Responsible Reform

A Report on the proposed changes to Disability Living Allowance

Diary of a Benefit Scrounger

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This report was entirely written, researched, funded, and supported by sick and disabled people, their friends and carers.

Thousands more supported it through social media.

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Executive Summary

1 This report is a comprehensive presentation of the most relevant evidence available on Disability Living Allowance (DLA) and the proposals to replace it with a new benefit, Personal Independence Payments (PIP). It gathers together existing information and analyses over 500 group responses to the Government's Response to Disability Living Allowance reform (obtained under FOI request 989).

2 The report is entirely written, researched, funded and supported by sick and disabled people, who came together through social media to share their experiences, skills and talents. It was felt to be vitally important that with such sweeping reform of every kind of support we rely on going through Parliament, there was a need for a transparent, fact-based analysis of available data that had been presented by us.

3 We argue that reform must be measured, responsible and transparent, based on available evidence and designed with disabled people at the very heart of decision-making. Currently, we do not believe this to be the case.

4 We find that the Government's response to the DLA consultation presented a highly misleading view of the responses it received. Overall,

- 74% of respondents were against the proposals for PIP;
- 19% had mixed views; and
- Only 7% supported it fully.

5 We find that the consultation process did not meet the Government's own Code of Practice on consultation. It was two weeks shorter than recommended and took place over the Christmas holidays. Crucially, the Welfare Reform Bill was presented to Parliament two days before the consultation ended, meaning that responses could not be taken into account when drafting legislation for PIP.

6 We find that the evidence does not support a 30% rise in DLA claims relevant to PIP as claimed by the Government throughout their consultation and Impact Assessments. The figure is actually 13%. These figures were not made clear to parliamentarians as they debated the bill, despite a Government report being signed off in May 2010. Government are still using the 30% figure despite admitting that it gives a "distorted view".

7 We cannot conclude that DLA receipt alone stops sick or disabled people from working, as claimed by the Government.

8 With reference to the specific questions asked in the Consultation on DLA reform, we find that there is overwhelming opposition to most of the Government's suggestions for reform. Opposition is so clear in many cases, that we believe that the Government must pause this reform until it can be reconsidered.

9 Taking each question, the responses for and against are as follows :

Changing rates of "care" from 3 to 2 **92% Oppose / 8% Support**
We find this part of the Government's response to be clearly misleading and that it fails to respond to the views and concerns of disabled people.

Should automatic qualifications to DLA stop? **87% Oppose / 13% Support**
We dispute the Government's interpretation of the data in this section. The Government response overrides the consultation.

Should the qualifying period be changed from 3 months to 6? **98% Oppose / 2% Support**
This is almost unanimously opposed. The Government fails to take the views of disabled people into account and far from improving equality law as claimed, may be contravening their human rights.

Introduction of new Assessments **90% Oppose / 10% Support**
We reject the Government's interpretation of the data and found overwhelming rejection of a WCA-style assessment. This section provoked the most responses and the highest concern in the entire consultation.

Change to the Review System **92% Oppose / 8% Support**
The Government fails to respond to the suggestions made by disabled people in this section.

Should any aids a person uses be taken into account? **88% Oppose / 12% Support**
The Government response is misleading and fails to take the concerns of disabled people into account.

New change-of-circumstance system involving sanctions **88% Oppose / 12% Support**
The Government fails to report disagreements or respond to concerns in this section.

Should advice and support be compulsory? **94% Oppose/ 6% Support**
We totally reject the wording of this part of the Government's response. Disabled people are absolutely clear that this benefit should not be condition.

Should "one-off costs" be funded from DLA **36% Oppose / 64% Support**
We call for clarification on what this question actually means. The Government fails to address any concerns in this section.

Removal of Mobility Allowance for care home residents **100% Oppose / 0% Support**
This has now been rescinded.

Should passporting be "streamlined" or removed from DLA? **99% Oppose / 1% Support**
This issue had one of the highest responses. Passporting was almost unanimously supported. The Government fails to mention that the Independent Living Fund and Severe Disability Premiums will be abolished, funds which support the most profoundly disabled. This contradicts Government promises to "protect the most vulnerable".

Should more be done to share information between departments? **46% Oppose / 54% Support**
The Government fails to mention overwhelming opposition to single assessments for different benefits. Furthermore, we found evidence that this appears to already be happening before legislation for PIP has been passed.

10 We find overwhelming opposition to an ESA style of Assessment for DLA (Work Capability Assessments). The Government presents no evidence that this is "the best way forward" as they claim and we call on the Government to reconsider.

11 **Equality Impact and Human Rights**
We find that :

- The Government assessment fails to note the impact on women
- The Government assessment fails to note the impact of those with mental health conditions
- The Government assessment fails to note that the impact on disabled people will be negative.

We note that disabled people's rights are protected under

- The Universal Declaration of Human Rights
- The International Covenant on Economic Social and Cultural Rights (ICESCR)
- UN Convention on the rights of people with disabilities, Articles 28, 26 & 4 (UNCRPD)
- The Disability Discrimination Act, 1995
- The Equality Act, 2010

Respondents to the consultation repeatedly warn that plans for PIP may be in breach of some or all of these.

12 Despite not being asked in the consultation, respondents felt strongly enough to mention that this was :

- A change motivated only by cost.
- There is a lack of clarity over future plans for children and the over-65s.
- It would be prohibitively expensive to implement and administer (£675 million).
- It would cause greater pressure on social care services and the NHS.

13 **Overwhelmingly, we found that disabled people do *not* agree that there is a need for an entirely new benefit. (PIP). It was clear that whilst disabled people do support some reform of DLA (they make many suggestions in this report) they do *not* want a new benefit. They believe it is a costly irrelevance during times of austerity. Disabled people are clear and emphatic – keep DLA and reform the existing benefit.**

14 We find that much more could be done to address the rise in mental health conditions, which account for a large part of the rise in DLA claims. We urge the Government to do more to support, treat and understand these conditions. We believe money spent on introducing an unpopular benefit (PIP) would be better spent trying to alleviate some of the human suffering that these conditions cause. If this helps to stem the rise in DLA claims as a result, then the policy will have been doubly successful.

15 In Conclusion, we remind the government that DLA is already a **cost-saving benefit**. Cuts to DLA cannot cut disability, they simply shift the costs elsewhere. One in three disabled people already live in poverty and many feel proposals for PIP can only see this increase. **We find the Government's response to the DLA consultation highly misleading throughout.**

Introduction

For many years, Welfare Reform has not served sick and disabled people well. For this group, above any other, social security is not an abstract term. It is often, literally, the security to live in society with the same inherent freedoms that anyone might enjoy.

If an illness or disability is so debilitating, so disabling, that you become unable to work, or your barriers to work become greater, then it is only this social security that can ensure those freedoms. If you rely entirely on the support of the state and there is little or no chance of that every changing, then it is not just desirable that reform is fair, it is vital. Reforms that do not have a strong base in the needs of disabled people will fail.

"Failure" however is simply a word. When any welfare reform fails, the human cost can be great. When it affects sick and disabled people who may be unable to provide for their own basic human needs independently it can be catastrophic.

If the evidence at the heart of a policy is not sound, the reform will not work. If reviews are not rigorous, impact assessments are not comprehensive and consultations take no account of their own findings, we risk alienating the very people we need to engage with.

We have seen this very clearly with Employment and Support Allowance. Following his two-year review[1], Professor Harrington admits that the effects of his improvements will not filter through for at least three years. Meanwhile, that is three years of chaos, spiralling costs and human suffering that will never be undone. If we have learnt anything – anything at all from ESA – it is that we *must* get reform right the first time. Once a policy is in place, it is almost impossible to change effectively.

Rushing policy to meet parliamentary schedules can never result in successful reform. If it is done with genuine motives the only outcomes considered should be "Will this work?" "Will it improve lives?" "Will it increase efficiency?" All too often it feels as though the only question that drives reform is "Will it win votes at the next election?" Getting a policy right, listening to the people it will affect, considering a wide range of evidence with an open mind – these are the key components to successful reform.

There is now a terrible "Trust Deficit" between Government and disabled people. We have been subjected to poor reforms, ever tougher sanctions, and an insidious, scrounger rhetoric from both politicians and the press. Our input and opinions have all too often been ignored when, in fact, only sick and disabled people can know exactly how disability affects them. A return to a model that takes even more control out of our hands can only ever be regressive.

This report aims to give a voice to the millions of sick and disabled people who rely on effective support to live productive lives. It aims to present a strong evidence base on which to build effective reform.

Most importantly, it aims to provide an alternative plan for reform based on the needs and opinions of sick and disabled people themselves, a plan they could support and work with Government to implement.

Methodology

- This report is a comprehensive analysis of the 523 group responses (organisations) submitted to the Government's consultation on the proposal for Personal Independence Payments. Responses were obtained under FOI ACT, FOI No. **989, 'RE: DLA REFORM RESPONSE AS PUBLISHED APRIL 2011', which stated:**

  "With regard to the above document, please can you provide copies of all responses from organisations mentioned at 'Annex 2: List of organisations that responded' in full?" [2]

- Groups include national charities, local authorities, legal groups, user led organisations, advocacy groups, healthcare professionals and businesses.
  This enabled us to analyse the same set of data as the Government when drawing our conclusions.

Unless respondents explicitly expressed an opinion on DLA and PIP, responses were put into 3 categories.

1 Those who were totally against,

2 Those with mixed views

3 Those in total support

We dealt specifically with questions relating to proposed changes to DLA under the new PIP. Where the Government have specifically asked about a change, we analysed the responses. Where the question is simply asking for subjective opinions on DLA or more generally information gathering, we felt that this was beyond the remit of this report. Information on DLA and its uses are well documented elsewhere.

For each particular question, we have looked at the views of those who expressed an opinion on that issue and broken down their responses into Against/Support. We include the response rates for each issue, to give some indication of those which respondents felt the most strongly about.

Figures in brackets give both page and paragraph references to Government's Response to the Consultation to Disability Living Allowance reform. (Reference A)

It should be noted that responses should not all be given equal weight. One response might be the result of a workshop involving over 200 people, another, the official response from a charity or disability organisation and another, a response from a single individual. **Nonetheless the data still gives an overwhelming picture of a mass consensus against the changes, which is very different to the response to the consultation given by the Government.**

The Need for this Document

A Misrepresentation of Disabled People

Many disabled people have strong feelings about the abolishing of DLA and its replacement with PIP. One fear often expressed in the group responses was that this would not be taken into account and their responses to the consultation would be ignored or worse, misused. An example of this is the response by Pembrokeshire Association of Voluntary Services as follows:

> *"Some present at the DSIN meeting were concerned that any comments made within this response may be taken out of context, misinterpreted and used as justification to further policy aims which are not supportive of disabled people and the continuation of DLA. For this reason we would reiterate that the meeting and the organisations represented at the DSIN meeting were clear that they oppose the replacement of DLA with PIP, it is unnecessary, expensive and inequitable."*

Others felt the need to clarify that replying did not imply agreement to the need for reform (Partners for Inclusion).

> *"Responding to this consultation does not imply an acceptance of the need for PIP by those who have inputted into this collective response"*

Given the Government's interpretation of the consultation in the face of overwhelmingly negative responses (P3,6), it may be that their fears were justified.

Many responses started by saying they supported the Government's plan for a benefit which keeps some of DLA's features in particular a non-taxable, non means-tested benefit. However, it would be disingenuous to take this as support for a wholesale change of benefit. **Retaining DLA and modifying it slightly would work just as well and indeed is the preferred option of most respondents.**

Another point made was that agreeing that improvement could be made should not be taken as endorsing the changes proposed. Furthermore, although respondents agreed with the ideals put forward by the consultation, respondents expressed concern that they were not translated into practice. While much store was put into talking about a social model and a holistic view of disability, the result was moving towards a rigid, medical model with an apparent points type based assessment far too similar to the Work Capability Assessment (WCA) which has been found unfit for purpose by every inquiry into it[3] and plagued by appeals.[4]

Although not mentioned in the consultation, it was largely felt that the driving force for the reform was the aim to cut 20% from expenditure.[5] Despite the Government claiming to be working to further disabled people's independence, the consultation itself admits that some disabled people will have support withdrawn as a result. It is difficult to see how this would enable disabled people. **This was a concern for 43% of respondents yet was avoided in the Government's response.**

The conclusion of many respondents was that they were dissatisfied with the proposal in the current form but looked forward to working with the Government. However, a year on, with the welfare reform bill about to be passed, few changes have been made and none of the many concerns raised again and again have yet to be recognised let alone addressed. Many others rejected the proposal entirely and only a tiny minority supported the proposal in its current form.

The most recent Impact Assessment (Oct 2011)[6] is almost identical to previous versions[7] suggesting that few, if any, of the suggestions made by disabled people and their representative groups have been taken into consideration.

Whilst we will go into the detail of each part of the consultation throughout the report, our overall findings are that:

- **74% of respondents were against the proposals but open to discussion**
- **19% had mixed views, agreeing with parts of the proposal**
- **Only 7% supported them fully.**

It is very hard to reconcile these results with the Government's response to the consultation, which asserts that disabled people are in agreement with and supportive of their plans.

The Consultation Procedure

Code of Practice on Consultation[8]

Criterion 1: When to consult
Formal consultation should take place at a stage when there is scope to influence the policy outcome.

Criterion 2: Duration of consultation exercises
Consultations should normally last for at least 12 weeks with consideration given to longer timescales where feasible and sensible.

Criterion 3: Clarity of scope and impact
Consultation documents should be clear about the consultation process, what is being proposed, the scope to influence and the expected costs and benefits of the proposals.

Criterion 4: Accessibility of consultation exercises
Consultation exercises should be designed to be accessible to, and clearly targeted at, those people the exercise is intended to reach.

Criterion 5: The burden of consultation
Keeping the burden of consultation to a minimum is essential if consultations are to be effective and if consultees' buy-in is to be obtained.

Criterion 6: Responsiveness of consultation exercises
Consultation responses should be analysed carefully and clear feedback should be provided to participants following the consultation.

Criterion 7: Capacity to consult
Officials running consultations should seek guidance in how to run an effective consultation exercise and share what they have learned from the experience.

Around a quarter of respondents wished to register complaints and concerns at the way the consultation was handled. Poorly advertised, the consultation was two weeks shorter than the 12 weeks normally allocated, which was compounded by taking place over the Christmas period. **Furthermore the Welfare Reform Bill was announced two days before it ended, thus making it impossible for it to be taken into account when drafting legislation.**

Evidence suggested difficulties in obtaining the material in accessible formats, something which should have been given even greater consideration than usual given the nature of the consultation and its target audience.

> *" When we tried to order copies for our own consultation exercise we encountered a lot of barriers – despite over 60 disabled people being in attendance on the day, our reasonable request for multiple copies of the consultation documentation was not met. There were also major problems with the large print format (which was not provided in an adequate font size)."*

> *"This did not appear to be an open and transparent consultation: we are all relatively well known organisations of disabled people but were not aware of any public consultation events – either regionally or nationally – that we, or the people we work with, could have attended."*[9]

For the same reason the period given to respond should, if anything, have been longer as a reasonable adjustment.

Others complained that the consultation itself is misleading. Comments were made for instance about the failure to mention the intention to reduce expenditure on DLA by 20%[10] despite fraud only being 0.5%[11], which is regarded as one of the prime motives for the changes. Motives for change are cited by the Government regarding the

- rise in number of claimants,
- disincentives to work,
- automatic entitlement and
- use of aids.

However, many disabled people use their DLA in order to work and respondents noted that it is among the general public where the misconceptions lie. They also pointed out that due to strict DLA regulations, automatic entitlement depends on the effect of the diagnosis, rather than the diagnosis itself and that DLA already does take aids into account. The consultation document's language says otherwise and was deemed to be deliberately misleading by many.

A further complaint was that this was not a consultation document on reform, but rather a "confirmation" document. It was found worrying that decisions had been taken before answers regarding the problems and extra costs faced by disabled people and the usefulness of DLA (questions 1,2 and 3 of the consultation) could possibly have been taken into account. (P8,4) **We have found evidence that some elements of PIP appear to have already been enacted, though legislation has not yet been passed. (See Q20, Sharing Information.)** There were many queries over how the Government would act should the consultation reject part of the Government's plans, since the proposals were presented as *fait accompli*. **With this in mind there was a big question mark over the purpose and validity of the consultation exercise.**

In an article published by the *Law Gazette*, Steve Broach writes[12]:

> *"Whether or not there is a duty to consult, once a public body decides to consult it has to do so properly. This essential starting point was made clear in R v North and East Devon Health Authority ex parte Coughlan [2001] QB 213 (Coughlan). In other words, whether consultation is a duty or a choice, once launched the standard and quality of the consultation has to be the same.*
>
> *Even if there is no specific duty to consult on a particular issue, disabled people's organisations, parents' forums and other local groups may well have a legitimate expectation that there will be consultation about changes to important services. The recent Building Schools for the Future case provides an example of a failure to consult at all amounting to an 'abuse of power'; R (Luton BC and others) v Secretary of State for Education [2011] EWHC 217 (Admin). Once consultation begins, Coughlan makes clear that four things must be in place to make it lawful:*
>
> *1) Public bodies must consult in good time – so that responses to the consultation can still genuinely be taken into account before the final decision is made;*
> *2) There must be enough information so that people responding to the consultation understand the proposals and can make an informed response;*
> *3) There must be enough time for responses. Whether 'enough' time has been given will be judged by the court, if the consultation is challenged, on the facts of the individual case. However, for example, a very short consultation over a school holiday period in relation to a service used by disabled children is unlikely to be 'enough' time;*
> *4) There must be genuine consideration of the responses – not just 'lip service' paid to them.*
>
> *If a particular consultation does not match these requirements, any child, adult or family potentially affected by the proposed changes can bring an application for judicial review to challenge the consultation. If the court agrees that the consultation is unlawful then the court will quash it and make the public body consult again – and do it properly the next time."*

While some regarded the flaws in this particular consultation as simply an appalling failure on the Government's part, others attributed more sinister motives, feeling the exercise was for show only.

Several responses went so far as to suggest that the Government's proposals may violate disabled people's human rights.

Counter-argument to the Government's Response to the DLA/PIP Consultation

In this section we consider the Government's response to the consultation on Disability Living Allowance based on analysis of over 500 group responses. We will consider the questions specifically relating to proposed changes under PIP. We have divided responses to each question into percentages who "Support" and those who were "Against." We include the response rate as an indication of the strength of feeling expressed over each issue.

1. Foreword and Evidence base for Personal Independence Payments – Counter-argument

This section is a shorter version of an article by Declan Gaffney published on the website *L'Art Social* (http://lartsocial.org). It explores working-age DLA receipt over a 15-year period, from 1995 up to 2010. Unlike most of the analyses published to date, it attempts to take account of both demographic change and underlying disabling conditions. It shows that DLA receipt for 'physical' conditions stabilised about 10 years after the introduction of the benefit, consistent with a gradual catch-up with the population prevalence of physical impairments, and has remained remarkably stable since then once demographic factors are taken into account. DLA receipt associated with mental health and learning difficulties however has increased since 2002. In the case of mental health, by far the biggest driver of working-age caseload increase, this process is not well understood at this stage. However we note that even with continuous growth in DLA receipt since 1992, just over 1% of the working-age population is receiving DLA for reasons associated with mental health, a far lower figure than estimates of the population prevalence of more severe mental health problems. For 'physical' conditions, there is no growth in DLA receipt beyond what would be expected in a population that is larger and somewhat older than it was a decade ago. There is therefore no basis for the Government's claim, central to its case for reforming DLA, that "the complexity and subjectivity of the benefit has led to a wider application than was originally intended".

Why our figures are more relevant and reliable than those used by the government

The Government's case for abolishing Disability Living Allowance turns crucially on claims about trends in DLA receipt and expenditure between 2002 and 2010. In its consultation document on abolishing DLA, the Department for Work and Pensions stated: "In just eight years the numbers receiving DLA has [sic] increased by 30%. The complexity and subjectivity of the benefit has led to a wider application than was originally intended." In evidence to the House of Commons Work and Pensions Committee, Maria Miller stated that DLA expenditure had increased by 38% betwen 2002 and 2010. The Department for Work and Pensions representative stated: "To add to what the Minister said, *only one third of the growth in DLA in the last eight years can be attributed to what might be called demographic factors*, the remainder being accounted for by average receipts per head." (Our italics)

We have carried out an analysis of trends in DLA receipt from 1995, three years after the benefit was introduced, to 2010. We believe the figures we present here are more reliable than those cited by government, because they take more factors into account in explaining changes in DLA receipt. They are also more relevant to the government's case for reform because they focus on the groups that will be affected by those reforms rather than on DLA clients in general. The reasons for undertaking a more detailed analysis are as follows:

a **Numbers and rates** The Government has generally chosen to highlight figures concerning changes in the numbers of people receiving DLA. However, these figures are affected by population growth: the population in 2010 for example is larger than in 2002. Our analysis focuses also on the rate of DLA receipt, that is the percentage of people who are receiving DLA. (The rate is also affected by changes to the population, not in terms of size but of age structure, but we have taken account of this in our analysis – see below).

b **Age** The Government has used figures which concern the entire DLA caseload: however, the policies the Government is proposing concern only people of working age, so figures for all DLA claims are of little relevance. At the same time, as the Government has belatedly acknowledged, figures for the entire caseload give a 'distorted' picture (DWP's words) of growth. DLA receipt among people over retirement age has a

built-in growth factor because virtually nobody who retired prior to the introduction of DLA is entitled to DLA, while since 1992 people who are receiving DLA when they retire have been entitled to keep their award into retirement if their circumstances remain the same (rather than applying for Attendance Allowance). This intended feature of DLA is a major contributor to growth in the caseload. We therefore focus on DLA receipt among people of working age.

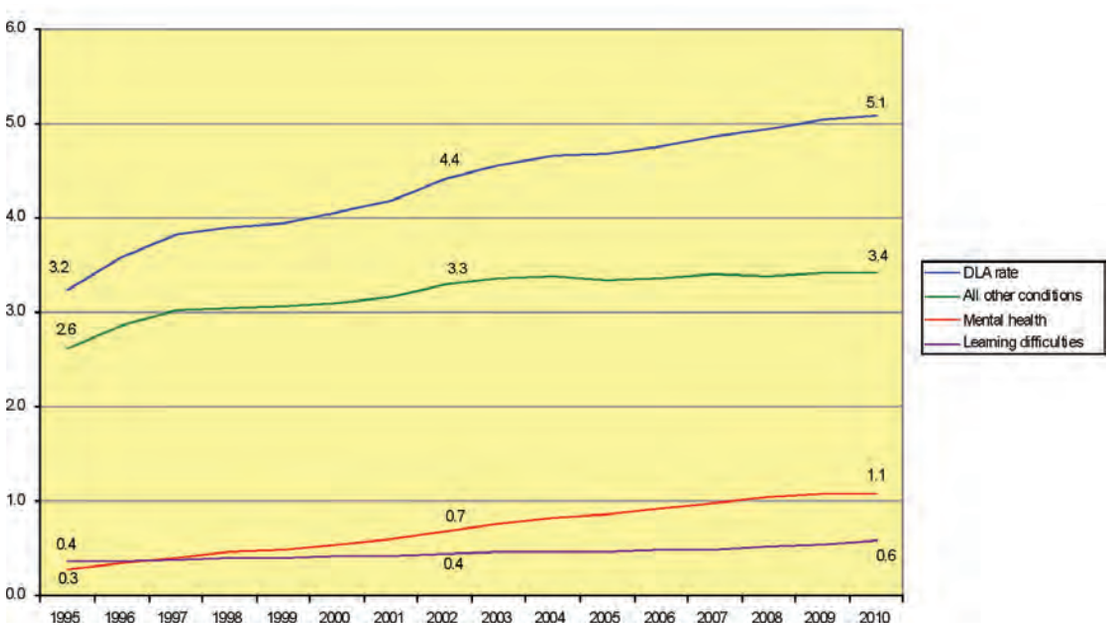
c **Condition** While Government has made numerous assertions about growth in the DLA caseload, it has said nothing about how DLA receipt has changed for different types of condition. Yet if the DLA caseload is increasing, it seems obvious to ask whether this is happening across the board or is growth particularly driven by specific conditions? We have looked at how rates of working age receipt have changed by broad condition categories (such as arthritis, heart disease and mental health), something the Government has not chosen to consider, publicly at least (it has published an analysis of change by condition, but not for the working age caseload, rendering it irrelevant for the reasons noted in (b)).

d **Timeframe** The Government's assertions about growth in the DLA caseload are almost entirely concerned with the period since 2002. There is a good statistical reason for focusing on this period, as the time series giving the most robust and detailed data on DLA only begins in 2002. However this means ignoring earlier trends, which makes it difficult to contextualise what has happened since 2002. We have therefore constructed a long-term time series for working-age DLA receipt, taking account of disabling conditions, using other Government data sources.

e **Accounting for change** Demographic change has affected the numbers of working-age DLA claims, not just because the working age population is bigger but because its structure has changed over time. Many disabling conditions are more common among older age groups, so changes to age structure are likely to affect the numbers on DLA even when we are only concerned with people of working age. We have taken this into account by analysing DLA receipt by age band (e.g. age 25–34) as well as condition. Bringing the age and disabling conditions of DLA clients and demographic change into the analysis allows us to break change in the working-age DLA caseload down into two components: changes in the rate of DLA receipt by age and condition on the one hand, and population change on the other. This is a much more relevant way of looking at changes in caseload than the crude analysis which government has offered.

Results

The chart below summarises the long-term development of DLA receipt from 1995 (just three years after the introduction of DLA) to 2010 (the last year for which detailed population estimates are available at time of writing). We have broken the caseload down into three broad categories: mental health, learning difficulties and 'all other conditions', for reasons which are perhaps obvious.



Overall, the rate of DLA receipt rose from 3.2 in 1995 to 4.4 in 2002, and then to 5.1 in 2010 (the blue line in the chart). This would seem to support the government's claims that DLA has grown continuously. But when we look at condition categories this picture proves to be quite deceptive. DLA receipt associated with mental health and learning difficulties has increased significantly since 2002 (the red and purple lines), but there has been very little change for other conditions (the green line). In fact, the rate of receipt for other conditions has increased by less than one tenth of a percentage point since 2002. So for what can very loosely be described as 'physical' conditions there has been virtually no change in DLA receipt since 2002, and all of the identifiable growth by condition is associated with mental health and learning difficulties.

A technical point is unavoidable here: this finding is not driven by the way we have combined different condition categories into the single group 'all other conditions'. We have checked this by calculating rates of receipt for the major 'physical' conditions identified in the government's data (such as arthritis and heart disease) and the pattern is one of minimal or negative change since 2002. (The exception is the 'other' category in DWP's 5% sample data, which is the only category apart from mental health and learning difficulties to show substantial growth since 2002. As this category is made up a set of more detailed condition categories which is not consistent over the period, it is unanalysable using the publicly available data.)

In the chart, we have simply shown the rates of receipt for all working-age people, without taking account of how the population age structure has changed over the period. In fact a more detailed analysis by age band strengthens the conclusion that working age DLA receipt has been remarkably stable for most conditions with the exception of mental health and learning difficulties. The results are shown in the table below, which shows how overall change in the DLA caseload excluding mental health and learning difficulties breaks down into 'rate of receipt' and 'population' components, up to 2002 and from 2002 to 2010.

Period	Change due to	Number	Per cent
1995–2002	Change in rate of receipt	218,169	74.2
	Demographic change	75,926	25.8
	Total	*294,095*	*100.0*
2002–2010	Change in rate of receipt	-7,670	-6.7
	Demographic change	122,231	106.7
	Total	*114,561*	*100.0*

There is a striking contrast between the two periods: between 1995 and 2002, most of the change (74%) is driven by the rate of receipt, while after 2002 all of the change is due to demographics – both population increase and changes in age structure. Because we have used more detailed age bands here, we can now see that rates of receipt for 'physical' conditions have actually fallen slightly, reducing the caseload by about 7%. So even the very small rise in receipt shown in the chart (0.1%) proves to be exaggerated.

Commentary

The contrast between the two periods shown in the table has an obvious explanation which is completely at variance with Government's claims that DLA caseload growth is driven by 'subjectivity'. The explanation is that DLA was introduced in 1992 with the aim of expanding the coverage of disability benefits. This meant that there was an inevitable 'catch-up' phase when rates of receipt rose quite rapidly for most conditions as the new benefit bedded down. The tail end of this process can be seen in the chart, where the increase in the rate for 'all other conditions' shows a marked levelling off around 2000. Once the catch-up phase was over, demographic change was the main driver of changes to DLA receipt for 'physical' conditions, as the prevalence of most disabling conditions does not change rapidly unless there is change to population size and age structure. There is therefore nothing mysterious or anomalous about recent trends in the DLA caseload for 'physical' conditions.

If Government wishes to argue that 'subjectivity' is a factor in increases in DLA receipt, it needs to explain why this is only the case for mental health and learning difficulties – and why this 'explanation' should be seen as more convincing than alternatives. In the case of learning difficulties, the rise in receipt is very concentrated among

younger working-age people: the obvious explanation is earlier diagnosis (in childhood) of certain conditions, leading to people carrying DLA awards over into adulthood. For mental health, the question is less about why receipt has grown as why it has taken so long to reach its current levels. Even after 15 years of continuous growth, only one in a hundred working age adults is in receipt of DLA associated with a mental health condition. This is far lower than estimates of the population prevalence of more severe mental health conditions from studies such as the *NHS Adult Psychiatric Morbidity Study* for 2007. By way of example, this study found that the prevalence of common psychiatric disorders with 'a level of severity high enough to require treatment' among people of working age ranged from 6.5% to 8.7% according to age. (These figures do not include psychosis, the fourth most common detailed condition category for DLA recipients.) Given these estimates, it is hard to see why the current rate of DLA receipt associated with mental health problems should be regarded as anomalous.

The Government has cited figures for growth in DLA caseload and expenditure as if these counted in themselves as evidence that the benefit is being awarded inappropriately. This argument falls apart as soon as the figures are subjected to routine analysis. If the DLA system were flawed in the way Government asserts, we would expect to see growth in awards associated with a range of condition categories, not just two. **This aspect of the Government's case for change is therefore without foundation.**

2. Is there a "DLA Effect" that Dis-incentivises Work as claimed by the Government?

In making their argument for reform of DLA, and in impact assessments of the policy, the Government has made much of an apparent effect of DLA receipt on disabled people's employment; the claim is that disabled people receiving DLA are less likely to start or remain in work, when compared to disabled people not receiving DLA. The principle source for this assertion is a research report commissioned by the DWP and published in 2010, entitled *Disability Living Allowance and work: Exploratory research and evidence review*[20].

This report goes into remarkable depth when reviewing existing research on the question. While there are unarguable statistics showing that disabled people in receipt of DLA are less likely to be in work than those not receiving DLA, the existing research indicates a range of factors that explain some of this difference. These include:

- The fact that DLA recipients are statistically more likely, than other disabled people, to suffer employment disadvantages unrelated to their disability (for example by virtue of being older, or female).
- The fact that DLA recipients tend to be more severely affected by disabilities, and more likely to suffer from categories of condition or impairment that create larger employment disadvantage (such as mental health problems, locomotor impairments, multiple conditions/impairments).
- That they are more likely to have been advised not to work, be on a 'trajectory out of work', or already have stopped working.

Two reports from 2009 are cited as showing that, after taking some other variables into account, there is a 'DLA factor'. It is important to note, however, that neither of these studies were looking at actual employment. Instead, it was looking at a claimant's own perception of how likely they thought they were to return to work, or whether they wanted to return to work. Furthermore, the studies were only looking at Incapacity Benefit recipients. The consideration of confounding factors is also acknowledged as limited, with

> *"all other likely factors taken into account as far as possible with the available data" (p.37)*

The two studies also reach very different conclusions as to the size of the DLA factor; in one, it was found to be the smallest contributing factor to a low desire to work, while on the other it was found to have a greater effect on expectation of working than the extent of self-reported health condition. The studies suggest that the money received from DLA reduces the financial incentive to take up paid employment, citing as evidence the fact that those receiving more money from DLA are more likely to have low desire or expectation of (re)entering work. As the report points out, however:

> *"It should also be noted that the monetary value of DLA is directly linked to the severity of a health condition, and so, again, this result may reflect differences in the severity of a health condition not captured in the control variable." (p.38)*

Ultimately, the report concludes that there is evidence for a DLA factor, something specific to DLA that makes recipients less likely to work. They do not state outright that it has been demonstrated, however, as one might expect in the case of strong, directly applicable evidence. Instead they state

> *"our research supports the hypothesis that there is … a DLA specific factor that makes it less likely that they will work" (p.105)*

If there were strong statistical evidence for this factor, one would expect it to be stated; instead, the report states limitations in the pre-existing statistical evidence, and acknowledges the limitations of the qualitative data from their own research.

Let us assume, for the sake of argument, that this DLA factor exists. While qualitative evidence is not good for supporting the existence of such a factor, it can be very useful in explaining it, and that is what the report's authors go on to explore. They divide the factor into two components: one in terms of perceptions of DLA, and the other in terms of financial disincentives.

The question of perception is examined in terms of what people perceive as their justification for claiming, what they understand to be the rules for claiming, and what can be deduced from the timing of the claim. In general, it amounts to:

- The fact that DLA is misunderstood to be an out-of-work benefit
  "For a great many DLA claimants, both applicants and recipients, there was a clear perception that DLA is a benefit for those who are unable to work, and that it is only payable when someone is not working and stops when they go back into work." (p.42)
- DLA isn't widely understood at all, so people claim only when it is suggested, and the circumstances in which it is suggested are generally associated with leaving work or taking sick leave
  "While in a job and working (and hence earning) many were either oblivious to the existence of DLA or perceived that they did not need it – or indeed that they could not, or should not, claim it. While the precise timing of DLA applications can be affected by several contingent factors, including hearing about the benefit for the first time, claims often indicated a response to some form of crisis that had changed people's priorities and perspectives. People generally claimed at the point when their ability to work became severely affected or their financial situation became untenable. This was not always when they first acquired a health condition or disability." (p.57)
- People feel that they shouldn't claim while they are making enough money to live on, and will even withdraw their claim if they find work, regardless of their condition.
  "while it is undoubtedly the case that there are people struggling on in jobs despite quite severe disabilities and health conditions, they are not making claims for DLA, despite their needs" (p.46)

The final question is financial disincentives, or reduced financial incentives. People on out-of-work benefits receiving certain awards of DLA get increased rates of those other benefits. This means there is less financial pressure on these people to enter work; it should be noted that, in the case of ESA and the remnant on IB, these are people who are acknowledged as not being expected to find and start work. However, these disincentives are not part of DLA itself, and it unclear how reform of DLA could address them; the system of disregards and single taper in Universal Credit, however, do address those points. Other financial disincentives mentioned are really aspects of perception – the fact that some believe, incorrectly, that DLA cannot be received while in work, and the fact that it is feared that entering work will trigger a review of the DLA award:

> *"Although employment status is not in itself relevant to DLA eligibility, there is also something of an acknowledged grey area in terms of what changes of circumstance should be reported, due to the relationship between needs and impairments and the requirements of different types of jobs" (p.81)*

> *"The simple fact that DLA reviews* **can** *be triggered by information about entry into employment which* **may** *lead to withdrawal or reduction of the benefit, and the difficulty of assessing the true level of risk, lends credence to the reported fears" (p.81)*

While the Government commitment to better understanding addresses the first of these, the report makes a specific recommendation regarding the second, and the Government has made no indication as to its implementation. That recommendation is simple: guarantee that entering work will never trigger a review, and that it won't be used as evidence of lower levels of disability.

There is also no indication of supporting other recommendations from the reports – encouraging earlier claims of DLA, while people are still working, and providing specific support to these people to help them stay in work. In reviewing previous methods of supporting and incentivising disabled people to return to work, the report suggests that most measures have supported people to remain in work, but done little to incentivise or hasten a return to work. The only one mentioned that did was the Return To Work Credit (RTWC), part of the Pathways to Work program, though it was also reported to have been taken up by those who would have returned to work anyway (p.153).

In essence, it comes down to the question of correlation and causation. By simply asserting the correlation supposed by this DLA factor, and stating that the reforms to DLA will reduce it, the implication is that some aspect of DLA itself is the cause of reduced likelihood of employment. However, researchers of all stripes recognise that correlation does not, in itself, demonstrate causation. The causative analysis in the report asks what the causal relationship is, and finds that it is principally connected to the design of other benefits (hopefully addressed by the introduction of Universal Credit), and to issues of perception, likely to be solved better by public education. Concerns regarding the changes in circumstance that prompt reviews do not appear to be addressed by the proposed reforms, and do not require such wholesale reform to implement.

As such, it is unclear what the DLA reforms themselves will do to help more disabled people into work and reduce this DLA factor in employment.

3. Change of rates and loss of eligibility

92% Against / 8% Support

61% concerned re eligibility/loss of income

Response rate: 66%

Question 4: The new benefit will have two rates for each component:

a. Will having two rates per component make the benefit easier to understand and administer, while ensuring appropriate levels of support?
b. What, if any, disadvantages or problems could having two rates per component cause?

Summary of findings

Dual concerns were made regarding the change from three bands of "care" rate to two, and loss of eligibility or loss of income for disabled people.

Regarding the change from three bands to two, it was agreed that this would make it easier to administer. However it was immediately pointed out that this was not an advantage or a step forward for disabled people, but simply for the DWP**.**

- It was generally contested that it would make it easier to understand as there would still be nine possible combinations of benefit.
- **It was completely rejected that having two rates would be better**.

- It was felt that it would be impossible to properly reflect the wide range of disabilities people experience with only two rates. A more graded system is needed. While the three-rate system isn't ideal it is still much better than one with only two. It was therefore felt that the new system would not be "fairer" as the rates would not better reflect the needs of the disabled person.
- In combination with the language used elsewhere in the consultation, the emphasis on those with "greatest need", it was widely felt that the effect would be to get rid of the current low rate of DLA care. This has several significant effects:

With the squeeze on local budgets a large number of disabled people don't qualify for any help from social services. Their low rate DLA is their only form of support. With this change it was widely agreed that they would no longer be eligible.

In particular, people with mental health problems would be disproportionally affected by this. Without this support, problems currently kept in check would deteriorate to a point where other services would have no choice but to step in. So there would be a financial as well as a human cost. It would in fact be more cost effective for these people to keep their low rate benefit, quite apart from the ethical aspect.

For others the issue is simply one of poverty. Although their needs may be considered to be "less severe", costs may still be high. The high number of disabled people living in poverty confirms this.[21] The loss of even the small amount afforded by low rate DLA could be devastating.

Another consequence of the two rates will be felt by those who drop a rate. As before, one consequence will simply be increased poverty, but there could be wider, knock-on effects.

As mentioned previously, DLA is a passport benefit. It is unclear how the three rates of benefits would map on to the 2 rates. For example, mid-rate DLA is currently necessary to qualify for Carer's Allowance, disability premiums and increased housing benefit for certain groups. If this is taken away if downgraded to lower rate PIP, the effect on individuals and families would be devastating. Many highlighted the important role carers play and the cost this saves social services and the wider community, recently estimated at over £119 billion[22]. Thus any loss of carer's allowance could have serious repercussions.

Counter-argument to Government Response

The Government claims that the majority of organisations welcome the move. (P17,18) This is clearly not true given that 92% of those who expressed an opinion are specifically saying they are against this move with only a tiny minority expressing their support.

The Government cites The National Aids Trust to **support** its case. (P17,18) This is disingenuous. This organisation does indeed support the principle of change but has deep reservations about PIP itself.

> *"NAT supports the principle or reforming DLA in order to make the system less confusing … but this cost-cutting approach to reform will have the opposite effect for many people living with HIV."*

Worse, it specifically says it does not support the move to two levels of care.

> ***"NAT is concerned that moving from three to two levels of the care/daily living component will adversely affect some people living with HIV who currently claim the lowest rate of care under DLA."***

As noted above, the DWP will welcome the move to two rates for ease of administration. (P17,19) However, this is not seen as an advantage for disabled people and any reform should be aiming to improve the lives of disabled people, not the lives of DWP workers.

In its response (P4, 14,15,18 21–23) the Government overrides the objections that the change did not make the benefit easier to understand.

- The consultation response overrides the concerns that two rates cannot reflect the wide ranges of difficulties disabilities bring and therefore are not fairer.

- It ignores all concerns regarding the removal of the lower rate of DLA, despite the very serious impact it would have on large numbers of disabled people.
- It ignores the knock-on effects this would have on social services and other national services and charities.
- It ignores the increase in poverty this move could bring through loss of eligibility and change of band.
- It ignores the large worries of loss of important linked benefits, in particular carer's allowance.
- It ignores the concerns of mental health groups over the disproportionate effect this would have on their users.
- It ignores the fact that people with so called "lower needs" may still face very large costs rising from disability.

This is despite all of these concerns being raised time and time again by the majority of respondents.

Conclusion: The Government response is clearly misleading and fails to respond to the views and concerns of disabled people in this section. (P4, 14, 15, 18)

4. Automatic qualification

87% against / 13% support

Response Rate 72%

Question 5: Should some health conditions or impairments mean an automatic entitlement to the benefit, or should all claims be based on the needs and circumstances of the individual applying?

Summary of findings

All agreed that automatic qualification should remain for those defined as terminally ill.

While it was agreed that it is obvious that for most people the award of the benefit should be on the merits of the effects of the disability or illness, a large majority felt that the criteria for automatic qualification for a few select cases should remain as it is for DLA, with only a minority feeling it should be changed to a case-by-case basis for all.[23]

The basis for this was twofold:

- One was simply the cost of assessing people who are obviously going to qualify.
- The other was the stress and discomfort for those people having to undergo assessment as well as having to deal with their disability.

The types of disability or illnesses considered to merit automatic qualification were mostly those which were rapidly degenerative, such as Duchennes muscular dystrophy, or highly disabling and easy to prove, such as blind/deafness.

Some even felt that the current list of exemptions was too prescriptive and should be reviewed and extended. It was felt much money could be saved this way.

Counter-argument to Government Response

- We find the Government to be quite misleading in this section (P19,20).
- We dispute the Government's interpretation of the data (P19,26). Although some organisations did cite their own impairment as a basis for automatic qualification, many did not but altruistically acknowledged that other illnesses or disabilities should be entitled to it.

- The Government reports that the respondents are "split" on the question (P19,26). A "split" implies an equal divide. The division is anything but equal. The majority were in favour of keeping the system as it is and continuing to assess those who do not qualify for automatic entitlement based on need.
- The Government makes no mention of the number of respondents who suggest the list of automatic entitlements is outdated and should be extended.
- We agree that the Government cites the same findings as we do for keeping the system as it is (P19,28).

The Government response overrides the consultation and decides to continue with its plans to get rid of all automatic entitlements in future.

Conclusion: The Government is misleading and fails both to respond or to take the views of disabled people into account in this section.

5. Extension of Qualifying Period

98% Against / 2% Support

Response rate: 25%

Summary of findings

The qualifying period is to be changed, allegedly to bring it in line with equality law. However this is opposed by an overwhelming majority and some point out that the proposal is in fact harsher than the equality law. Where the law says "is expected to last 12 months", for PIP it says "must last more than six months and be expected to last a further six".

This change was condemned by many, citing the fact that upon becoming disabled most people already experience poverty with a qualifying period of three months, a situation which will only get worse with a waiting period of six months. Furthermore, if there is any appeal, the total waiting time could be even longer, leaving disabled people without income for a prolonged amount of time.

Other concerns noted were that by the time of the application the disabled person's health may have significantly deteriorated and their needs may have become urgent. Questions were raised regarding the ability of the DWP to respond quickly enough. **The 3 month qualification period left enough leeway for benefits to take effect before crisis point.**

The increase in costs due to the advent of disability can hinder someone's ability to continue working. Increasing the qualification period is only going to worsen this, which goes against the Government's wish to increase the number of disabled people in work.

Counter-argument to Government Response

The Government admits that only a few organisations are in favour of this move (P20,33). **We would like to emphasise just how few, and just how many are against this.**

We dispute the claim that the benefit will be more in line with the Equality Act 2010[26] (P20,32 P21,34). A person diagnosed with, for example, MS or HIV is considered disabled from the point of diagnosis. Although this does not necessarily render them eligible for benefits, they are immediately protected by law and can access reasonable adjustments in the workplace as well as support such as Access to Work. However this is not the case for PIP. It was not the case for DLA either, but the extension of the qualification period moves even further away from this definition.

The move may be in conflict with the United Nation Convention of the Rights of Persons with Disabilities, article 26, "Habilitation and Rehabilitation"[24] which obliges the UK to organise such services and programmes to begin at the earliest stage. Making the stage later would be retrogression.

The Government's claim that extra costs may be covered by the NHS or local authority (P21,36) ignores the squeeze on budgets that these services are facing and the current long waiting times before support can be put into place. Furthermore PIP is designed to cover the costs incurred on top of the support offered by these organisations and these will be there regardless of whether that support is covered or not. It should be noted that the Government itself does not claim that the costs will definitely be met, only that they "may" be met.

The Government is proceeding against the express wishes and concerns of disabled organisations.

Conclusion: The Government fails to take the views of disabled people into account in this section and far from improving equality law, may be contravening their human rights.

6. The Assessment Process:

90% against / 10% support

Response rate: 85%

Question 7: How can we best ensure that the new assessment appropriately takes account of variable and fluctuating conditions?

Question 10: What supporting evidence will help provide a clear assessment of ability and who is best placed to provide this?

Question 11: An important part of the new process is likely to be a face-to-face discussion with a healthcare professional.

a. What benefits or difficulties might this bring?

b. Are there any circumstances in which it may be inappropriate to require a face-to-face meeting with a healthcare professional – either in an individual's own home or another location?

Summary of findings

Two main things stood out in group responses:

A A change to a mandatory face-to-face interview with an independent healthcare professional; and

B The removal from the form of a statement from "someone who knows you best".

The face-to-face discussion was the change that brought the most worry to respondents. The objections to the face-to-face interview were many but can mostly be summarised as follows:

- Too short to appropriately appreciate the effects of disability
- Lack of specialist assessors
- Quality of assessor
- Independence of assessor
- Target driven assessments
- Inappropriate to talk about intimate difficulties with a complete stranger
- Stressful
- Difficult for people with mental health disabilities
- Inappropriate for children

- Inappropriate for anyone with communication difficulties
- Inappropriate for fluctuating conditions
- Inappropriate for "invisible" conditions such as chronic illnesses or mental health
- Medicalised view of disability
- Only provides a "snapshot" view
- Too subjective
- Large cost
- Difficulties attending an assessment centre (transport, carer to accompany, accessibility)

The majority of responses specifically made mention of the ESA Work Capability Assessment (WCA) with fears that this approach would be adopted. The feelings were that it had failed and this approach is intrinsically flawed. The system is backlogged with appeals at great cost.[25]

It was widely felt that to roll out a similar system for DLA or its replacement would be doomed to failure and a repeat of a mistake with disastrous consequences.

Even the respondents who were in favour of a face-to-face assessment called upon the Government to first undertake further consultations in order to learn from the mistakes of the WCA, and only to use specialists rather than general healthcare professionals.

> *"The Mayor is opposed to using independent healthcare professionals to provide advice on an 'individual's condition'. Supporting evidence should only be sought from healthcare professionals who are familiar with the individual, for example their GP or Consultant. They will be familiar with the claimant's case, the barriers they face and will be much more aware of their particular circumstances… It would be difficult for a healthcare professional, in a one-off meeting to elicit a comprehensive response about the daily reality for each claimant…"*
> (Response to consultation from Mayor of London)

The second biggest cause for concern in this general section was the removal from the assessment form of a box for "someone who knows you best". It was felt that the form had moved too much towards a medical approach. It was pointed out that not all disabled people are sick and in frequent touch with their GP, nor necessarily have hospital consultants. In this case the best person to ask about the effects will be someone else who has regular contact with the disabled person, and witnesses the effects on their life.

This can be the case even when the disabled person sees their GP regularly. One GP commented that although they may be well versed in the medical condition of their patient, they don't know necessarily know the problems they have getting dressed in the morning because they aren't there and it isn't something they have asked about in their regular consultations.

More generally it was felt that the current system worked well, as the person best placed to give information about the effects of their disability or illness is the disabled person themselves. Despite any expressed misgivings about the current form, self assessment was generally praised as the best way to find information. Back-up should be sought from the person's GP and consultants if they were in frequent medical contact and from carers or family members as mentioned above if not, **but the most emphasis should be given to the information provided by the disabled person themselves.**

Finally it was still felt that the proposed system would be extremely poor in identifying and supporting those people with fluctuating conditions, in particular with the move away from self assessment and input from people around the disabled person. Suggestions were made many times that a diary over a period of time should be made instead for the cases of long term fluctuating conditions.

Counter-argument to Government Response

The Government hides the opposition to its proposals in its Executive Summary (P4).

The Government's own admission (P4,18) that **the assessment is being developed with "a group of independent specialists" leads us to question the commitment to involving disabled people and organisations over the reform of this benefit.**

We question the Government's claim that "Many individuals and organisations welcomed the recognition that variable and fluctuating conditions will be reflected in the design of the assessment" (P24,43). **We found no evidence of this**. On the contrary respondents expressed serious reservations about the nature of the new assessment, in particular for fluctuating conditions.

The Government makes no mention of the valuable contributions made for alternative arrangements for such conditions including the use of diaries.

The Government makes no mention of the failure of the WCA to evaluate these conditions accurately and the huge risk it would pose to roll out a similar system for PIP.[26]

We reject the Government's interpretation of the data regarding face-to-face assessments and find this section highly misleading (P27,54). Only a minority of responses felt that these would be beneficial while the rest feel the problems by far outweigh benefits (if any). **This area provoked the most responses and the highest concern in the whole consultation.**

The Government's response fails to mention many of the concerns highlighted by the respondents, including **cost, independence of the assessor, the lack of time per appointment, the inevitable, medicalised, tick box result of such a system, the subjectivity of the individual assessor, the inappropriateness of such a system for "invisible" conditions including chronic illnesses and mental health, the failure of a similar system to cater for fluctuating conditions.**

Although the Government acknowledges that specialist assessor knowledge is a big concern and essential, it makes no commitment to ensure it will be available. It only promises to "consider it" (P28,59).

The Government accepts that face-to-face assessments may not be appropriate for those with "the most severe impairments", however it makes no promise to make any exceptions, again, only to "consider it".

Although the Government mentions the WCA it does not say how it is going to improve it. The latest Harrington report says that while there has been some progress, it will take at least three years to see if his recommendations are working. This is hardly a glowing success and does not give enough confidence to roll out a similar system for PIP (P28,57).

The only positive concession is the promise to ensure that any assessment will take "place in the most appropriate setting and that any assessment facilities are fully accessible" (P29,61). **It should be noted that this is not currently the case for the WCA.**[27]

The Government refuses to take on board the overwhelming response that the best person to give information about their disability is the disabled person themselves. **The new system appears to give equal if not more weight to the opinion of medical or independent professionals and none at all to the people around the disabled person.**

The Government completely fails to mention the concern that the views of the people who either care for the disabled person or know them well will no longer be taken into account, even though it was an overriding theme throughout the consultation.

Despite all the concerns raised against a face-to-face consultation, the Government overrules them and persists in saying it "believes" it is the best way forward **without any strong objective evidence (P28,59).**

Conclusion: The Government is both misleading and fails to respond to the concerns of disabled people in this section.

7. Change to Review System

92% Against / 8% Support

Response Rate 72%

Question 12: How should the reviews be carried out? For example:

What evidence and/or criteria should be used to set the frequency of reviews?

Should there be different types of review depending on the needs of the individual and their impairment/ condition?

Summary of findings

The change to the review system was felt to be unnecessary. Many felt that the consultation document and recent media claims[28] had been disingenuous in the way it had approached this question.

It was felt that some conditions, those which were permanent or progressive, should still have indefinite awards with the option for the claimant themselves to ask for a reassessment if they wished.

For others the frequency of reviews should be based on need and not be the same for all. This was felt to be a waste of time and money as well as a source of unnecessary stress.

Furthermore it was felt that reviews should be different to new claims. Requests were made that for conditions unlikely to change a simple change of circumstances form could be signed either by the claimant or their doctor. It should be unnecessary to submit a brand new claim each time.

It was felt that the new system would be far too costly and fears were expressed that this money would come out of that available to give as benefits for disabled people.

Mention was made of the Benefit Integrity Project *(see Annexe 1)* with warnings not to repeat the same mistake.

Counter-argument to Government Response

The Government overrides the overwhelming responses of this part of the consultation.

Although it makes a point about the cost of some overpayments (P32,70), it ignores the points made about the cost of regular reviews for people for whom it is obvious the condition is never going to change. **When offset against the cost of underpayments (P32,70) we strongly question whether there is a financial or a political motive to this change**.

The Government pays no attention to the considerable number of suggestions for improving the current methods of review so that possible changes of circumstances might be better reported. The Government refuses to respond to the suggestions of simpler and easier reviews which would both lessen the stress for the disabled person and the cost of the review.

It fails to mention the Benefit Integrity Project completely.

Conclusion: The Government fails to respond to the concerns and suggestions of disabled people in this section.

8. Emphasis on Aids

88% Against / 12% Support

Response rate: 68%

Question 8: Should the assessment of a disabled person's ability take into account any aids and adaptations they use?

a. What aids and adaptations should be included?

b. Should the assessment only take into account aids and adaptations where the person already has them, or should we consider those that the person might be eligible for and can easily obtain?

Summary of findings

It was almost unanimously felt the Government has an overly optimistic view of life for disabled people in the United Kingdom today. Some were so keen to help the Government understand that their responses simply gave many examples of the problems disabled people still face rather than answer the specific questions of the consultation.

When asked about the problems faced and the costs rising from disability in questions 1,2 and 3, the overwhelming response was **transport**. Despite the DDA[29] and Equality 2010[30], many buildings remain inaccessible and most public transport, especially in rural areas, is similarly inaccessible or unreliable. Most must still rely on taxis or their cars.

Many must buy adaptations or improvements to their mobility aids. Others cite maintenance and insurance as further costs. Furthermore the aids don't work all of the time or in all circumstances. Hills, bad weather, pain, or simply broken equipment all present problems.

Thus even with aids such as a wheelchair, mobility is still greatly restricted and mobility costs still much greater than non disabled people. It is a source of great concern that people who can use a manual wheelchair on a flat surface may be deemed completely "mobile".[31]

Other types of aids are also prohibitively expensive, especially communication aids, be it visual or audio. These are not routinely provided.

Some deaf groups were fearful of being forced to use aids such as cochlear implants or being refused benefits.

Many were also fearful that they would be forced to use aids which were inappropriate and benefits may be taken away if they refused to use them.

It was noted that taking aids into consideration to the extent which is proposed for PIP is at odds with the DDA definition of disability.[32]

> *"The Disability Discrimination Act (DDA) defines a disabled person as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities."*

It was commented that contrary to what was implied by the consultation document, aids are already taken into consideration in an application for DLA and there is no valid reason for the system to change.

The only other overriding comment was a plea for the DDA and Equality 2010 to be enforced.

Counter-argument to Government Response

We agree with the Government's findings that there are ongoing costs associated with aids that have already been purchased.

We concur with the Government's statement that some aids are already taken into account under DLA where they enable the disabled person to carry out activities under daily life (P25,49). We note however that this was not made clear in the consultation documents.

We agree with the Government's findings that some organisations agree with the proposals to take greater account of aids. (P25,48) We agree that these tend to be health and medical professional organisations. We submit that

these organisations have a lesser understanding of the degree of independence these aids offer on a daily basis than the disabled people who actually use them.

However we also point out that the organisations which agree are in a great minority and we are very concerned that the Government does not point out the large number of organisations registering their rejection of this proposal.

The Government fails to mention the real concerns raised over their assertion that the DDA and Equality 2010 have removed all barriers to disability. **Yet this is key to their argument for taking greater emphasis on aids at assessment**. For instance, until disabled people really do have equal access to buildings and transport they still retain large costs and mobility is greatly restricted. It is therefore totally unreasonable to take, for example, a wheelchair into account at assessment.

The Government cites the support given in the form of aids and adaptations through the Local Authorities (P26,51). **However it fails to mention that many disabled people either fail to qualify, receive equipment which is ill suited to them, or have to top it up with their own money either through savings or their DLA.** This is well documented throughout the consultation. It also makes no mention of the very long waiting lists which plague Local Authorities, nor the fact that some forms of adaptations may be means tested. Furthermore, due to shrinking budgets, Local Authorities have to cut back on what they offer. For example only shower chairs may be allowed, while help with bathing equipment is deemed a "luxury". Accessible taps may only be allowed in one sink, not the whole house. The list goes on.

It fails to mention the concerns that taking into account aids that "may be available" could be used to deny benefit to people who don't actually have access to those very aids, or who may have to wait for it, and worse may force people into using inappropriate equipment. **Until a person has used a piece of equipment there is no way of knowing how much it will help them.**

It does not take into account what will happen if an aid fails.

It makes no mention of the fact that this policy potentially puts the decision over the use of medical aids into the hands of DWP workers.

The quotations the Government has chosen to support their decision (P25,26) have been cherry picked and are deliberately misleading. When the huge majority are not in favour of a proposal it is rather disingenuous to take an equal number from people who support it as from people who do not.

It is clear that this proposal is counter to what disability organisations wish. It goes against the mandate of "nothing about us without us", going instead with the wish of medical professionals and Government officials.

It raises fears of disabled people being forced into using inappropriate aids and being denied benefits while being on long waiting lists.

Conclusion: The Government fails to address the concerns of disabled people in this section.

9. New Change-of-Circumstances System with Possible Sanctions

88% Against / 12% Support

Response rate: 46%

Question 13: The system for Personal Independence Payment will be easier for individuals to understand, so we expect people to be able to identify and report changes in their needs. However, we know that some people do not currently keep the Department informed. How can we encourage people to report changes in circumstances?

Summary of findings

This was widely discredited and it was disputed that PIP would be any easier to understand than DLA.

The low fraud rate of just 0.5% for DLA was pointed to and it was felt that this initiative was pandering to recent media activity.[33]

Reminders were made of the Benefit Integrity Project which, rather than finding people were over claiming, found that people were under claiming.

There was great concern among mental health and age concern groups about this proposal. People with some types of mental health problems or some types of senility can find it very difficult to report changes in circumstances at the time they happen and should not be unduly punished for it.

It was instead felt that the onus should be more on the DWP to make it easier to report a change in circumstance and to make any change faster.

It was commented that currently the DWP does not actually say what changes one must report and it would be unreasonable to set up new punitive rules until every claimant is sent out a list of changes which have to be reported.

It was widely felt that the current system is enough and a punitive system for disabled people is totally inappropriate.

A number of suggestions for improvement were made which could be implemented by the DWP. This included sending out a list of changes of circumstances which must be reported with the PIP award, a change of circumstances form to be signed yearly, or a confirmation from the GP that circumstance had not changed.

Counter-argument to Government Response

We agree with the Government findings that a list of changes of circumstances should be given to all individuals and that annual reminders would be helpful (P38, 78, 79).

The Government fails to say that respondents disagree that PIP will necessarily be easier to understand. In fact it actively contradicts the consistent reports from the consultation that PIP is not easier to understand.

The Government fails to report the concerns among mental health and age concern groups and the clear disadvantage that these claimants would face with these proposals.

The Government fails to report that respondents feel that this proposal is targeting vulnerable people on a false assumption of fraud and is a response to recent media stories.

The Government fails to report that respondents feel the current system does not need change other than perhaps the improvements suggested to be undertaken by the DWP.

The Government makes no clear commitment to follow up on these specific improvements.

The Government reiterates its intention to follow through with a punitive system which will disproportionally affect people with mental health disabilities, people with learning difficulties and older people (P34, 82).

Conclusion: The Government fails to report disagreements and fails to respond to concerns in this section.

10. Proposal for Compulsory Support

94% Against / 6% Support

Response rate: 41%

Question 15: Could some form of requirement to access advice and support, where appropriate, help encourage the minority of claimants who might otherwise not take action? If so, what would be the key features of such a system, and what would need to be avoided?

Summary of findings

While it was felt that more could and should be done to give support to disabled people, it was almost unanimously felt that there should be no element of compulsion to DLA or PIP.

In particular support should be a choice, not a condition. Treatments, aids and support for disabled or sick people are highly individualised and DWP staff are not qualified to impose them.

Counter-argument to Government Response

We totally reject the wording of this part of the Government response. This proposal was almost unanimously rejected by respondents who felt that conditionality had no place in this benefit. This is not at all clear from the phrasing

> *"However, some people commented that this measure could appear to introduce conditionality into Personal Independence Payment, and that this would not be appropriate for a benefit designed to contribute towards the extra costs of disability." (P35,84)*

While we welcome the comment from the Government that "We do not intend to make Personal Independence Payment conditional on taking up certain activities or support", we are extremely concerned that the Government admits "we will keep this under review" (P35,86).

The Government goes on to say

> *"We might reconsider this if it became clear that a proportion of people were failing to access available aids, adaptations or services that would significantly help them." (P35,86)*

Disabled people are absolutely clear that this benefit should not be conditional and that DWP advisors are not people qualified in any way to assess what sort of support would be helpful.

We noted from the consultation that disabled people are highly individual and while a support or aid may help one person, it may not help another even though they share the same diagnosis.

We ask for clarification from the Government on who will decide on whether people are failing to access aids, adaptations or services.

We note in passing that it is against the law to force people to receive medical treatment and question whether it is legal to force people to access similar treatment under threat of withdrawal of essential benefits.[34]

Conclusion: The Government hides the degree of opposition to this proposal and overrides any concerns in this section.

11. One-off Costs

36% Against / 64% Support

Response rate: 42%

Question 16: How do disabled people currently fund their aids and adaptations? Should there be an option to use Personal Independence Payment to meet a one-off cost?

Summary of findings

There was a mixed response to using PIP for one-off costs. Some were confused and concerned by this question. DLA is currently used as wished by the recipient and so could be used for one-off costs. Is PIP to be different?

Others felt that if PIP were to be used for a one-off cost nothing would be left for day to day needs and this should be avoided.

Others felt that there are other avenues for one-off costs such as DFG, direct payments and/or local authorities, and that PIP should not be used as an excuse for local authorities not to fulfil their obligations.

Finally, some felt that there should be a bolt on application to PIP for extra one-off costs on top of the usual payments. **Many responses ask for clarification.**

Counter-argument to Government Response

In particular it fails to address whether there would be an element of compulsion over how PIP is used, since currently DLA can be used as wished by the recipient and one-off costs are possible.

It fails to mention or address concerns that one-off costs may in future have to be met by PIP instead of local authorities.

Conclusion: The Government fails to address the concerns raised in this section (P36, 89).

12. Removal of Mobility Allowance for Care Home Residents

100% Against / 0% Support

Response rate: 42%

Summary of findings

This was unanimously rejected, pointing out that there was no overlap in funding and this ruling would leave many people unable to leave their homes. Some even felt it could contravene their human rights.

NB This has now been rescinded.

13. "Streamlining" / Removal of Passporting

99% Against / 1% Support

Response rate: 63%

Question 18: How important or useful has DLA been at getting disabled people access to other services or entitlements? Are there things we can do to improve these passporting arrangements?

Question 19: What would be the implications for disabled people and service providers if it was not possible for Personal Independence Payment to be used as a passport to other benefits and services?

Summary of findings

There was great concern that there was a question about the passporting system intrinsic to DLA, in particular the comment "what benefits (if at all)". **This was one of the most highly responded to issues.**

The large majority of respondents felt that this was a vital concept and opened up further income which helped cover some of the costs of disability. It should be noted that it by no means covers everything since a full one in three disabled adults live in poverty.[35]

Some of the direct passported benefits mentioned included the blue badge, bus passes and some leisure activities.

It is noted that the Government intends to remove some of the passported additions currently guaranteed by DLA in the name of simplification, such as Severe Disability Premium[36] and the Independent Living Fund.[37] This will by definition hit the most disabled people and goes against the Government's often stated aim of protecting "the most vulnerable".

There was also great worry about passported housing benefit and carer allowances. If carers are no longer supported, families may have to adapt through other ways. Social services may have to step in. The other parent may have to give up work and claim benefits. The disabled person may have to go into residential care.

There is a lot of worry about how the change of bands will affect passported arrangements. Loss of a band will have knock on effects and huge financial repercussions.

The loss of passporting would also cause a lot of administration and paperwork at great stress to the disabled person and great cost to the Government.

Counter-argument to Government Response

We agree passporting is important and saves administrative costs (P38, 96).

We agree with the Government findings that the passporting arrangements allow access to other entitlements including "the Blue Badge scheme, the warm front scheme, bus passes, special educational needs assessments, benefit entitlement, and travel and leisure activities" (P38,97).

We agree with the findings that if passporting were stopped the results would be "reduced mobility, greater social isolation and that fewer people would be able to remain in work" and a "financial impact" (P38,98).

The Government fails to mention the knock on effect on carers and social services.

The Government acknowledges the importance of passporting arrangements but fails to confirm that these will continue as they exist under DLA (P38,99).

The Government fails to admit that some current passported benefits will cease to exist in the name of "streamlining".

The Government fails to address the fears that other proposed changes such as the change from three rates of benefit to two mean the loss of some passported benefits with serious knock on effects both to the finances of the disabled person but also to the wider community.

The only promise made in this section is that where a passported benefit exists it will be easy to access. No promise is made that passported benefits will in fact continue to exist. Quite the reverse, the Government seeks to "streamline" the process (P39,100).

Conclusion: The Government fails to address the concerns in this section and actively hides changes which will negatively affect many disabled people.

14. Sharing information

46% Against / 54% Support

Response rate: 48%

Question 20: What different assessments for disability benefits or services could be combined and what information about the disabled person could be shared to minimise bureaucracy and duplication?

Summary of findings

There was a mixed response to the idea of sharing information and/or assessments.

All are keen to have to fill out as few forms as necessary. Many feel that much could be done to share basic information although some worry was noted over data protection.

However there is deep concern over a single assessment as different benefits are for different things. DLA is not an out of work benefit whereas IB and ESA are. The assessments should therefore be very different. Receiving one should not automatically mean receiving the other and vice versa.

We found evidence from different parts of the country that in fact, this is already happening, despite legislation for PIP still under debate in the House of Lords. DLA decision makers are clearly citing as reasons given for rejecting a claim "the healthcare professional who examined you for Employment and Support Allowance." Coventry Citizen's Advice Bureau[38] also confirm that in their experience this is increasingly the case.

Likewise a social service assessment for care is not necessarily appropriate for DLA or PIP. It was felt that all three should be left totally separate and in particular that PIP should not be drawn in to the social services care budget.

Counter-argument to Government Response

We agree with the findings over administrative savings and concern over data protection (P39,101).

We agree with the concern over differing eligibility criteria and keeping PIP separate from Social Care Services (P39,101,102).

We find that the Government response fails to take these concerns into consideration. Despite the views that the assessments measure different things, the Government persists with its commitment to "streamlining assessments" (P39,103). While this may be cost-effective, it will be to the detriment of fairness to the disabled person.

The Government also talks of considering working with the Department of Health, putting aside the concerns of data protection noted in the consultation (P39, 103).

The Government also talks about "an interaction between Personal Independence Payment and the social care system" despite the clear concerns that PIP should remain separate from social services (P39, 104).

We find that the Government already appear to be sharing information between the ESA and DLA systems expressly against the wishes of disabled people and before PIP has actually come into effect.

Conclusion: The Government fails to take the views of disabled people into account in this section. What's more, they appear to have gone ahead with this change before legislation for PIP is passed.

15. Equality Impact and Human Rights

Question 21: What impact could our proposals have on the different equality groups (our initial assessment of which is on page 28 of Cm 7 9 8 4) and what else should be considered in developing the policy?

Summary of findings

A significant number of respondents didn't answer.

An equally significant number asked for further assessments to be undertaken by the Government.

A number of respondents answered this section with consistent responses.

It was felt that women would be disproportionally affected by these proposals. This was because of the potential loss of carer benefits as a knock on effect from removing a band from the care or daily living element of the benefit. Carers are predominantly women.

It was felt that people with mental health disabilities would be disproportionally affected by these proposals. This was deemed to be because they would suffer from the type of assessment proposed which would perform poorly at assessing fluctuating conditions, so called invisible disabilities, people with poor communication skills and people who might be unable to communicate changes of circumstances, all of which apply in particular to people with mental health disabilities. **Furthermore people with mental health disabilities are disproportionally represented among those receiving lower rate DLA and are considered to be the most likely to suffer from any cuts**.

Ironically it was felt that disabled people would be negatively affected by these proposals. Due to cuts of 20% there would be a significant loss of income to large numbers of disabled people who would lose valuable support. It was also reported that some might be unable to continue working and others would be unable to continue socialising. It was felt that there could also be a negative impact on their health and wellbeing. It was suggested that there might be a contravention of human rights in these proposals.

The Government fails to disclose that disabled people do not wish a change to the current benefit.

As previously stated, to achieve a target of 20% cuts, a substantial number of disabled people who currently receive DLA will have to lose that support. This is a step back rather than forwards.

The reforms will focus on those "that need the greatest help". Disabled people fall into broadly five categories: the sensory impaired, the mobility impaired, those with mental health or learning difficulties, those with a hidden disability and those with a combination of the above (The access group). These proposals could limit support to only some of these categories.

However the UK is bound by the Human Rights Act 1998, in particular Article 8[39] which guarantees the right to independent living and article 9 which guarantees the right to free association. Furthermore under the CRPD[40] (United Nation Convention of the Rights of Persons with Disabilities), the UK recognised under article 19 "the equal right of all persons with disabilities to live in the community, with choices equal to others". **Under these articles, all disabled people have these rights, and narrowing support given to uphold these rights could be considered retrogression.**

Under Equality 2010[41] it is illegal to treat one group of disabled people less favourably than another.

If removal of DLA from people with so-called "lesser needs" removes or limits those choices, the UK Government will be in breach of their human rights obligations.

Counter-argument to Government Response

The Government Equality Assessment recognises that some disabled people will lose their entitlement to DLA.

We dispute the Government's claim that losing DLA will increase disabled people moving into work.

We suggest the opposite. During the consultation many disabled people reported that losing their DLA would leave them unable to continue working, most often citing travel costs. **This misunderstanding underlines the Government's deep misconception of DLA as an out-of-work benefit rather than a benefit which enables work for those disabled people who are capable of it.**

We totally reject the Government's claim that losing DLA may have a positive health impact.

We suggest the reverse which is noted in many of the consultation responses.

If a sick person who loses DLA tries to work in order to compensate for the loss of income, this will lead to a deterioration of their condition, not an improvement.

Furthermore, as noted in the consultation losing DLA may leave a person unable to fund help for themselves making their condition more likely to deteriorate. This may cause an escalation of their needs. Alternative funding would then need to be found from other budgets.

The Government assessment fails to note the impact on women.

The Government assessment fails to note the impact on those with mental health disabilities.

The Government assessment fails to note that the effect on disabled people will be negative.

A recent report of the **Human Rights Joint Committee made the following points:**[42]

1.27 The right to social security and the right to an adequate standard of living are both widely recognised in international human rights standards to which the UK has bound itself by international treaty. These are derived from the recognition in the Universal Declaration of Human Rights of the right to "security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control."[19] *That Declaration was itself inspired by President Roosevelt's "Four Freedoms" in his 1941 State of the Union address to Congress, including "freedom from want" and "freedom from fear".*

1.28 The UK is a party to the International Covenant on Economic Social and Cultural Rights (ICESCR), which guarantees amongst other things the right to an adequate standard of living and to social security. Article 11 ICESCR makes clear that circumstances where an individual is permitted to become destitute would be in breach of the right to an adequate standard of living, which includes 'adequate food, clothing and housing […] and the continuous improvement of living conditions".[20]
The UN Convention on the Rights of the Child similarly provides, in Article 27, for recognition by States of the right of every child to an adequate standard of living.

1.29 The right to social security has been subsequently incorporated in a range of international human rights treaties by which the UK has agreed to be bound, including the International Convention on the Elimination of All Forms of Racial Discrimination (Article 5(e)); the Convention on the Elimination of All Forms of Discrimination against Women (Articles 11 and 14); the UN Convention on the Rights of Persons with Disabilities (Article 28); and the UN Convention on the Rights of the Child (Article 26). The UN Convention on the Rights of Persons with Disabilities also requires the State to take progressive measures to promote the right of disabled people to live independently in the community and to refrain from retrogressive measures which undermine this right (Articles 4, 19 UNCRPD)."

1.13 The quality of the impact assessments conducted within Government becomes increasingly important for the purposes of analysing potential discriminatory impacts when little wider detail is available. Concern has been expressed about the thoroughness and coverage of the impact assessments carried out by the Government. Carers UK, for example, have pointed out that the impact assessments make no mention of the impact of some of the changes on carers, even where this impact will be very significant, in particular in the case of the proposed reforms to DLA. Equality Impact Assessments were not published by the Government until the Bill was in Committee in the Commons, and, while equality impact assessments have now been published for distinct parts of the Bill, these do not attempt to assess the cumulative impacts of multiple provisions in the Bill on particular groups with protected characteristics. This is of concern, since individuals will experience these changes cumulatively, and their impact needs to be understood in this way. For example, a disabled person may find that they lose their lower rate DLA, and therefore become subject to a cap on their housing benefit such that they cannot afford to remain in their home. Moving may disrupt informal patterns of care and support at the same time as they have increased reliance on these supports.

1.14 Whilst accepting that such assessments of cumulative impact would be analytically complex and challenging, they nevertheless should be feasible.

In a key response to the consultation, EHRC say:

2.3 "The proposals recognise the need to support those 'who face the greatest challenges to leading independent lives' but the overview impact assessment concludes that this may mean a reduction in support for some people. Whilst the stated intent to focus on those facing the greatest barriers to independent living is welcomed by the Commission, our view is that this aim does not justify and will not be achieved by putting targets in place to reduce the number of DLA recipients. It is critical that the assessment is about the individual and is not subject to targets or quotas based purely on reducing the number of DLA claimants. ***The Commission is concerned about the impact this could have on individuals' standard of living, and could be counter-productive to Government policies and initiatives to overcome barriers to work.***

6.4 The Commission welcomes the stated commitment to the social model of disability. However, 'a focus on the ability of an individual to carry out a range of key activities necessary for everyday life', will indirectly build in the medical model to the assessment process. An approach which focuses on the provision of resources/support to enable disabled people to overcome socially constructed barriers e.g. inaccessibility, unemployment, socio-economic disadvantage, lack of educational opportunities would ensure compatibility with the Government's commitment.

12.1 For the reasons set out above, ***the Commission has a number of concerns about the proposed reform of DLA, including a concern that if the proposals were to be implemented in their current form, they might potentially be in breach of equality and / or human rights legislation****. We also consider that some of the specific proposals – such as, the withdrawal of the mobility component from those in residential care, extending the period before which DLA is payable and how account may be taken of aids and adaptations (including educational provision for children and young people) in the assessment process – will result in outcomes contrary to the stated aims of the reforms to maintain and strengthen DLA as a benefit contributing to the extra costs incurred by disabled people and helping to overcome barriers to independent living.*

Conclusion: The Government Impact Assessments appear to be flawed and we call on them to address the issues raised above urgently.

Addendum: responses that despite not being requested in the consultation were mentioned in significant numbers

A change motivated by cuts (43% responses)

Summary of findings

It was found disappointing that despite Government claims, the case for reform seemed mainly cost driven. It was felt that any reform should start from a careful, independent and objective review of disabled people's needs, not a quick way to cut costs. While some felt that DLA could be improved, few could see how a 20% cut[43] could possibly improve the lives of all disabled people currently in receipt of this benefit. As a result it was felt that these proposals represent a retrograde step and would result in further poverty for a group already known to be disproportionally impoverished[44], as well as potential loss of independence and health risks.

Counter-argument to Government Response

The Government fails to respond to these concerns.

Over-65s (14% Responses)

Summary of findings

Of other concern was lack of clarity over whether over-65s would indeed continue to be eligible for PIP if they were currently eligibly for DLA. The consultation document says "might" not "would", leaving room for PIP to be withdrawn from this group.

Concern is expressed about what will happen regarding reassessing over-65s and appeals.

As a general comment, many felt that it is wrong that the over-65 group is discriminated against in general with the distinction between AA and DLA and that PIP should be available to all.

Counter-argument to Government Response

The Government state only that they "intend" to allow over-65s already in receipt of PIP to continue receiving it (P43,122).

The Government fails to address concerns about appeals for reassessments for this group.

The Government fails to address any concern regarding age discrimination.

The Government has given assurances over this issue, but fails to answer this question definitively and allay disabled people's fears.

Administration Costs (19% responses)

Summary of findings

It was widely felt that there was no need for such large changes to DLA. The "rebranding" would be hugely expensive and this cost was cited many times. **DWP estimates put the cost of introducing PIP at £675 million.**[45]

Administrative costs were a concern not only to disabled people but to social services and councils. The cost of reassessing all current DLA recipients followed by subsequent frequent reviews was seen to be prohibitive and taking money away from the disabled people who needed it.

Counter-argument to Government Response

The Government fails to address this issue.

Knock-on Effects (16% responses)

Summary of findings

Many responses pointed out that although the Government hoped to make a reduction of 20% in expenditure, this would cause costs elsewhere in the system.

The first direct cost would be to social services. With changes in eligibility criteria, it is inevitable that some disabled people will drop a band. There is also no news on rates and it is possible they will be lower. Currently, under the fairer charging scheme, social services can take all of mid-rate DLA as contribution to social care charges. If the client loses their DLA local services will have to make up the shortfall.

As mentioned previously there is also the risk that some families will lose their carer's allowance. If the carer has to go out to work as a result, then social services will have to provide care instead at much greater cost.

If "lower needs" disabled people lose their DLA there is a risk that they will end up with no support at all. If they don't have enough money or can't look after themselves properly, their condition could deteriorate. This could end up as costs either to the NHS or social services.

Counter-argument to Government Response

The Government announces that Carers allowance will continue (P43,123) but fails to address the issues of loss of carer's allowance due to re-banding once reassessment to PIP occurs.

The Government fails to mention repercussions to social services. With loss of income there will be further cuts to their services which will in turn negatively impact on disabled people.

The Government fails to mention the target of 20% reduction in expenditure on DLA/PIP. Given a fraud rate of only 0.5% and an inevitable increase in administrative costs there can only be negative financial repercussions on disabled people.

The Government fails to address this issue.

DLA is Not in Need of Total Reform (27%)

Summary of findings

Despite not being asked, more than a quarter of respondents felt strongly enough about this to specifically express their opinion that DLA did not need reforming. This is almost three times as many as those who agreed it did.

It was felt that DLA is a well-targeted benefit which is working well and a lifeline to many disabled people.

It was felt that any problems currently identified could easily be corrected at a fraction of the cost by small modifications to the DLA system. These included a simplified review form, an annual change of circumstances form and better advertising.

It was felt that many of the problems identified in the Government consultation were overstated or simply wrong.

This concern is not mentioned anywhere in the Government's response.

Annexe 1: The Benefit Integrity Project

The Benefit Integrity Project was an initiative started by the Conservative Government during the 1997 general election. When Labour won, mistakes were made that meant this wasn't immediately cancelled. The BIP lasted until March 31st 1999. Whilst it was denied the intention was to root out fraudulent claims, that seemed to be the overriding purpose, yet only 1.5% of the reviewed cases were found to be fraudulent. The BIP looked at higher-rate DLA claimants only and made the extraordinary claim that 22% more claims could be 'incorrect'. This seems to oddly coincide with subsequent years of politicians looking to cut an arbitrary '20%' from DLA prior to the current Government's plans for PIP.

By the time the BIP had ended, 138,991 cases had been reviewed but as of March 1998 the outcomes to that point had been:

- 72,470 cases had been examined
- 16,198 cases had been changed, and of these
  - 5,331 had benefit withdrawn
  - 1,699 had benefit increased
  - 9,168 had benefit reduced.

The overall level of 'incorrectness' was 22.35%. This is reported to be proportionate to what the BIP produced when it ended in 1999. Due to a lack of proper online archiving, information about the BIP is sparse and mainly sourced from non-Government branches of the civil service.

In the Social Security Committee's reports on BIP the first in March 1998 and the second in February 1999, they mention the following features, finding:

1 A lack of consultation and *meaningful participation* involving disability organisations, campaigners and people. In March 1998 they wrote: "**This failure to undertake even the slightest consultation was a serious error with serious consequences. The breaking by the DSS of the undertaking given by the former Minister of State for Disabled People is regrettable."** (SSC Fourth Report, Disability Living Allowance).

2 Decisions made by BIP assessments could not be appealed and overturned in reasonable time. This was significantly improved in May 1998, though much of this stems from BIP assessors being given *two days* extra training and different questionnaires and forms to use.

3 The presumption of savings for DLA was based on a presumption of high levels of inaccuracy in DLA awards, especially fraud. The basis for this was a Benefit Review of DLA carried out in 1996 and published in 1997 that found '73% of claimants were receiving DLA at the correct rate' and the 'headline rate' for fraud was 12%. That figure includes cases categorised as 'level 3 and level 4 and confirmed fraud' (3 and 4 mean 'strongly suspected' and where 'it is known but unprovable' respectively). From this the report put 'overpayment due to fraud' at £499 million. But after a year and a half of the BIP, only 79 cases were investigated for fraud and none were prosecuted. When the National Benefit Review for DLA started in 2004 and was published in 2005, the focus would change to overpayments due to claimants failing to inform the DSS' successor, the DWP of changes to their circumstances. **The issue here is that both the 2005 NBR of Disability Living Allowance and the 1996–1997 Benefit Review took a sample of people and extrapolated figures for all claimants from those samples. This had a very large degree of human error which would be disproportionately magnified without proper correction.** Those corrections didn't happen; it did not take appeals or reconsiderations into account nor acknowledge that two different decision makers for a benefit can come to different conclusions about the same claimant. Without acknowledging them, the figures for claimants being overpaid are bound to be inflated.

> *"**It is important to record in detail the origins and timetable for the implementation of BIP. Many of BIP's subsequent failings have their roots in the early period of its planning. The origins of BIP can be found in the Benefit Review of DLA, part of the previous Government's analysis of incorrect payments within individual benefits.**"*
> *SSC Fourth Report, Disability Living Allowance*

The Social Security Committee made no comments on the methods of the Benefit Review but did say something about how the BIP failed to back up its findings:

> *"**These findings were extrapolated to provide an estimated annual expenditure loss from overpayments due to fraud of around £499 million.[40] After a year and a half of the project being in operation, there are just 79 cases being investigated for fraud.[41] None have been referred for prosecution.[42] This is a severe indictment of the approach that was taken in the initial stages of the project.**"*
> *SSC Third Report, Disability Living Allowance*

Annexe 2: Mental Health – Trends and Opportunities

As we saw from our analysis of DLA trends, there has been an increase in mental health conditions and learning difficulties that almost entirely explains the working-age rise in claims.

It is vital to remember that this is an **international** trend seen in all developed nations. "The Mental Health Context, World Health Organisation 2003 aims to explain these trends and advise Governments on the best ways to react to them."[46]

Globally:

> *"121 million people suffer with depression, 70 million with alcohol-related problems, 24 million with schizophrenia and 37 million with dementia"*
>
> *"It is estimated that the burden of mental disorders will grow in the coming decades. By 2020 mental disorders are likely to account for 15% of disability-adjusted life-years lost."*
>
> *"possible reasons for the increase in the burden of mental disorders include rapid urbanization, conflicts, disasters and macroeconomic changes"*
>
> *"Effective interventions are available but are not accessible to the majority of those who need them."*
>
> ***"The indirect costs attributable to mental disorders outweigh the direct treatment costs by two to six times in developed market economies"***
>
> *"there is a significant discrepancy between the burden of mental disorders and the resources dedicated to mental health services."*

Given our own trend in rising mental illness, it would seem that very much more could be done to address rises in DLA by focusing NHS resources on better mental healthcare, treatment and support. Evidence suggests this would improve the lives of many and lead to fewer and less serious episodes of ill health. We welcome announcements from the Government aimed at improving mental health conditions[47] but urge them to prioritise this area still further.

Conclusion

Without in-depth understanding of the complex interactions between the provision of health, social care and welfare, it is tempting to believe that a 20% reduction in overall claimants of Disability Living Allowance is a sensible austerity measure. However, proceeding with this assumption risks extending the confusion over 'double' funding', which led to the Government's widely condemned proposals to remove the mobility element of DLA from state funded care home residents.

Despite media vilification of 'benefit scroungers', public perception is that genuinely sick and disabled people are well supported, provided with accommodation, home helps, equipment and free cars. Sadly, the reality is only a tiny minority of those in need qualify for state social care support. Pre 2010 the situation was bleak, with only DLA managing to paper over the cracks.

By providing qualifying individuals with a cash benefit to be spent as the recipient sees fit, DLA has kept costs down for Local Authorities and the NHS as it is used to purchase those services the state is not able to provide; eg help at home, or equipment such as wheelchairs which the NHS only funds for a minority of those in need. DLA is money immediately spent in the wider economy either directly paid to LA's, providing them with revenue in return for care services or into the local economy eg to taxi drivers or food delivery charges. Without understanding that DLA receipt is not additional money to local authority support, it is tempting for Government to think cutting DLA, particularly for those with lower support needs is justified. But this is a fundamental misunderstanding of the role DLA is already playing in preventing further deterioration and total dependence on Local Authorities. It will ultimately increase the burden on LAs, the NHS and community services at the very time they are seeking to find savings by reducing eligibility, particularly for social care support.

The proposals outlined in the Welfare Reform Bill have created a climate of fear and mistrust amongst sick and disabled people towards Government. Politicians may claim DLA is a poorly understood benefit, but our consultation shows this is not the case and claimants understand exactly the role DLA plays in supporting their lives. Although DLA is not a work related benefit, in many cases respondents clearly laid out how the funding through DLA covered their additional disability expenses without which they would not be able to afford to work, either practically or financially.

There was also a clear desire to reform the current DLA system without need for PIP, which was considered to be expensive and unpopular. PIP is mistrusted and overwhelmingly rejected by respondents. PIP is perceived as impersonal, mechanistic and clearly in the mould of the condemned Employment and Support Allowance which is a cause of fear and misery for sick and disabled people. Although sick and disabled people are terrified of the current welfare reform bill, they are also prepared and willing to contribute to society wherever possible. It is overwhelmingly clear that this will not be possible under any of the current proposals.

Sick and disabled people have voluntarily combined our skills, experience and talent to produce this report, demonstrating that if we are able to work in the way our conditions demand we can participate in the world of employment, but only if it is willing to receive us on those terms. There are huge benefits to employers, the economy and the environment in tapping into this skill and talent base. Many of us need to work primarily from home thus reducing the burden on the widely inaccessible public transport system. It is a mystery to sick and disabled people that these more flexible forms of working and participating are not being considered in conjunction with the Welfare Reform Bill, or that employers are not being incentivised to make it attractive to them to access this skilled and experienced group of people who are prevented from contributing not by lack of desire, but by the inflexibility of traditional working models.

In the 60s, disabled people told governments that there should be "nothing about us, without us." Sadly, over 40 years on we must produce a report that clearly reminds politicians of this principle.

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