Time to think again

Disability benefits and support after COVID-19

Matthew Oakley



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FIRST PUBLISHED BY

The Social Market Foundation, February 2021 11 Tufton Street, London SW1P 3QB Copyright © The Social Market Foundation, 2021

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ACKNOWLEDGEMENTS

The Social Market Foundation is grateful to Scope for sponsoring this research. The views in the report do not necessarily reflect those of Scope. The Social Market Foundation retains full editorial independence with respect to its research.

Thanks also go to Anna Bird and Tom Pollard for discussions over the last five years that have contributed to the thinking behind this report. Finally, thanks go to analysts at the Social Metrics Commission who undertook new analysis of poverty amongst disabled people for inclusion in this report.

As always, all analysis and views remain those of the author.

ABOUT THE AUTHOR

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ABOUT THIS REPORT

The analysis in this report is based on a range of approaches, these have included:

- Qualitative research with disabled people, including eight semi-structured interviews and two focus groups;
- Polling undertaken by Opinium on behalf of the Social Market Foundation; ¹ and
- Original analysis using the Labour Force Survey and Family Resources Survey/Households Below Average Income.²

EXECUTIVE SUMMARY

The benefits system for disabled people, and the support that accompanies it, are broken.

Through a combination of quantitative analysis, focus groups and semi-structured interviews with disabled people, this report shows that across a range of metrics, the system is failing disabled people and their families and communities.

These failures also contribute to the UK economy missing out on all that disabled people can bring and the UK taxpayer seeing money wasted on ongoing reforms of a failing system.

This is not through lack of effort on the behalf of governments over the last few decades. The Department for Work and Pensions and its predecessors have been providing some form of employment support to disabled people for over 50 years. Employment and Support Allowance (ESA), and an accompanying package of reforms were introduced over a decade ago by the New Labour Government, with the aspiration to break "a lifetime of dependency" and "reduce the number of incapacity benefits claimants by one million over the course of a decade". Reforms of "extra cost" benefits, further reforms to employment support and a range of targets, ambitions, programmes and approaches have followed in the last decade.

Each of these policy efforts has been delivered with the intention of improving outcomes and accompanied by a similar set of ambitions. These have ultimately failed, as summarised as below.

Providing adequate support that helps give disabled people financial security	 Nearly half of all people in poverty in the UK are either disabled themselves or live with someone who is disabled. More than four in ten people (42%) living in families that rely on disability benefits are in poverty. There are 1.8 million more people in poverty who live in a family that includes a disabled person than there were fifteen years ago.
	P
A system that supports those that can, to stay in or return to work	 Real-terms costs of disability benefits rose by £16 billion (48%) between 2000/01 and 2018/19, and are forecasted to rise by another £4 billion up to 2024/25.
	• The number of people on a range of disability benefits is broadly the same or higher (depending on the benefit) than it was two decades ago, despite consistent attempts to reduce caseloads.

Reducing numbers on benefits and reducing costs	 The promised revolution in employment amongst disabled people has failed to materialise. Disabled people are still more than two and a half times more likely to be out of work than those who are not disabled. The disability employment gap remains above 40 percentage points for many disabled people, including those with a primary mental health condition and those with a learning disability.
A system that builds public trust and is supported by disabled people	• The process of developing and delivering these reforms has cost hundreds of millions of pounds, and years of DWP capacity and focus.
A system that supports wider economic and social goals	 The ongoing assessments, reassessments, delays, appeals and subsequent results have caused trauma and upheaval to millions of people, and created an environment of fear and distrust towards the DWP among ill and disabled people, and the organisations representing them.

Disability benefits after COVID-19: designing a better, fairer system

As we begin to adjust to life living with, or after, COVID-19 tackling these issues is essential. We have already seen that disabled people have been hit particularly hard by the pandemic. **Now is the time to think again.**



of people living in families that rely on disability benefits are in poverty A failure to place improving support for disabled people at the centre of the post-COVID-19 policy agenda risks:

- A continuation of poverty;
- Poor labour market outcomes; and
- A lack of dignity and increasing costs and claims that have become a central part of the existing failing system.

The Department for Work and Pension's long-awaited Green Paper and the Government's equally anticipated cross-Government disability strategy provide key opportunities to lay the foundations to deliver the improvements needed.

In many respects, the Government could achieve much by using the opportunity to make some of the changes that disabled people, and those who work with them, have been calling for over many years. Some of these changes may be straightforward.

For example, many of the disabled people we spoke to highlighted that a simple change in attitude and approach would significantly improve the system: "Given the [DWP] has had programmes in place to support disabled people for over half a century, it is disappointing that it is not further ahead in knowing what works [to increase disability employment]"

National Audit Office

"One way [to improve the system] would be kindness not always assuming that everyone is trying to do the system over...to be dealt with a sense of kindness and humanity"

"The one thing they need to change more than anything is to make [the system] more person-centred and find out what the person in front of them needs"

Here, the Government could follow the lead of Scotland, where "Dignity, Fairness and Respect" are the key principles through which the Social Security system is viewed, policy formed, and benefits delivered.

However, following these principles and adopting much-needed reforms within the current system can only go so far. And doing so would miss a vital opportunity to think again about what, as a society, we want the benefits system and associated support to achieve, and how that could be delivered.

1.8 million

more people in poverty who live in a family that includes a disabled person than there were fifteen years ago. To grasp this challenge, the Green Paper should acknowledge the failings identified in this report – and many others - and commit to engaging on a significant programme of work with disabled people to develop a system for the future that works better. This report puts forward a suggested process through which this work could be taken forward by Government, in partnership with disabled people and a wide range of stakeholders.

Through this process, it is conceivable that a comprehensive plan for a benefits system and wider approaches to support that work for disabled people could be delivered within this Parliament. This may seem like a long time to wait, but it is essential that enough time is taken to get it right.

In this respect, we believe the Green Paper should clearly set out:

- 1. The process of policy development, including setting reasonable expectations of when each of the steps will be completed.
- 2. How it will develop a clear articulation of the outcomes that we want the system to achieve and from there, how policy will be developed.
- **3.** How to ensure the process is led by and includes the views and experiences of disabled people.

Given the failings of the past, the importance of getting reform right is clear, and could advance the Government's policy priorities and, most importantly, improve the livelihoods of disabled people and their families.



"The whole system can make you feel very suicidal. It's all about what you can't do, and your bad days".

"Every now and then, the brown envelope arrives...MS is not curable – it's insulting [to have to have to go through the process and prove myself again]"

"People who don't know the system, you tell them this stuff, and they think you're crazy."

"The thing with Jobcentre is that they tend to send people for unsuitable jobs. I keep telling them I can't do them because of my disability...they don't seem to understand"

"Am I able to meet my basic needs? Yes. Am I loving the life I'm living? No."

Extracts from SMF semi-structured interviews

CHAPTER 1 – TWENTY YEARS OF DISABILITY BENEFIT REFORM

While there is much to celebrate in the UK economy and society, it is clear that across a range of economic and social outcomes the UK is highly unequal. This is accepted by researchers, charities working on the front line, businesses and government alike.³

These inequalities are long-standing and entrenched, but the COVID-19 pandemic has laid them bare. The scale of both existing inequalities and the action that has previously failed to tackle them, alongside the new challenges provided by the COVID-19 pandemic, have demonstrated that, if any Government is serious about tackling both the entrenched inequality in the UK and the unequal impacts of COVID-19, it will need new ideas and approaches.

There are few other places where these new ideas are needed more than with respect to the support available for disabled people in the UK. Here, across social security and the broader range of support available, it is clear both that the state is failing and has failed for decades.

The costs of this failure to individuals, families, communities and, ultimately, the economy and Exchequer are significant. This report argues that this situation will not be fixed by small changes. Instead, improvements in this system will require a fundamental rethink about what the system is for, how this is delivered and how, ultimately, we can ensure it works better for disabled people.

To understand why, it is important to first highlight that disability benefits in the UK have gone through significant changes in the last 20 years. Under governments from across the political spectrum, these changes have come with commitments, promises and ambitions of creating a better system. For example, Employment and Support Allowance (ESA) and an accompanying package of reforms were introduced over a decade ago by the New Labour Government, with the aspiration to break "a lifetime of dependency" and "reduce the number of incapacity benefits claimants by one million over the course of a decade".⁴

More recently, the Conservative-Liberal Democrat Coalition Government introduced legislation to replace the benefit to provide for extra costs of disability (Disability Living Allowance, DLA) with a new Personal Independence Payment (PIP). Amongst other goals, the intention was to create a simpler, more flexible system, cut the numbers on the benefit by 20% over three years and target more support at those with the greatest needs.⁵

Below these headline changes, there has been a relentless stream of schemes, reviews, ambitions and targets. These have included:

- Additional employment support, first through Pathways to Work, then the New Deal for Disabled People, then the Work Programme, Work Choice, Specialist Employment Support and the Work and Health Programme.⁶
- Changes to regulations and the approach around sickness absence and support when entering or returning to work, including the introduction of fit notes, fit for work, Access to Work and changes to Statutory Sick Pay.
- The introduction and subsequent removal of financial incentives to work, through the Return to Work Credit.⁷
- The introduction, reform and (most recently) temporary suspension of requirements for some disabled people to be seeking or preparing for work (and associated benefit sanctions).
- Numerous independent reviews of the Work Capability Assessment, Personal Independence Payment, sickness absence, health at work and conditionality (amongst others).
- Ambitions to halve the disability employment gap,⁸ and then to increase the number of disabled people in work by one million.⁹

Whilst seeming like a disparate set of policies, with each government (and different Ministers within the same government) often unpicking, revising or reversing policies that had been introduced under the last, there are two things that unite them. The first is that changes were undertaken with the intention of making the system work better for disabled people and their families (although it is worth noting, and as shown below, that this is not a view commonly held by disabled people). The second is that the changes have, almost universally, failed to achieve their goals.

To understand why, it is first important to outline a broad set of ambitions that underpin a wide range of the changes that have been made to the system. These can be summarised as the following, which have been drawn from discussions with policymakers and politicians, reviews of government Green and White Papers and the author's own experience of working within government:

- Providing adequate support that helps give disabled people financial security.
- A system that supports those that can, to stay in or return to work.
- Reducing numbers on benefits and reducing costs.
- A system that builds public trust and is supported by disabled people.
- A system that supports wider economic and social goals.

The next sections present evidence that the last two decades of changes have failed to meet these ambitions, before outlining the case for change and what needs to happen next.

CHAPTER 2 - PROVIDING ADEQUATE SUPPORT THAT HELPS GIVE DISABLED PEOPLE FINANCIAL SECURITY

A previous Social Market Foundation paper outlined a basic principle that, in combination with earnings where that is feasible, the benefits system should provide adequate support and dignity for the individuals and families that rely on it. ¹⁰ As highlighted above, this has also been a consistent theme of Green and White papers that formed the basis for previous reform of the benefits system as it applies to disabled people.

This is also a concept that the public agrees with. Polling undertaken for this report asked the public about the level of benefits that should be provided to people unable to work because of a health condition or disability.¹¹ It found that 92% of people thought the benefits system should be generous enough so that, at the very least, it ensures that they are not in poverty. Nearly four in ten (37%) of the general public believe that benefits should be high enough to allow disabled people who are unable to work to afford "the same sort of things as the typical person in society"; a financial bar set much higher than the poverty line.

However, this is not the reality for many disabled people. Recent research by the Social Metrics Commission has already shown that close to four million disabled people in the UK live in poverty (Figure 1) having risen from three million in the early 2000s.



Figure 1: Number of disabled people in poverty, by age

Source: Social Metrics Commission

Even this masks the scale of the issue, as we need to consider the families, parents and carers of these disabled people.

When we do this, we see that half of all people living in poverty in the UK are disabled themselves or live in a family that includes a disabled person.¹² This is driven by rates of poverty amongst disabled people and those living with disabled adults or children, that are far higher than other groups in society.



In 2018/19 (the most recent data available), ¹³ 18% of people living in families that do not include a disabled person were in poverty, compared to 28% of those who were living in a family that includes a disabled person. New research undertaken for this report shows that, for people living in a family where someone is claiming disability benefits, the poverty rate rises to 42%. Poverty rates are higher still for people living in out-of-work families where someone is disabled (66%).





Source: Social Metrics Commission analysis of FRS and HBAI dataset (1998/99–2018/19)



The prevalence of poverty amongst people living in families where someone claims disability benefits has also risen over time; it was 38% in 2003/04, compared to 42% in 2018/19.

Equally concerning is the fact that the number of people in poverty who are either disabled themselves, or living in a family with a disabled person has increased steadily over the last 15 years.

Figure 3 shows that 1.8 million more people living in a family that includes a disabled person were in poverty in 2018/19 than was the case in 2003/04. This is in stark contrast to those living in families where no-one is disabled, where the number in poverty was the same in 2018/19 as it was in 2003/04.





Source: Social Metrics Commission

These statistics on poverty clearly show that many disabled people and their families are living in poverty, even when the state is providing support through the benefit system.

Disabled people we spoke to as part of this research shared a range of views over the adequacy of benefits. Everyone we spoke to recognised the role that benefits already play in providing financial support and some believed that the level of benefits they received was sufficient both to allow them to lead their day-to-day lives and meet the extra costs they faced because of their disability. However, where this was the case, it was often recognised that this was because they had limited their day-to-day activities.

Summarising these issues, one focus group participant said that she felt "backed into a corner, with little options for how to live or a chance to get out". Others agreed with this sentiment, for instance one participant shared that "...we'll never be able to move, because I can't afford it. We're not going to have any more children".

Others said that they could not afford to buy Christmas presents, or treats like an ice cream for their children or visit their parents as often as they would like, as they could not afford the taxis (that were needed because of their limited mobility). Another told us that that she was unable to engage in any activities beyond "basic survival". Summarising this situation, she commented "...it's not nice, it doesn't make you happy...you can't participate in society".

Others highlighted other severe impacts associated with benefit levels that they viewed as insufficient. For example, one participant said that, because of the low level of benefits she received, she had to rely financially on her partner, which has placed her in a situation of financial abuse; an experience which "...the benefit system should never allow to happen".

CHAPTER 3 - A SYSTEM THAT SUPPORTS THOSE THAT CAN, TO STAY IN OR RETURN TO WORK

For those disabled people that are able to, work can provide a vital boost to incomes, financial security and quality of life.¹⁵ However, disabled people of working age are over two and a half times more likely to be out of work than those who are not disabled.¹⁶ As a result, official Government statistics show that only just over half (54%) of working-age disabled people are in any kind of work.¹⁷

These official statistics consider the experiences of all disabled people, regardless of whether their condition limits the type and/or amount of work that they can do. They suggest a disability employment gap (the distance between employment rates of disabled people and non-disabled people) of 28 percentage points in 2020, as shown in Figure 4.

Perhaps unsurprisingly, employment rates are lower for those disabled people with a condition that limits the type or amount of work they can do; 51% of this group is employed. The official statistics also include people who are of working age but have retired and are not seeking or wanting work, which puts a downwards bias on the employment rate of non-disabled working-age people.

By addressing each of these points, the analysis below shows the disability employment gap for people with a work-limiting health condition or disability. This stands at 39 percentage points in 2020, having been as high as 45 percentage points in 2008.



Figure 4: Employment rate gap over time, for all disabled people and those with a work-limiting health condition or disability

Source: SMF analysis of Labour Force Survey (January to March quarters)

Notes: Figures for all disabled people differ slightly to official statistics, as they are based on Jan-March quarters of the Labour Force Survey, for consistency with other figures in this report.

Of course, it is positive that the disability employment gap has fallen over the last 15 years. However, as the National Audit Office (NAO) highlights, increasing employment rates have not led to a reduction in the number of disabled people out of work and it is less than clear the extent to which actions from DWP have had any meaningful impact.¹⁸

The overall disability employment gap also masks significant differentials between disabled people of different ages and with different primary conditions that limit their ability to work. Figure 5 shows that the disability employment gap is as low as 10 percentage points for some groups (those aged 25-39 with a sensory impairment). However, for those with a primary mental health condition, or with a learning disability or autism, it stands at above 40 percentage points.



Figure 5: Disability employment rate gap, by primary condition (2020)

Source: SMF analysis of Labour Force Survey, Jan-March 2020

Given the potential positive financial and wellbeing impacts of work for disabled people and their families, it should come as little surprise that many out of work disabled people want to work.¹⁹ In fact, more than 1.1 million of those disabled people out of work say that they want to work.²⁰

In this respect, many focus group participants and interviewees highlighted their work ambitions and expressed their frustration that they felt their experience and skills were being wasted. A particular theme was that they felt they needed support to find work and workplaces that could meet their needs, but that the support available was too generic and often led to suggestions of employment opportunities that they felt they would be unable to undertake. This frustration was often focussed on Jobcentre Plus.

Examples include the following:

"...I'm very unsteady on my feet...I almost feel unemployable because they give me silly suggestions like bar work or warehouse work, I've got no chance of carrying a round of drinks for anyone...I'm trained in IT, all my prospects are mental, not based on my physical attributes, which I've always understood, being born with [cerebral palsy]."

Focus group participant

"I was in my wheelchair when I went to my first [Jobcentre Plus] interview, and the woman leaned over and asked how I'd feel about manual health care...I can barely do that for myself, let alone someone else."

Focus group participant

"The thing with Jobcentre is that they tend to send people for unsuitable jobs. I keep telling them I can't do them because of my disability...they don't seem to understand."

Focus group participant

Others felt that Jobcentre Plus had actively side-lined them and restricted the range of support options they received because "...they had been told to focus on people who had lost their job because of COVID". Other previous work supports these findings. For example, research from Scope found that some people avoid the Jobcentre "at all costs".²¹ Other research demonstrates the significant negative impacts that experiences of Jobcentre Plus can lead to:

"I can't count the number of times I've had panic attacks in Jobcentres or how anxious even the thought of them makes me feel." ²²

Other research has focused on those expected to be preparing for work (rather than actively seeking). Here, 90% of respondents in a study of 550 people in the work-related activity group reported that the activity they were required to undertake was unsuitable for their needs.²³

Not all previous work provides such a poor assessment of Jobcentre Plus. For example, other work the SMF has undertaken with Jobcentre Plus staff and benefit claimants has often shown Work Coaches doing all they can to support people into work (where appropriate) and to flex the system to meet the needs of disabled benefit claimants.

However, this must be viewed alongside the significant cuts to specialist employment support for disabled people that have been seen over the last five years and the failure of high-profile programmes to try to support businesses to employ disabled people.²⁴ Overall, the NAO have found that DWP's state of knowledge over what works in supporting disabled people into work is "disappointing".²⁵

Disabled people we spoke to also had significant underlying concerns that

"Given the [DWP] has had programmes in place to support disabled people for over half a century, it is disappointing that it is not further ahead in knowing what works [to increase disability employment]"

National Audit Office

any attempt to seek work would undermine their benefit claim. One commented that "...the benefits system is a barrier, not an aid to [my work ambitions]". This finding is also echoed in recent DWP research which found that, whether or not technically true, claimants had concerns that moving into work would "trigger a Work Capability Assessment", create an income gap when moving into work or mean that they would have to reapply for benefits should the work opportunity not be sustained.²⁶

For many we spoke to, these multiple challenges culminated in the view that the benefits system pushes them further from work and a feeling that they had been "written off". Again, these themes are echoed in recent DWP research, which found that some disabled people "...distrusted the motives behind any DWP/JCP offer of support, even if they were attracted to what was on offer in theory".²⁷

Another concern of disabled people who contributed to this research was that employers discriminate against them and, together, this meant that they had given up on trying to find work. One summarised these feelings:

"I want to work but I'm never going to be able to. I'm not well enough, not fit enough and the fact is no one would take someone on who most of the time will ring up and say 'I can't even get out of bed today'"

Focus Group participant

With this in mind, it should come as little surprise that close to two million disabled people say that they do not want to work.²⁸ For some, this reflects the fact that they are unable to find work that will meet their needs, or caring responsibilities. For others (as with those above), it simply reflects the loss of will after years of discouragement and a benefits system that is viewed as actively discouraging disabled people from fulfilling their work ambitions.

Whatever the route, the loss of potential and significant detriment to the lives of disabled people and their families is clear. It is also clear that the goal of supporting many more disabled people into work has largely failed.

In fact, if the Government had been able to meet its 2015 Manifesto ambition of halving the disability employment gap, close to one million more disabled people would be in work today.²⁹ Based on Government methodologies and our own research,³⁰ we estimate that, were this to be the case, it would:

- Boost UK output (GVA) by around £50 billion a year;
- Lead to Exchequer Benefits of around £17 billion a year (£5.5 billion reduction in social security payments and an increase of £11.5 billion in tax receipts).
- Provide a huge boost to the incomes of disabled people and their families, helping them to escape poverty.



Despite these potentially positive impacts, it is also important to remember that work on its own is not always enough. Poverty rates amongst people living in working families that include a disabled person stand at 22%, far higher than the poverty rate for working families that do not include a disabled person (16%).

Part of the challenge here is that, as well as facing a disability employment gap, disabled people face a pay gap when they are in work. Even after accounting for a range of factors including age,

qualification levels and length of time on the job, on average, an employed disabled person faces a pay penalty of around 21% compared to an otherwise equivalent non-disabled person.³¹ Based on the average pay of a non-disabled person, that means a disabled person, of similar age and with similar levels of qualifications, being paid close to £6,500 less a year.

CHAPTER 4 - REDUCING NUMBERS ON BENEFITS AND REDUCING COSTS

Given the substantial Exchequer savings involved, it is no surprise that at least part of the desire of successive governments to support more disabled people into work has been to reduce the number of people claiming disability benefits and, therefore to reduce the costs. However, despite bold ambitions to do this, depending on the benefit in question, the number of people claiming disability benefits has either plateaued or risen over the last 20 years.

Figure 6 shows that, while the number of people on out of work income replacement benefits related to a disability has reduced since the early 2000s, it has plateaued at around 2.5 million people over the last decade.





Source: SMF, DWP

Notes: Precise figures for the number of people on Universal Credit, who would previously have been eligible for ESA are not available. This chart uses a proxy of those in the "no worksearch" requirements group. While this includes some non-disabled people (e.g. lone parents with very young children), overall it is likely to be an underestimate, as many disabled people have found themselves in conditionality groups where they are required to prepare for work. Averages for calendar years given. Incapacity Benefit (IB) and Severe Disability Allowance (SDA) were pre-cursors to Employment and Support Allowance (ESA).

Figure 7 provides an equivalent analysis for extra cost disability benefits. It shows that, since 2002, the number of claimants of DLA or PIP has increased steadily from around 2.5 million people in the early 2000s to 3.9 million in 2020, a 57% increase.

Combined with Attendance Allowance, this means that more than five million people are now claiming benefits related to the extra costs of disability.

These rises in caseloads are also expected to continue. The Office for Budget Responsibility (OBR) expect the proportion of children receiving DLA to rise to 5% by 2023/24 (from 3.7% in 2017/18) and the proportion of working-age adults receiving DLA or PIP to rise to 8.5% (from 6.7%).³²





Source: SMF, DWP

Notes: Averages for calendar years given.PIP began to be introduced in 2013.

Partly driven by this rising number of claims, but also by increased severity of conditions, rising benefit rates and wider factors like increases in the costs of housing,³³ the overall costs of providing benefits for disabled people have also increased over time.

In fact, whilst being stable as a proportion of GDP, between 2000/01 and 2018/19, realterms costs rose by £16 billion (48%), and are forecasted to rise by another £4 billion up to 2024/25.

£16bn

real-terms cost of providing benefits for disabled people rose by 48% between 2000/01 and 2018/19 – an increase of £16 billion



Figure 8: Total cost of benefits for disabled people, £billion, 2019/20 prices

Source: SMF, OBR

Notes: (F) denotes forecast.

CHAPTER 5 - A SYSTEM THAT BUILDS PUBLIC TRUST AND IS SUPPORTED BY DISABLED PEOPLE

A significant driver of the failure to reduce the number of claims and costs associated with people on disability benefits has been the assessment processes that determine eligibility for the benefits. The ambition was that the Work Capability Assessment (the WCA judges eligibility for ESA and, now, Universal Credit) and PIP assessment would narrow the eligibility criteria for the benefits and thereby, reduce caseloads, allow government to focus more support on those who had the greatest needs and move more disabled people from "inactive" benefits to receiving some kind of support to enter work. For ESA (and the associated WCA), the 2007 Command Paper summarised:

The new Employment and Support Allowance reflects our vision of what the benefits system should do for claimants. It will provide financial support to some of the most vulnerable people in our society whilst ensuring the system retains the support of the public by applying a fair but rigorous test of eligibility.³⁴

This was embodied in the expectation that a large proportion of (new and retested) claimants going through the WCA would be found to be fit for work (not eligible for ESA) or to be able to prepare for work (placed in the Work Related Activity Group). A later White Paper outlined plans to re-test all existing Incapacity Benefit claimants and introduce requirements to prepare for work. All of this was framed by the desire of not repeating the experience of previous recessions, where "...Governments made the mistake of shuffling people on to inactive benefits, and then trapping them there".³⁵

However, in practice, this has failed; more people have been found to be eligible for the benefits, at higher rates of award and for longer periods of time.³⁶ Figures 9 and 10 demonstrate, while much lower when the WCA first started, more than eight in ten people being reassessed for ESA through the WCA now find that they are placed in the Support Group (with no expectation to seek or prepare for work, and with higher benefit payments). So, if avoiding "shuffling people on benefits" and winning public trust was reliant on an assessment process that restricted access to benefits, this has seemingly failed.



Figure 9: Results of Work Capability Assessments, initial assessments only

Source: DWP



Figure 10: Results of Work Capability Assessments, repeat assessments only

Source: DWP

At the same time as failing to deliver a reduction in the number of people on disability benefits and the associated costs, the ongoing assessments, reassessments, delays, appeals and subsequent results have caused trauma and upheaval to millions of people, and created an environment of fear and distrust towards the DWP among ill and disabled people, and the organisations representing them.

In fact, whilst some of the wider challenges of the lack of progress in increasing employment or tackling poverty amongst disabled people are the most visible impacts of a failing system, an extensive range of existing literature, and the focus groups and interviews undertaken for this work, highlight the assessment processes for ESA, PIP and Universal Credit as being one of the major problems with the system.

Many interviewees highlighted the feeling that the system was set against them, making them focus on "what was wrong with them", and prove that they were not able to work. For many, including those who fed into this research and to previous research,^{37, 38} this felt demeaning, and contributed to a feeling of worthlessness. For example, participants in this research commented:

"[the WCA] was a very negative experience as it focuses on
everything that I can't do."
Interviewee
"[the assessment] it's like a slap around the face – a reminder
that we're ill. It throws you into a depressive manner to look at
yourself - you're no good at anything."
Focus group participant

what you can't do, and your bad days."

Interviewee

Evidence from a number of sources also highlights that disabled people were commonly made to feel like their condition was not legitimate, even so far as to be made to feel like a fraud.^{39,40} Participants in focus groups for this work highlighted:

"The whole system can make you feel very suicidal. It's all about

"You just feel like you're a fraud...and all at the same time as having a life changing experience that I was trying to come to terms with."

Focus group participant

"...not everyone who claims these benefits is guilty - that's just how it feels."

Interviewee

"The hours that I've spent doing forms and waiting, the hours I've spent talking to a social worker, putting together the bits to prove I need this help. Nobody else has to live their life minute by minute and write it down. The sad thing is you have to do these things."

Other work in this area also supports these findings, with one participant commenting:

"The disabled person I accompanied was made to feel like a fraud despite having a visible disablement that prevents him from leading a normal life. The assessor... was ... appalling."41

Others in this research highlighted the seemingly callus nature of repeated reassessments even for those with lifelong conditions that had no expectation of improvement, and that this continually made them relive bad experiences in order to receive payments.

"...I've lost a leg - it's not going to grow back. I've lost my sight in one eye, it's not going to get better...it's a waste of time, resources and money to keep reassessing people when things are only going to get worse." Focus group participant

many conversations, attention focused on th

In many conversations, attention focussed on the "brown envelope" that would come through the door to signal that they were going to be reassessed, and the resulting anxiety and impacts on mental wellbeing:

> "You think oh my god here we go again [when brown envelope lands on mat] ...you just dread it."

Focus group participant

"Every now and then, the brown envelope arrives...MS is not curable – it's insulting [to have to have to go through the process and prove myself again]."

Focus group participant

"I'm always living under a dark cloud of 'when is that brown envelope going to come through the letterbox'...it could mean [the difference] between eating and not eating."

Interviewee

As well as these broad failures of the system, our research identified a range of more specific failures, relating to individual cases. Many complained about their views and explanations not being listened to, information being recorded inaccurately, the advice and views of medical experts being ignored and a lack of understanding, empathy and compassion from staff.

As a result, many found they disagreed with their initial assessment, and then needed to engage in a lengthy appeal process in order to ultimately have the original decision overturned in their favour.⁴² As reported in other research, the mental health impacts of this are clear to see:

"I had to wait 12 months for an appeal date. The effect the
whole process had on my mental health was a dramatic
worsening of it. It is a horrible system to navigate when you are
so weak mentally." ⁴³
"I am so terrified of getting something wrong or being
misunderstood or not explaining myself (it is very hard for me to
describe accurately my own mental state) and so losing my
benefits." ⁴⁴

The extent and range of the problems surprised many of the participants, who thought that they might be the only ones who had experienced issues. Others were not surprised, having been claiming benefits for many years, experiencing many problems and speaking to others who had similar experiences. Overall, there was concern that the general public viewed the system more through the eyes of "The Daily Mail" and did not understand the experiences of disabled people and the challenges they face with the system. One participant summarised "...people who don't know the system, you tell them this stuff, and they think you're crazy".

Overall, our discussions with disabled people revealed a number who felt they were simply "existing, not living", moving from assessment to assessment, not being shown any trust or respect and repeatedly needing to prove they deserved the benefit. With this, and the general view that all previous changes were simply a cost-cutting exercise from the government, it should come as little surprise that there was wholesale lack of trust in the government, the system and those delivering it, either in terms of delivering what it should now, or improving in the future.

A system that that supports wider economic and social goals

Whether framed as the need to rebalance or level-up the country, regenerate local areas, achieve opportunity for all, or focus on social justice, over at least three decades, governments of all colours have tried to develop policy solutions to ensure that outcomes of those living in deprived areas improve. A key route through which this can be achieved is by providing better support to disabled people, and a failure to achieve this has undermined this agenda.

There are a number of reasons why outcomes for disabled people are central to these agendas. To understand why, we first need to consider Figures 11 and 12 which show that claims for disability benefits and the associated costs vary significantly across the country.

Figure 11: Deciles of disability benefits claims per 100,000 population, by Parliamentary Constituency



Source: SMF analysis of DWP and ONS $^{\rm 45}$



Figure 12: Deciles of disability benefits costs per head or population, by Parliamentary Constituency

Source: SMF analysis of DWP and ONS $^{\rm 46}$

Whilst the incidence and cost of disability benefits claims vary significantly across the country, they do not do so in a random way. In fact, disability benefit claims and their associated costs are far higher in more deprived areas.⁴⁷

Overall, this means that, whether by tackling the disability employment gap or reducing poverty amongst (working and non-working) disabled people and their families, improving outcomes for disabled people would have the most significant impacts in more deprived areas and could provide a significant contribution to the Government's levelling-up agenda.

CHAPTER 6 - WHY IT'S NOW TIME TO THINK AGAIN

The previous sections have shown that the current system of benefits for disabled people has failed to deliver on the objectives set when previous changes were announced. To some extent these failures are starting to be understood. There have been numerous reviews of the functioning of both the WCA and PIP assessment process from both independent advisors and others including the Work and Pensions Select Committee, think-tanks and bodies supporting disabled people.

In response, some limited changes have already been implemented. Further changes are also in the pipeline. Under the last Government, a cross-departmental disability team was established to create a new strategy to tackle barriers faced by disabled people.⁴⁸ The then Secretary of State for Work and Pensions, Amber Rudd, also announced the Government's intention to reconsider a range of elements of the social security system for disabled people, including assessment processes, and launched a Green Paper on the issue. Whilst there have been delays to their publication, that Green Paper, and a cross-government Disability Strategy are currently being developed.

More recently, significant temporary changes have been made to account for the impacts of COVID-19. For benefit claimants generally, Universal Credit and Working Tax Credit have been increased by £20 a week and conditionality, the sanctions regime and face-to-face PIP assessments and the WCA temporarily suspended.

Many of these reforms, and those which have been signalled for the future, are welcome. In fact, if temporary measures taken as a result of the COVID-19 crisis were made permanent, they would likely lead to a benefits system that worked significantly better for disabled people, in terms of providing both better financial support and an assessments system that improved disabled people's experiences (for example the introduction of telephone-based assessments).

However, whilst these would be positive steps, they would all function within the context of a system which leaves many disabled people living in poverty and has been shown to have little success in supporting more disabled people into work. This means that, overall, while they may tackle some of the most apparent and damaging failures of the current system (and gain support from disabled people from doing so), it is unlikely that they will provide the scale of reform needed in order to ensure that the social security system and wider systems of support meet the needs of disabled people. In short, more is needed.

Of course, significant reform is hard to consider right now, and there are no doubt challenges; the country is currently in the midst of an unprecedented economic and social crisis resulting from the COVID-19 pandemic, the prospect of the UK leaving the EU has now become a reality, and a new benefits system (Universal Credit) is still being rolled out. Each of these issues (and others) are taking up political, policymaker and public time, effort and money.

However, if one thing is certain it is that, as we begin to live with, or after COVID-19, policymakers will need to take significant further action across a range of policy areas. In part, this will be required to rollback temporary support measures and make significant changes to meet the costs of those measures. Those in Government, and Opposition, will also need to begin to set out an agenda to tackle the inequalities that have become all the more apparent throughout the COVID-19 crisis.

A failure to place improving support for disabled people at the centre of that agenda risks a continuation of the poverty, poor labour market outcomes, lack of dignity and increasing costs and claims that have become a central part of the existing failing system

What needs to happen?

The Government is right to be seeking to improve the assessments process for disability benefits, as well as trying to ensure that disabled peoples' experiences of the benefits system improves and allows them to build trust in the system. It is also right to think about how the existing employment support offer can be improved.

In each of these areas, the Green Paper will provide an opportunity to make some of the changes that disabled people and those who work with them, have been calling for over many years. Some of these changes may be straightforward. Many of the disabled people we spoke to highlighted that a simple change in attitude and approach would significantly improve the system:

"One way [to improve the system] would be kindness - not always assuming that everyone is trying to do the system over...to be dealt with a sense of kindness and humanity." "The one thing they need to change more than anything is to make it more person-centred and find out what the person in front of them needs."

In this respect, the Government could follow the lead of Scotland where "Dignity, Fairness and Respect" are the key principles through which the Social Security system is viewed, policy formed and benefits delivered. This may seem like a small step, but by explicitly embedding these principles in the system, the Scottish Government has clearly signalled its ambitions for the Social Security system, how it expects claimants to be treated and how it expects those delivering the system to act. International evidence suggests that approaches such as this can be successful and people we spoke to in Scotland and more broadly as part of this research, have suggested that the approach has prompted a noticeable improvement in how claimants (including disabled people) are treated in the Scottish system.⁴⁹

As such, explicitly applying this approach to the disability benefits assessment process, and the UK-wide Social Security system more broadly, could provide some of what is needed to make the system work better for disabled people.

However, given the scale of the problems with the existing benefits system and associated employment support highlighted above, and the lack of understanding on what could actually make a difference, it is unlikely that changes being considered for the Green Paper will be enough. Such actions would do little to tackle poverty (for working and non-working disabled people), the broader issues facing disabled people on benefits or the underlying issues with the nature and level of the benefits that disabled people receive and the support that is made available to them.

Another challenge, specific to plans to redesign the assessment process, is that it is impossible to design an effective assessment process until we fully understand what it is looking to make assessments for. So, if it is accepted that significant changes are needed to tackle the issues highlighted above, the Government must accept that, alongside short-term reforms to improve the functioning of the existing system, a longer-term programme of work will be needed to design a new approach based on a clear articulation of what the overall system is trying to achieve.

This means that the Green Paper should focus on two distinct aspects:

- 1. Short-term changes that can be implemented easily and quickly to improve the system now; and
- Acknowledging the broader problems of the current benefits system as it applies to disabled people, setting out a bolder vision of what the future system should achieve and committing to a process of more significant reform to get there.

Recommendation: the Green Paper and short-term reforms

It is right that the Government's upcoming Green Paper on disability benefits should focus on the assessments processes, improving disabled peoples' experiences of the system and employment support. However, within that it should:

- Acknowledge the wider long-standing problems facing disabled people within the benefits system and the fact that these cannot all be solved through reform of the assessments process and other marginal changes to processes within the existing system.
- Focus proposals within the Green Paper on changes that will improve the process within the context of the existing Social Security system, without introducing major change programmes that will take years to roll out.
- Introduce a guiding principle for both short and long-term changes which mirrors the Scottish Government's commitment to delivering a Social Security System that is built around "Dignity, Fairness and Respect".

Of course, it is not enough to simply "park" longer-term challenges under a commitment to turn attention to them in future. Instead, the Government's Green Paper should also outline a firm commitment to, and details of, a significant programme of policy development work that can be used to create a future Social Security system that works for disabled people.

This will not be an easy task. However, if approached in the right way, in partnership with disabled people and those that represent them, positive changes can be made, and the significant benefits of success delivered. Figure 13 sets out an illustration of what the process of policy development could look like, and how this could be delivered within this Parliament.

Figure 13: Illustrative example of how policy formation could work in this Parliament



Again, it is important to highlight that none of this will be straightforward. The first challenge will be to clearly articulate what the system is trying to achieve. This report has used our understanding of the principles behind previous reforms to show that they did not achieve what they were supposed to. However, there is no guarantee that the principles of previous reforms should inform future approaches, or that disabled people and those that represent them would agree with those principles.

Other principles have also been highlighted. In this respect, previous work by the Social Market Foundation outlined a set of principles that could be applied. It outlined that the system should be one that:

- **Provides adequacy:** By ensuring that a combination of earnings and benefits provide adequate financial support and dignity for the individuals and families that need to use it;
- Works for disabled people: This will mean working with disabled people to create a system that is adequately personalised and tailored so that it reflects the range of needs that different disabled people have. In particular, it needs to recognise that, for some people with a health condition or disability, work should not be the primary objective and may not ever be the desired outcome. For others, it will need to provide appropriate, effective and personalised support to enter work and ensure that those at risk of falling out of work because of a fluctuating condition or the onset of a condition are given all the support they need to stop that happening; and
- Works for and with employers: By enabling them to fulfil their ambitions for a diverse, flexible and productive workforce.

Building from principles identified from previous attempts at reform, others could include:

- **Delivering value for money:** Both by ensuring that resources are effectively targeted at those with the greatest needs and that, overall, the number of people claiming benefits falls over time.
- **Supporting work:** A system that supports those that can, to stay in or return to work.
- **Building trust:** A system that builds public trust and is designed with and supported by disabled people.
- **Supporting the levelling-up agenda:** A system that supports wider economic and social goals, including wider Government policy on ensuring that all parts of the UK grow and no areas are left behind.

Whilst many of these are, to some extent, overlapping (for instance, achieving a system that "works for disabled people" and "works for and with employers" would also "support work"), it is important to develop and clearly articulate a set

of principles, as these will guide all future work. Moving on from here, there are also likely to be disagreements over the evidence on the extent to which these principles are currently being delivered.

To tackle these issues, we have suggested a process of Independent Review for the first year, to outline a set of principles, evidence on the extent to which the current system meets these and an articulation of what the future system should achieve (in measurable terms). This would allow for an independent person, or panel to take the widest range of evidence possible, including from government and disabled people themselves, in order to make a firm set of recommendations to the Government. There are examples of where this approach has work well in a devolved context, and could be used with impact here.

In this context, having an independent person or panel undertake this work will also allow for a much broader consideration of the full range issues involved, avoiding siloed working that can sometimes occur within government. Given the overlapping and interlocking nature of the issues being considered, this holistic approach is essential in developing a clear ambition for the future.

When taking this work forward, a key guiding principle is that, whether led by an individual or panel, there should be representation from those with lived experience of disability.

Recommendation: the Green Paper and long-term reforms

The Green Paper should commit to a programme of work to develop a longer-term strategy for developing the benefits system, and associated non-financial support, for disabled people. This commitment should detail:

- The process of development, including setting reasonable expectations of when each of the steps will be completed.
- Overall, the process must set out the scale and nature of the challenge, alongside a clear articulation of the outcomes that we want the system to achieve in the future and the steps that need to be taken to ensure that the vision becomes a reality. Perhaps most importantly, this must be developed with and by disabled people themselves.
- How to ensure that the process is led by and includes the views and experiences of disabled people.

Once this process has been concluded, based on the agreed principles and goals for the future, the Government can set about a process of policy development. Again, it is important here that the set of principles is considered in the round. This means that, while DWP will be central to policy development, other government departments and local government are also likely to be closely involved.

CHAPTER 7 - CONCLUSION

This report has demonstrated the many failings of the current systems of support for disabled people and argued that a new approach is needed. We have not claimed to know exactly what this new approach should look like; the issues presented are complex and developing a new system will not be straightforward.

Instead, we have put forward a clear process through which this work could be taken forward by the Government, in partnership with disabled people and a wide range of stakeholders. Through this process the Government could win back the trust of disabled people and, with this, it is conceivable that a comprehensive plan for a benefits system and wider approaches to support that work for disabled people could be delivered within this Parliament. This may seem like a long time to wait, but it is essential that enough time is taken to get it right.

Given the failings of the past, the importance of getting it right is clear. For Government, it could provide a key plank of the levelling-up agenda, as well as delivering a stronger economy and significant Exchequer savings.

But most importantly, a system of benefits and associated support that work for disabled people could boost disability employment, reduce poverty (both for those in and out of work) and ensure that disabled people that need to rely on this system do so within an approach that delivers dignity, fairness and respect. In doing so it could deliver a huge improvement in living standards and wider outcomes for a group who have clearly been left behind.

ENDNOTES

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³⁸ https://www.mind.org.uk/media-a/4276/mind-briefing-on-mental-health-and-benefits-reassessments.pdf

³⁹https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_d ata/file/387981/pip-assessment-first-independent-review.pdf

⁴⁰ Scope, Phil Hastwell and Brendan McGinley, 'Our lives, our journey' Wave 1. Cohort 2. Report V3.0 Disabled people who've recently acquired an impairment/ long term condition

⁴¹https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_d ata/file/387981/pip-assessment-first-independent-review.pdf

⁴² For example, recent data shows that appellants were successful on 73% of appeals against initial fit for work outcomes of the WCA. See https://www.gov.uk/government/publications/esa-outcomes-of-work-capability-assessments-including-mandatory-reconsiderations-and-appeals-march-2020/esa-work-capability-assessments-mandatory-reconsiderations-and-appeals-march-2020 Accessed 01/12/20.

⁴³https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_d ata/file/604097/pip-assessment-second-independent-review.pdf

44 https://www.mind.org.uk/media-a/4267/83484.pdf

⁴⁵ Claimant numbers from DWP via Statxplore, mid-2019 population estimates from ONS (https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populatione stimates/datasets/parliamentaryconstituencymidyearpopulationestimates). Accessed 03/12/20.

⁴⁶ DWP (https://www.gov.uk/government/publications/benefit-expenditure-and-caseload-tables-2020)

Claims scatter Claimant numbers from DWP via Statxplore, mid-2019 population estimates from ONS

(https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populatione stimates/datasets/parliamentaryconstituencymidyearpopulationestimates). Accessed 03/12/20.

⁴⁷ For example, see here:

https://www.bristol.ac.uk/poverty/downloads/keyofficialdocuments/CONDEM%20-poverty-report.pdf Accessed 28/01/21.

⁴⁸ https://www.gov.uk/governme/nt/news/pm-launches-new-drive-to-tackle-barriers-facedby-disabled-people

⁴⁹ For example, see

https://www.equalityhumanrights.com/sites/default/files/social_security_systems_based_on_ dignity_and_respect.pdf Accessed 08/11/20.