but he had epilepsy, bipolar effective disorder, rheumatoid arthritis and diabetes... They got him on a good day, they didn't see him on a day when he was in bed crying and couldn't get up. He pulled himself together as best he could for the medical and was told his benefits were stopping.... Three months later he was gone. That's the kind of impact these things have.”

And while the correlation between benefits cuts for individuals and suicide is difficult to establish definitively, efforts have been made to record cases where there is a strong link.

For example the organisation, Black Triangle has recently published a list of cases.⁴⁶ This list contains 69 people, ranging in age from 28 to 74, who had lost benefits, had been threatened with the loss of benefits, been found ‘fit to work’ at an ATOS assessment, or who were being forced to work hard to prove their eligibility to the DWP.

Decisions can of course be appealed, and the number of disabled people regaining entitlements to benefits such as ESA after an appeal has risen dramatically since the benefits changes began.⁴⁷ However, the stress of gathering medical evidence and ‘pleading’ disability before a tribunal can be debilitating.⁴⁸

⁴⁶ see <http://blacktrianglecampaign.org/2014/10/21/uk-welfare-reform-deaths-updated-list-october-21st-2014/>

⁴⁷ See article from Voices of eXperience (VoX) for example <http://mikesivier.wordpress.com/2013/06/28/esa-appeals-more-than-double-and-decisions-in-the-claimants-favour-are-increasing/>

⁴⁸ GPs usually charge for medical evidence that has been requested by claimants.

An extra layer of bureaucracy has recently been added to the appeals process. Since October 2013, all benefits decisions being appealed must go through a process called 'mandatory reconsideration'. This means that the DWP will review the decision internally before an appeal can be undertaken by the claimant.

However the DWP's 'reconsideration' is not time-limited, and this has resulted in extreme delays during which time claimants do not receive any benefit.⁴⁹

For women who develop mental health conditions after experiencing sexual violence, the application and assessment process can be uniquely traumatic.

For example one woman had to give evidence in front of an all-male panel at a tribunal for ESA. She found this intimidating and experienced anxiety during the tribunal session. Another woman was forced to disclose her rape to a male doctor during a past assessment for DLA.⁵⁰ In a later application she expressed the constraints her condition places on facing male assessors. Nonetheless, a male GP came to her door unannounced on a Saturday evening and spent 15 minutes knocking on her door. She was **"terrified"** and forced to call the police.

3.2. To add to the difficult application and assessment process, there is a lack of reliable or consistent information about the benefits changes.

There is confusion around the timelines for implementing all of the changes, particularly Universal Credit and Personal Independence Payment; and **"not knowing what's going to happen or when it's going to happen"** causes considerable worry.

Information is available from organisations such as Citizens' Advice Bureaux, Shopmobility offices, housing associations and local support groups, but this has not always been consistent:

"the Housing Benefits section had told us that we would have to pay the bedroom tax, but ARK (housing association)... told us we didn't... it was a bit confusing in terms of one person saying one thing and another saying something else."

⁴⁹ See report Voices from the Frontline: Mandatory Reconsideration for a discussion of delays and the impact this has - <http://www.cas.org.uk/publications/voices-frontline-mandatory-reconsideration>

⁵⁰ In 2012, just before the introduction of PIP.

Participants also reported that it is difficult to get consistent and accurate information about entitlement: **“when you ask what your entitlement is, you never get the same answer”**.

For example, confusion exists around whether PIP can be claimed if the applicant is working. One participant reported that a DWP advisor had attempted to make her feel **“caught out”** when she revealed that she worked; while another participant felt as though he was being **“interrogated”** and was under **“suspicion”** during his initial phone call. PIP can of course be claimed whether in work or not.

The density of information and lack of consistent advice meant that interviewees often felt that they were struggling to stay abreast of their entitlements and all of the details about their benefits. They felt ‘caught out’ and penalised when they missed something. For example, one person commented:

“I'm quite good at pushing doors and saying can you help me, but I'm struggling. We didn't realise that ESA was means-tested, that's something that nobody tells anybody.”

For this person, ESA was awarded and then withdrawn a short time later, creating uncertainty and worry about when and how things might change in the future. This happened despite the claimant being pro-active in seeking help with organising his benefits. Although he and his partner had good general knowledge about their benefits, they wished that **“someone would just sit down with us and look at everything, what we're entitled to, what we're doing...”**

The **“absolute fear of not knowing”** is stressful in itself and can cause damage prior to any assessment taking place. For example, some interviewees had Multiple Sclerosis (MS) and emphasised the particularly dangerous effects of stress on their condition:

“Stress is one of the main conditions that causes MS to worsen, that's widely recognised. If people are put into that situation, that they're worried about their living, how their life is going to pan out because of this PIP, then it will affect them.”

3.3. Participants felt that a greater level of support for disabled people who claim benefits is needed.

Many felt that there is **“no support”** for disabled people, who experience difficulty in getting the right information, having enough time and help with completing applications, and keeping Job Centre Plus appointments.

Citizens Advice Bureaux no longer have the resources to support people through their applications. One participant recalled that in the past a claimant could go in to a CAB office and be supported through an application by an advisor. However the increasing pressures faced by local offices, along with lengthier application processes for benefits like PIP, now make this impracticable.⁵¹

In fact, support cannot be gained at each stage of the application. In the case of PIP, CAB advisors are forced to take a back seat because the onus is now on individual claimants to get the process started themselves with a telephone call to the DWP. This means that a ‘Catch 22’ situation has arisen where -

“if you’re a vulnerable person who can’t make a phone call, you need to make a phone call to tell them you're a vulnerable person who can’t make a phone-call.”

For people with mental health conditions, or people who simply do not feel comfortable revealing personal details to a stranger on the phone, an initial phone call is a particular barrier to applying. On the whole disabled people feel disempowered instead of supported, and this has been accentuated by negative attitudes from members of the public as well as from some Job Centre Plus staff, making it more challenging to understand entitlement and claim benefits.

Some interviewees noted a recent rise in negative attitudes towards disabled people amongst the general public. For example, a blind couple recalled that they had gone in for a cup of tea (at a local café) and had people say **“you shouldn't be able to afford that”**. This made them feel **“like second class citizens”**, not entitled to the same quality of life because of their disabled status.

⁵¹ Although the PIP application form is shorter , applicants must now begin the application process with an initial phone call to the DWP. After receiving and completing a form, there have been delays of around 6 months - more in some cases - before the applicant receives a face-to-face assessment and is awarded the benefit. This means that Job Centre staff are unable to move things along for applicants so effectively during one visit.

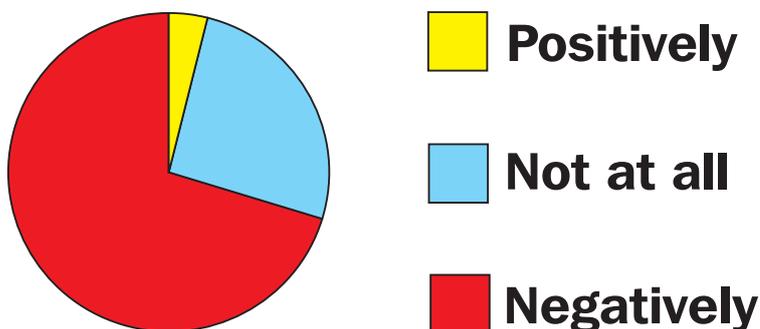
Participants reported that Job Centre Plus advisers have used passive aggressive tones, and made inappropriate comments to people using their services.

Some interviewees for example reported hearing advisers use derogatory language to describe benefits claimants. In one case a claimant was shown a tin of air freshener which advisers said they used because **“the people who come in here stink”**.

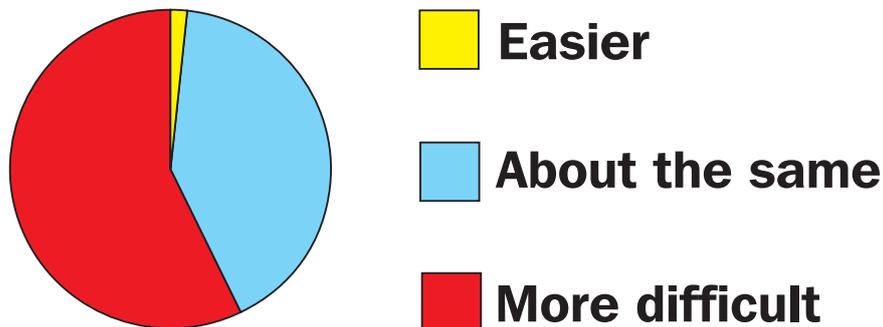
This demonstrates an alarming lack of professionalism and bullying behaviour which has unfortunately characterised the benefits system for some applicants. Job Centre Plus offices were described as **“intimidating”**, and interviewees generally felt that advisers were looking for reasons to reject their claims. It is not just disabled people who need support at this time, but their families and carers too.

According to our survey, disabled people feel that those closest to them have also been negatively affected by benefits changes, Over 70% reported a negative impact on family and friends compared to 25.9% who felt that family and friends had not been impacted and only 4% who cited a positive impact. For those specifically in supporting or caring roles, over 57% of disabled people felt that things had become more difficult compared to 41.2% who felt that things had remained the same.

Changes in Benefits Have Impacted the Well Being of My Family and Friends



For Those Who Support or Care For Me, Changes in Benefits Have Made Things



3.4. Political and media rhetoric around the changes has left disabled people feeling stigmatised within wider society.

The media is perhaps the main source of information for most people, so the way in which welfare reform is reported really matters.

While people have struggled to stay up-to-date with the changes and how they will be affected, they have been faced with an onslaught of political rhetoric about the need to cut the welfare bill and catch the benefits cheats. Media stories have repeated this rhetoric, or else focussed on the dismal situations of service users who have lost their benefit. Neither approach offers reassurance to disabled people who are concerned about their futures.

Current political rhetoric and media reporting has a **“stigmatising”** and **“intimidating”** effect on disabled people. Interviewees felt that TV programming around welfare reform and benefit recipients conveys negative stereotypes of disabled people and misrepresents the prevalence of fraudulent claims for sickness and disability benefits. Participants felt **“persecuted by the media and public”** and isolated within their communities.

While the process of claiming benefits can be difficult enough,

“the attitudes surrounding it ... (are) all about Iain Duncan Smith beating the desk saying everybody was a benefits scrounger and they’d all be weeded out.”

One participant said this rhetoric made him feel as though he was **“going to be stood against a wall and shot”**, rather than given the support he needed, while others felt they needed high personal resilience to apply for benefits and

move through a process which **“tries to catch you out”** to save money on the benefits bill. One participant reported that some of her disabled friends avoid claiming the benefits they are entitled to because **“they just can't face it”**.

According to one participant, negative media and public attitudes signify

“a step-change since the coalition came to power... it's very much like when [Margaret Thatcher] was in power. We're going backwards instead of forwards.”

Interviewees also suggested that the government has a **“divide and rule”** agenda:

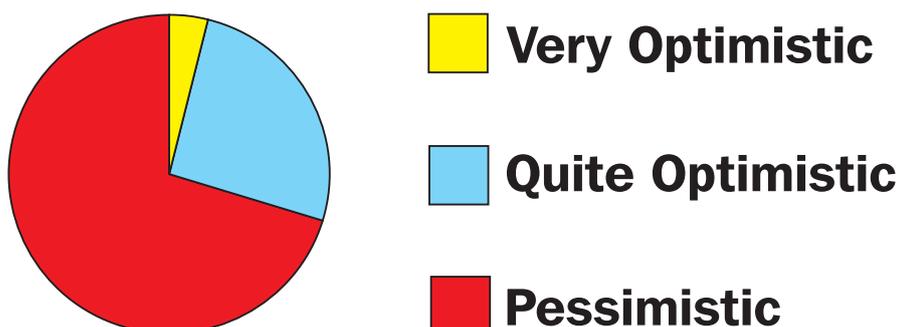
“we've got to the point where people are working hard but need to have benefits to top up their money, so they now begrudge people who don't work.”

Disabled people experience a climate of intimidation, with some participants reporting that even family members believe the ‘scrounger’ rhetoric. As one survey respondent put it:

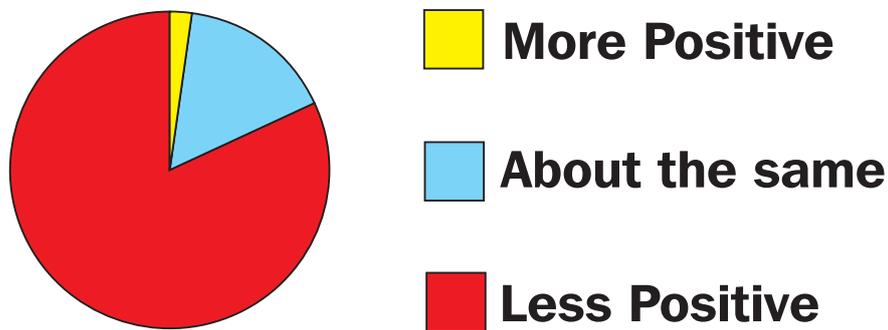
“No matter what long term illness you have or disability, the first thing people think is that we are benefit cheats. As a disabled person I feel more isolated, disrespected and sometimes live in fear. I have never felt so vulnerable as I do now.”

All of this of course impacts on the ways in which disabled people feel about their future. And our survey indicated that the feelings here are overwhelmingly negative. In fact, over 50% of our respondents felt pessimistic about the future and over 82% reported that benefits changes had made them feel more pessimistic. Only 2.3% of respondents reported increased positivity about their future as a result of benefits changes.

Feelings About the Future



Changes in Benefits Have Made My Thoughts About the Future



3.5. Fear of losing benefits adds to the financial pressures which disabled people already face.

Participants with learning disabilities highlighted that they have never been able - or adequately supported - to work or sustain jobs, and their long-term reliance on benefits means that they have never had much money.

Managing the little money available can be difficult; and pay day loans are sometimes used to keep up with bills, which increases financial pressure overall. Participants report rarely being able to afford new clothes or go on holiday; and find it particularly difficult to buy Christmas or birthday gifts for family and friends.

They testify that a life on benefits does not provide luxury, but a frugal and often stressful day-to-day existence. Although benefits pay very little the threat of losing has a very significant impact on disabled people's lives - with politics, the media and wider society continually reinforcing this threat. As Aditya Chakraborty writes in the Guardian newspaper, **'to be disabled in post 2010 Britain is to be unsure when and whether your benefits will be paid because the new system keeps chopping and changing...'** ⁵²

Participants who had benefits reduced or temporarily stopped dealt with this by turning off their heating, eating less and buying lower quality food. For example, one participant **"lived on a baked potato and beans"** each day until her benefits were re-instated, and rarely had the energy to get dressed or leave the house.

⁵² <http://www.theguardian.com/commentisfree/2014/oct/20/disabled-lord-freud-austerity>

Others have stopped shopping in supermarkets like Tesco or Morrison's as they are **“too expensive”**, and now rely instead on the cheaper supermarkets they can access. Iceland and Farmfoods were the most popular, and this involved a compromise on fresh food and a greater reliance on tinned or frozen food. Additionally, some participants eat mostly ready meals because their impairment or health condition impacts on their ability to cook safely - but this can be **“a more expensive way to eat”** and means making some tough choices about what is affordable.

3.6. Overall, participants were negative about their prospects of finding or staying in paid work and about their future prospects.

Research participants came from a diverse set of backgrounds in terms of skills and work history and educational attainment. Almost unanimously, participants were keen to contribute as a part of the workforce but felt that employers' attitudes coupled with the limitations placed on them by their impairments or health conditions would make their search for work fruitless. Phrases such as “who would give me a job?” were common, for example.

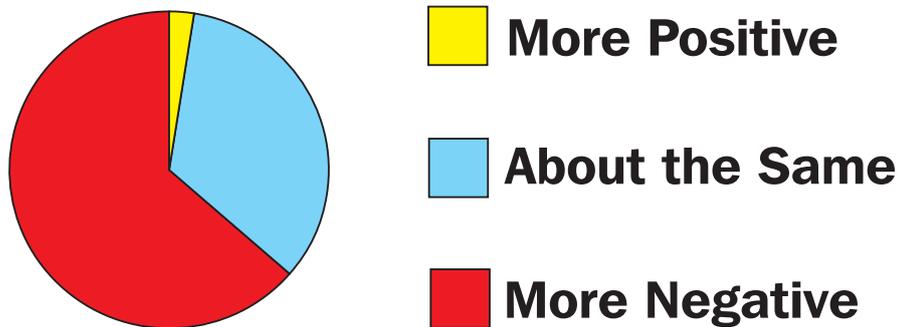
On the whole, disabled people felt negative about their prospects of finding and staying in work; and reported that their feelings of negativity had been accentuated by changes to the benefits system.

For example, 72.5% of survey respondents felt pessimistic about their prospects of finding and staying in work, with 63.4% reporting increased negativity as a result of welfare changes. This compared to a small 3.2% who felt positive and an even smaller 2.7% who felt they had actually become more positive. The charts that follow illustrate this:

Feelings About Finding/ Staying in Work



Changes in Benefits Have Made My Feelings About Work



One survey respondent offers an example of the deep sense of frustration which disabled people feel around work:

“Our safe work environments like Remploy were forced to shut down, yet the Government could find billions to keep our failing banks open. We are left with no work, no income, no support and no hope for our futures.”

4. CASE STUDIES

In this section of the report, we present some of the case studies we gathered. The cases describe the lived experiences of particular disabled people - individuals, couples and families - living with different impairments and health conditions and dealing with the changes in the benefits system. These cases help to demonstrate some of the issues we have discussed above. Where interview participants have requested anonymity, names have been changed.

4.1. Nan and Gerry

Nan and Gerry are married and both are registered blind. Nan also has arthritis, carpal tunnel syndrome and depression. The couple live in one of the UK's top 5% deprived areas and care for their 25 year old grand-daughter, who has additional learning needs.

Nan and Gerry are active members of their local community. They helped to establish, and now run, a local community support group after being awarded Big Lottery funding. The funding enabled the group to appoint a support worker to help local residents with anything from completing household tasks to filling in forms and assisting people to access the services they need.

Both Nan and Gerry were in receipt of DLA and ESA when first interviewed. However, Nan's ESA was means-tested and she lost her payments several weeks later because she has a private pension.

The couple have suffered a cash loss of £161 per fortnight as a result of this, and are left with a total of £214 per fortnight to live. They struggle to support themselves and their grand-daughter on this budget. One of the key reasons they struggle is the additional costs they have to budget for. Nan and Gerry were wrongly allocated a council tax rebate and are now re-paying £120 per month. Their housing benefit payments have also been cut whilst the cost of their rent has risen.

Further Nan has to repay some of the ESA she wrongly received. This payment comes out of her DLA, at a rate of £43 every four weeks. Finally, living with a visual impairment creates additional costs:

“...our clothes get caught in things and ripped... there's no direct route to the doctors so that's £4 odds up the town, so that's £9 (altogether)... we can't cut our grass so we've got to pay someone to cut our grass. We've got windows to clean... everything has to

be paid for. But people don't understand because people can do these things themselves. We can't."

Nan and Gerry have had to make cutbacks to their daily living costs, and this has impacted on the quality of food they can afford, the frequency with which they use their heating, and the choice of activities they have outside the house. For example, Nan said **"there's a lot of stuff I get in tins now because it's a meal... it's not what you want to do, it's what you're forced to do. You're not getting the quality stuff. It's what you have to do"**. Gerry said **"you've got to watch every penny... Just a simple thing like going into town, getting a cup of coffee and coming home. You can't because you think about how much you'll spend, so you're isolating yourself "**.

Although Nan and Gerry feel fortunate to be active in their community, a major concern amidst the benefits changes has been a lack of support and the presence of stigmatising attitudes. Together, these signify a worrying shift in society's view of disabled people. Gerry said **"there's no support for disabled people at all"**. Both Nan and Gerry feel that they have often been given incomplete or inaccurate information - for instance, nobody explained that ESA could be means tested - and this has often left them at the mercy of a seemingly sporadic benefits system. Aside from a lack of reliable information, in the Jobcentre.

"attitudes have changed. They make you feel as though you're begging... they make you feel so small, and they're so smug." Outside the Jobcentre, "a lot of people think you're getting too much money... you've got the public against you... We've gone in for a cup of tea before and had people say you shouldn't be able to afford that. We are blind but we're certainly not deaf and we hear a lot of the comments. You're second class citizens."

4.2. Daniel ⁵³

Daniel is registered blind and also suffers from severe arthritis, which can make movement difficult. He receives DLA and ESA, as well as housing benefit for the property he rents from his local council. He has a 'spare bedroom' which he uses when family members come to help out, and has had to start paying the 'bedroom tax'. Paying the bedroom tax has meant that the housing benefit he receives has been reduced by 14% and he has to pay an extra £11 per

⁵³ pseudonym

week. Daniel feels grateful for the help he has received with housing costs since having to sell his own property when his eyesight deteriorated and he had to give up his job as a salesman. However, he has had to cut down on his food expenditure and he says **“the way I live now tends to be out of Farmfoods or Iceland”**.

Daniel read in his local paper that his local council would be setting their own cap on Discretionary Housing Payments (DHPs) - payments which help council tenants with the additional cost of the ‘bedroom tax’. He contacted the council to obtain advice on this and request an application form. He was informed that the level of financial assistance the council is willing to provide depends on how much money he has left at the end of each month. However, this can be difficult to calculate when also considering unexpected costs - such as broken appliances or the occasional need for new shoes and clothes.

Daniel was keen to point out that - **“the effects of the new legislation have not been entirely financial, there seems to be a new wave of thought that anyone claiming any benefit is a scrounger or a malingerer”**.

He said **“it makes me feel that everyone thinks that's the case, that's what they're thinking about me”**. Daniel’s experience of applying for ESA, for example, was coloured by **“the thought of what Iain Duncan Smith was saying that people's benefits would be stopped... I felt like I was going to be stood against the wall and shot”**. Further, his advice worker, who stayed with him for 4 days to complete the application, advised that the DWP culture operates around targets to get people off benefits.

This meant that engaging with the system and claiming entitlements was a highly stressful experience for him.

4.3. Chris

Chris lives with multiple sclerosis (MS) which affects her balance, memory and mobility. She was forced to give up a career she loved a few years ago when her MS became more difficult to manage, and she now receives benefits including: Employment and Support Allowance (ESA), Disability Living Allowance (DLA) and Housing Benefit (HB). An administrative error resulted in her HB payments being stopped for 2 months, which had severe financial and health implications.

Chris was renting privately while on the waiting list for a council property when she realised that she would not be able to afford her next rent payment. She

was granted HB, which helped towards the shortfall in her rent. However, she still found the rent difficult to afford and looked forward to moving to a more affordable property.

Two months later her HB was not paid, and she phoned her local authority to find out what had happened. She was advised that the DWP had stopped this payment, believing that she had enough in savings to pay her rent.

This was not true. Chris had some funds after a divorce, but had lived on this money until it had run out - only then claiming benefits.

Chris had to prove her financial status to both the DWP and her local authority before her benefit could be reinstated. This involved printing bank statements and highlighting her expenditure. However, as she crept into rent arrears she faced eviction and was unable to afford basics, including the necessary print-outs of her bank statements. She turned to her MSP's office for help and was relieved to receive real, practical support in printing and sending the necessary documentation.

Although this assistance made things easier, her difficulties continued to grow. She **“spent quite a lot of days living on a baked potato and beans and nothing else”**. The pressure she felt affected her so severely that she began to have severe anxiety attacks, **“almost lost some good friends”**, and stopped attending her usual social activities. She also had to stop taking specialist medication as it was not available on the NHS.

Seven weeks after sending evidence of her financial position to the DWP, Chris received a phone call advising her that no evidence had been submitted. This was a mistake, and was corrected when Chris questioned it. Her case was then sent to a decision-maker, and her HB was reinstated a week after this. Chris believes that an ineffective system for processing claims is largely to blame for the poverty, stress and anxiety she experienced over these two months. She said:

“the main thing is that I lost my confidence, I almost didn't make it through the maze... It took a very long time for me to get the money and come out of that, and all because of their system of not communicating and not flagging that I'd sent that evidence in. My feeling is that I'm quite tenacious and I knew who to ask, but there must be people out there who just don't know .”

4.4. Tracy and Keith

Tracy and Keith, a married couple, both have additional learning needs. Keith receives Severe Disablement Allowance (SDA) and Disability Living Allowance (DLA); while Tracy receives Employment and Support Allowance (ESA) and Disability Living Allowance (DLA). To date, only Tracy has been affected by benefits changes. The Incapacity Benefit (IB) she was receiving changed to ESA, she has lost her 'plus one' entitlement on bus travel and now has to pay bus fares for any support staff who accompany her on journeys, and she has also completed an application for Personal Independence Payment (PIP).

A challenge for Tracy throughout these changes has been in receiving the support she needs. When she attended her assessment for ESA, staffing issues at her Housing Association meant that she was assigned an agency support worker whom she had never met before. This impacted on her comfort levels during the assessment because she was not accompanied by anyone familiar to her.

A more regular support worker helped her to complete a PIP application form, but Tracy feels that her needs were not listened to or adequately reflected in the application. Her support worker stated on the form that Tracy does not need support in travelling, but Tracy is very clear that she does - to help with a physical impairment in her legs, to provide support with new journeys, and to help with shopping. Losing her 'plus one' entitlement for bus travel has impacted on her both in terms of her confidence in moving around and also financially. Tracy has recently had to begin paying for support staff who accompany her. She says she simply **“can't afford it”**.

The couple experience substantial financial pressure and worry that future changes in their benefits may make life even more difficult. Currently there is little money to replace clothes, and they rely on pay day loan companies to afford Christmas and birthday gifts for family and friends or to pay off unexpected bills. The anticipation of future changes causes the couple stress and anxiety.

No decision has been returned on Tracy's PIP application, but Keith hopes that the process will be straightforward and the outcome positive because life is already challenging enough. Their biggest concern is **“having enough money to pay the rent, pay the bills... that causes enough stress already”**.

Further, the high rate of appeals does little to guarantee a smooth ride.

People with learning disabilities can find money management is challenging if they do not receive support with it. The idea of Universal Credit is particularly

worrying. Under this scheme, several benefits are packaged together in a single, four weekly, payment to a single householder. As part of this, Housing Benefit will be paid to the claimant, and the option of direct payments to landlords will be removed. This will place more responsibility and more pressure on couples like Tracy and Keith. They will not only have to learn to manage household budgets over a four week period, but will also have to ensure that sufficient funds are available to pay their landlord and that rent is paid on time.

A further issue here is that one person in the couple will have to rely on the other for money and the management of bills, since the bulk of funds goes to a single account. Tracy, for example, expressed that having her own bank account with her own benefits offers some protection when there is no money left in Keith's account. This 'safety' would be jeopardised with the introduction of a single payment to a single account.

4.5. Sarah ⁵⁴

Sarah was a victim of sexual violence and experiences on-going mental and physical health issues as a result. She has received DLA since 2010 and has recently been awarded ESA and placed in the work-related activity group. However the process of attaining the ESA award re-awakened some of the trauma she had experienced. She is also dissatisfied with the category of ESA she has been awarded, but does not feel that she has the resilience to challenge it.

After escaping an abusive relationship, Sarah lost her job and experienced deteriorating health including two nervous breakdowns. She applied for, and was awarded, DLA. After living on her savings for 4 months, she also applied for ESA. She does not remember much about this application, other than appealing the decision at a tribunal in front of an all-male panel.

Sarah said **“I just remember the tribunal being all male. (I had a letter from Rape Crisis that I had pretty much taken off me, looked at, and thrown back”**. In a vulnerable condition at the time, she was intimidated by the male-dominated hearing and felt that she was not taken seriously. Following this however, she was awarded ESA and received a letter informing her she would be in the support group until 2015.

However, just last year, **“out of the blue”**, Sarah got a letter asking her to go for another ESA medical. She said:

“I was told I was getting 3 years of support in the category I was

⁵⁴ pseudonym

in, then they dropped a medical in and said, ok, that's not what you're getting anymore, we're going to stop it now. It's your stability that's lost, you lose your stability at every stage in the way. It affects your confidence. It affects your ability to cope."

She found it very difficult to capture her health condition in the ESA 50 form, experiencing symptoms including back pain, a feeling of being grabbed by the neck during stressful situations, stress incontinence, seizures, migraines and stress induced fluctuations in the pitch and tone of her voice -

"they say attach an additional sheet if necessary, but its making what you've got fit the boxes."

When the medical took place, Sarah recalls that it lasted 90 minutes. She found it hard to focus for this length of time and felt increasingly anxious as the questions did not allow her to speak properly about her condition - **"(they asked) can you lift a box? Well, I can lift a box but that's not really relevant to what I'm going through"**.

At the end of the medical, she had attained 0 points, and had to contemplate another tribunal. She felt that she was not supported to prepare adequately for this tribunal and that receiving advice from her welfare advisor during the tribunal itself confused and disorientated her to the point that on many occasions she **"didn't know what to say"**.

Sarah again felt that her condition was being overlooked. She was also supported at the tribunal by someone from Rape Crisis but this person was ignored when she asked a question, further adding to Sarah's feeling that it was her condition that was being ignored.

The decision on this occasion was to place Sarah in the work related activity group (WRAG), and she recalls, **"I was told later that if I appeal the decision they could open up the whole tribunal again. And that for me would be too stressful"**.

Sarah had hopes of returning to university to study, feeling that education is a 'safe' environment in which she could regain the confidence to return to work. However, the disruption and uncertainty caused by the ESA process has reduced her confidence and ability to engage in the process of applying for a university place:

"I've not had the opportunity to return to education because of the stress of the tribunal system. It sounds pathetic but I've not been able to proceed with the application."

4.6. Megan⁵⁵

Megan has Myalgic Encephal (ME) and has also suffered post-traumatic stress disorder (PTSD) after being raped. On each occasion that she has applied for disability benefit, her experience has been very negative, causing her health to deteriorate and her PTSD symptoms to re-surface.

In 2006, Megan claimed DLA. She requested that her medical assessment be carried out by a female doctor, but this was ignored and she was examined instead by a male doctor. She recalls her discomfort in discussing her PTSD with him, and his persistent questioning which eventually saw her break down and disclose her rape. She felt that the DLA process had been deeply insensitive, and did not renew her claim when it ran out. Instead she relied on her (male) partner's income, until he left her. She then applied for both DLA and ESA out of financial necessity.

This time, Megan - a graduate in English Literature - carefully wrote a cover letter to accompany her DLA application, explaining that she felt unable to attend a medical assessment as a result of her PTSD and fear of a male doctor, as well as her debilitating ME symptoms and suicidal feelings. A separate letter from her GP supported this.

However, one Saturday evening - without fore-warning - a male doctor buzzed her flat, asking to come in to do a DLA assessment. She said, **"I was absolutely petrified... I got no warning"**. She told him to go away but a neighbour let him in, and he then **"hammered on (her) door for a solid 15 minutes"**, prompting her to call the police. When the police arrived the man had left, leaving a hand-written note to indicate that he would try again on Tuesday. He included a contact number, which was illegible to Megan and several of her friends who attempted to call it.

After seeking help from Sense, an advocate was able to determine that the assessment could be cancelled with another doctor's note. However, it was a bank holiday weekend and Megan's GP could not be contacted. Megan took an overdose to avoid the assessment and was rushed to A and E. Her advocate eventually managed to get both her DLA and ESA without the need for assessment. However, her DLA expired only one year later. On this occasion, Megan's GP letter arrived 3 days late and her application was rejected.

⁵⁵ pseudonym

She was invited to apply for PIP instead and managed to secure this with the support of AdvoCard.⁵⁶

⁵⁶ AdvoCard provides advocacy services for mental health service users. See <http://www.advocard.org.uk/>

5. CONCLUSION

A consistent theme throughout this report has been the sense of alienation and social isolation which disabled people have felt as the welfare reform agenda is rolled out. This alienation has come from various different sources - a lack of accessible information about benefits changes, poor assessment and administration systems, stigmatising political and media rhetoric, and hostile attitudes from Job Centre Plus staff and members of the public - all of which link back to UK Government policy which is premised on the idea that our welfare system has been overly generous.

Being disabled has never been a ticket to a luxurious life, but we are now in a startling situation where disabled people are being targeted by the government's cuts agenda. Disabled people face losing vital life-lines such as help with mobility. Sick and disabled people are being forced to rely on food-banks as government bureaucrats catch up on their paperwork.⁵⁷ And the very idea of being disabled is being challenged as the government argues for the need to re-assess those claiming disability benefits, amidst a furore of rhetoric about 'benefits cheats' and 'scroungers'.

This report has highlighted that details about changes to the benefits system are often difficult to acquire, and provided in inaccessible formats. The onus has been on disabled people to seek out the information and support which they need. Whilst good levels of support have been provided by third sector organisations and local authorities, the Department for Work and Pensions (DWP) and Job Centre Plus offices have often been obstructive. Further, disabled people have largely felt shut out of a professionalised system on which they rely but are rarely empowered to fully understand.

Disabled people have been inundated with negative messages: the financial support they receive can easily be removed, pulling a vital safety net from under their feet. Benefits applications must be written in specific, professional, language and assessments are conducted by people who do not understand disability and are interested in reducing the number of people eligible for benefits. Politicians, their staff and members of the public are suspicious of disabled people and feel that they are a costly burden on society.

⁵⁷For instance, see this article in The Mirror newspaper: <http://www.mirror.co.uk/news/uk-news/labour-say-sick-disabled-forced-4688894>

Cumulatively, these messages meant that their standard of living and their identity were under constant threat.⁵⁸

Such a hostile climate inevitably impacts on the health and well-being of disabled people, and this was also particularly notable. We are disturbed by the way in which disabled people seem to have been worn down - targeted financially, politically and socially - by the UK Government's welfare reform agenda. Our research has uncovered increased levels of stress and reduced levels of personal resilience. Further, it was harrowing to hear even two of our survey respondents - both women - say that they felt suicidal due to the "stress and anxiety" they are experiencing as a result of benefits changes and the climate which has simultaneously been engendered.⁵⁹

While identifying and raising awareness about these issues is a good first step - and the step taken in this report - we believe that more is needed in order to address the economic, social and attitudinal barriers which the Welfare Reform Act (2012) has built for disabled people. As such, we recommend the following on the basis of our findings:

- **That the culture in Job Centre Plus offices is reviewed with a view to ensuring that claimants are treated with dignity and respect, and are given relevant and accessible information about their entitlements;**
- **That the barriers to employment which disabled people face are recognised and consistently challenged in workplaces, public policy, and our national media;**
- **That our national media works to rectify the negative stereotypes attributed to benefits claimants and disabled people, telling a fuller and more accurate story about the challenges faced by these groups;**
- **That the Scottish Government takes a human rights approach to any future policy-making powers it obtains in relation to social security, which should include detailed consideration of the impact on groups with protected characteristics.**

⁵⁸ The increasing negativity pointed out by Emma Briant et al. (2012) in 'Bad News for Disabled People', a report commissioned by Inclusion London, was felt in the daily, lived experiences of our research participants. http://www.inclusionlondon.co.uk/domains/inclusionlondon.co.uk/local/media/downloads/bad_news_for_disabled_people_pdf.pdf

⁵⁹ We asked at the end of the survey if we had missed anything, with a text box for responses

APPENDIX A: BENEFITS AND CHANGES TO BENEFITS

This note explains the benefits which have been referred to in this report, including the changes which have been made to these benefits under the Welfare Reform Act (2012).

Employment and Support Allowance (ESA)

Employment and Support Allowance is a means-tested benefit which offers financial support to people who cannot work, or find it difficult to work, due to illness or an impairment. It can be paid to people who are not currently in work, or it can be used to help people to stay in work.

To qualify for the benefit, you need to attend a Work Capability Assessment (WCA). Here, your illness or impairment will be assessed to find out how much support you need. Depending on the decision, you will be placed in either:

- The work related activity group, where you will receive some money and also attend regular meetings with an adviser who can help you to find suitable work; or
- The support group, where you will receive some money but will not be expected to meet an adviser and try to find work.

Personal Independence Payment

Personal Independence Payment (PIP) started to replace Disability Living Allowance (DLA) in April 2013. Just like DLA, PIP is non-means tested, non-contributory and non-taxable. It intended to help with the extra costs of living with a health condition or impairment. This means that you might use it to pay for things like transport to the shops or hospital, or products that can help you around the house.

As with DLA, PIP contains a 'mobility' component to help with travel and moving about; and a 'daily living' component - previously called a 'care' component - to help meet care costs. For each component there is a 'standard' and 'enhanced' rate, which indicate how much money a person will receive. This is judged in accordance with the severity of impairment or health condition.

The policy announcement which introduced PIP as a replacement for DLA included a commitment to cutting expenditure on the benefit by 20% - and this

is reflected in changes to eligibility criteria which make it tougher to claim PIP than DLA. Lots of disabled people are expected to lose support as a result. In fact, the Scottish Government estimates that by 2018 56,000 working-age DLA claimants will lose their entitlement to PIP entirely.

To qualify for the Enhanced Mobility Rate of PIP, claimants must be unable to walk 20 metres unaided. This was reduced from 50 metres under DLA. Further, the lower rate of care has been abolished so that many who qualified for this will no longer be entitled to any assistance. DLA contained a 'lowest' 'middle' and 'highest' care rate, while PIP has a 'standard' and 'enhanced' rate.

If you need to claim this benefit for the first time, you must apply for PIP. If your DLA is due to be renewed or your circumstances have changed, you will also be invited to apply for PIP. You will need to complete a paper form as well as a face-to-face assessment. At the moment, it can take up to 6 months from when you submit an application for PIP to receive your payments. This is because the UK Government's Department for Work and Pensions has struggled to manage the change from DLA to PIP.

Universal Credit

Universal Credit (UC) was introduced in the UK in October 2013. It replaces and combines several working-age, means-tested benefits, including: **Jobseeker's Allowance, Housing Benefit, Working Tax Credit, Child Tax Credit, Employment and Support Allowance, and Income Support.**

Under UC the majority of disabled people across the UK will largely become financially worse off. Disabled Child Additions will replace Child Tax Credit Disability Additions and will be worth over 50% less - £28 per week compared to £58 per week. Recipients will receive 15% less towards childcare costs, and this is likely to affect parents with disabled children disproportionately since disabled children need childcare until they are much older.⁶⁰ The Severe Disability Premium, which gives additional support to disabled adults, will be abolished at a loss of £58 per week for recipients. Disabled householders who are couples will not be able to claim both a Disability Addition to UC as well as a Carer's Addition.

There is however some 'transitional protection', and severely disabled adults may be better off. Households where at least one adult works should also be

⁶⁰ See UNISON 2013: 5 Welfare Reform Changes Affecting Disabled People

better off. However, this ignores the market conditions which make it difficult for disabled people to attain employment.

UC will be paid every 4 weeks, while most of the benefits it replaces were paid every 2 weeks. It will be paid to a 'household', or into one person's bank account. We anticipate budgeting difficulties for some impairment groups, and unequal financial power relations within households. At least, this severely reduces the independent financial resources of one partner in the household. However this is also likely to place disabled women and their children, particularly those who are vulnerable to domestic abuse, at increased risk.

Universal Credit has not yet been rolled out in full across the UK. In Scotland, it is being trialled in Inverness for single people and couples without children. You should be notified when you need to apply for Universal Credit, but it is expected that it will not be fully rolled out in Scotland for a couple of years yet.

Bedroom Tax

From April 2013 the UK government changed Housing Benefit rules so that a proportion of financial assistance is lost if a Local Authority or Registered Social Landlord (RSL) property is deemed to have one or more 'spare' bedrooms. A spare bedroom is a bedroom that no-one sleeps in.

This does not take into account bedrooms used when carers need to stay the night, or bedrooms that are used to store medical equipment. As a result, disabled people have been disproportionately affected. For example, 80% of affected households in Scotland contain a disabled person.

However the Scottish Government has decided to pay the cost of the Bedroom Tax for everyone in Scotland who is affected. This was possible because the UK Government transferred powers to the Scottish Government, allowing it to decide how much local authorities can pay in Discretionary Housing Payments (DHPs). DHPs are payments made by local authorities to those receiving Housing Benefit who are still struggling to meet the cost of their accommodation. The Scottish Government has given extra money to all local authorities and advised that anyone paying the Bedroom Tax should receive DHPs to cover the cost.

Passported Benefits

Entitlement to UC and PIP also brings entitlement to other benefits, called

'passported' benefits. For example, if you receive UC you are also entitled to: budgeting advances, free dental treatment, housing grants, free school meals and help with travel fares for getting to and from hospital.⁶¹

If you are entitled to PIP can also receive help with some childcare costs, a bursary fund for 16-19 year olds, national insurance credits and those on the PIP Mobility components can also receive discounts on Vehicle Excise Duty, and access to the 'blue' parking badge scheme.⁶²

There are currently some issues with blue-badge entitlement in the transition from DLA to PIP.⁶³ Children (under 16 years) are not yet being moved to PIP but in some instances a PIP assessment is required for blue badge eligibility.

⁶¹ See Disability Handbook 39th Edition April 2014 - April 2015 p.108-9

⁶² This is not an exhaustive list. See Disability Rights Handbook 39th Edition April 2014 - April 2015 p.28

⁶³ Blue badge scheme: <https://www.gov.uk/blue-badge-scheme-information-council>



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Disabled People's Organisation

Our voices ■ Our choices

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