Summary and context

We are concerned that the overarching Government objective is to cut 20% of the projected funding to support disabled people with unavoidable higher living costs through the abolition of working age Disability Living Allowance (DLA) and introduction of the ‘Personal Independence Payment’ (PIP).

We believe that the proposed assessment process to move people off DLA is being designed not to meet genuine needs or support disabled people’s essential higher costs of living, but to meet an arbitrary reduction in expenditure. We are also concerned that the proposed new assessment system is being delivered in an unduly hasty timeframe without adequate recognition and redress of the concerns of disabled people and relevant stakeholder organisations.

The experience of the introduction of the Work Capability Assessment (WCA) and face to face interviews for out of work benefits holds lessons for the introduction of the PIP assessment which should not be ignored. The WCA process costs £100 million per annum to run plus a further £26 million in the last financial year in appeals costs (of which a large proportion – 40% – were successful). It is essential that the Government approach the new PIP assessment process very carefully – to ensure the process works as smoothly as possible to avoid needless suffering and wasted public resources.
It is also essential that disabled people are able to understand the new processes, have accessible communications with/from DWP and any private organisations running assessments and can source expert, independent information and advice to help navigate the new systems and processes.

We are also concerned that the sample group of disabled people used to test the initial assessment plans and subsequent trialling of proposals may not reflect the impairment types of all the disabled people receiving DLA. DWP research suggests that over 90% of DLA recipients have two or more health conditions/impairments and that 56% have four or more. We are very concerned that people with fluctuating, multiple or rare health conditions and/or impairments are likely to be particularly poorly served by the proposed assessment.

Our fear is that a combination of an inadequate sample, a restrictive set of descriptors and weightings, undue haste and an ‘opt-in’ system will mean the DWP estimate of 500,000 disabled people likely to be made ineligible for support is conservative. Far more disabled people could lose out with dire consequences of individuals, families and even the ability to retain employment for some of the estimated 180,000\(^1\) disabled people currently receiving DLA in work, as well as potentially representing a new and significant barrier to work for informal carers in the UK.

**Cutting the linking rules (Chapter 3)**

We are concerned about the intention to cut the linking rule from two years (under DLA) to one (proposed for PIP). A one year linking rule, both for re-claiming the benefit, and for moving back up to the enhanced mobility rate after the age of 65, could significantly disadvantage many disabled people with fluctuating conditions. We recommend that in both instances, the linking rule should be at least two years.

Had an adequate impact assessment been undertaken, DWP would be aware that this measure could significantly disadvantage many disabled people with fluctuating conditions. The proposed reduction in the linking rule period does not appear to be founded on an evidence-based analysis of the conditions where such fluctuations are prevalent. For instance, the most common type of MS, ‘relapsing remitting’ (which affects 85% of the people diagnosed with MS) displays periods of remittance, which are often substantially longer than 12 months.

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\(^1\) DWP estimate 9% of DLA recipients are in work. This is likely to be a conservative estimate as it may not include all part time work. See: [http://www.disabilityrightsuk.org/dlaimpactassessment.doc](http://www.disabilityrightsuk.org/dlaimpactassessment.doc) for further information on disabled people receiving DLA in work and the costs/effect of losing eligibility for DLA/PIP.
Developments in medication and treatment have been extending symptom free and reduced symptom periods across a range of conditions. In the light of such developments, it would seem reasonable to extend the linking period.

We believe DWP should commission a study of the current nature of relapses in the most common fluctuating conditions prior to any amendment to the linking rule. In the mean-time we believe the 2-year linking rule should be retained.

It is also very important for an upfront, adequate definition to be provided for assessors and disabled people. Clarity is needed on how a linked claim will be defined and how it relates to an existing, or similar, condition. The Government, in the rush to introduce the new assessment, risks some disabled people losing support through assessors inaccurately judging (or making assumptions) about what is the result of an ongoing impairment or health condition and what could be attributed to other issues (or put down inaccurately to ageing for example). We would like regulations to be clearer about linking rules to ensure transparency for disabled people and assessors.

Payability of the benefit (Chapter 4)

Assessing older people
The DBC believes that it is important that older disabled people who may have been receiving DLA for many years understand the Government’s plans and feel secure about future support arrangements.

The consultation states that those aged 65 or over on 8 April 2013 will remain on DLA ‘as long as they continue to satisfy the entitlement conditions’. However we understand that this applies only for the period of reassessment for working age claimants. The Government also plans to make a decision about extending PIP to those over 65. We would welcome urgent clarity on this issue – including when a decision is likely to be taken.

It is essential this information is made available. The lack of clarity is causing undue worry, stress and confusion for people who rely on DLA and have less of a guarantee they will receive it under PIP, as support from DLA mobility payments in particular represent a real lifeline for thousands of disabled people. We also suspect the proposals may not make financial sense as people made ineligible for PIP are likely to be advised to apply for Attendance Allowance (i.e. providing a net cost through reassessments but potentially no reduction in payable support).
However, it would be reassuring to older claimants if the Government could make an early decision not to put them through the process of reassessment especially given that over 91,000 DLA recipients are 80 years of age or older.

The Government plans to reassess existing DLA claimants who are aged 16 to 64 from 8 April 2013. This means that some will be aged 65 and over when they are reassessed. We believe that as the broad intention is to reassess people of ‘working age’ over the period April 2013 to March 2016 it would be more reasonable, and clearer to explain, if anyone who reaches 65 during that time is excluded.

This recommendation meets the precedent set in the process for people being ‘migrated’ from Incapacity Benefit to Employment and Support Allowance. This process did not include those reaching state pension age during the reassessment period.

We also note and welcome that for people over 65 years of age, it will be possible for those on daily living PIP (either rate) to establish this component post 65, providing they are already on mobility PIP (either rate) and move up or down daily living PIP rates depending on whether care needs are better or worse. However, the proposal that people on PIP enhanced mobility can move down to standard rate should be accompanied with a rule that people can also move up from the standard rate to the enhanced rate of the mobility component as needs intensify.

It seems discriminatory that people (solely through being working age) whose care needs increase can have support increased, but people whose mobility needs increase after the age of 65 are denied additional support. This discriminates against people with degenerative conditions which limits mobility such as rheumatoid arthritis, motor neurone disease or Parkinson's.

**Hospital treatment and Motability**

The current proposals will mean many disabled people undergoing routine medical treatments and requiring regular inpatient care will lose access to potentially the only accessible vehicle at their disposal.

Under DLA an agreement with Motability means disabled people can retain vehicles/scooters etc even if in hospital for 28 days in any 365 day period. Under PIP the Government intends for this support to be removed.

Whilst most people will not perhaps receive inpatient care in any given year, it seems likely that, for the 56% of people with four or more health conditions receiving DLA, hospital stays could form part of routine life. Under the current plans however, even needing 3 days of inpatient care per month would see
access to a Motability vehicle lost every ten months – potentially requiring a reclamation of the vehicle by Motability and a whole new ‘revolving door’ of assessments for the disabled people affected having to seek PIP again and again.

**Case study:** David has Sickle Cell Disorder. He gets enhanced rate PIP mobility component, which he uses to lease a car on the Motability scheme. He has a crisis about once a month, usually requiring a hospital admission of approximately four complete days in hospital. Because of the 28-day linking rules, after seven such monthly admissions, David would lose his mobility component. Though he could still get the mobility component on daily rate provisions for the majority of days he spends out of hospital, this would not cover a Motability lease. He would thus lose the car.

New costs to the NHS are likely if the loss of the accessible, adapted vehicle meant disabled people being unable to leave hospital after treatments. Many vehicles are driven by family members and this new rule would also affect the ability to collect a loved one from hospital. Vehicles are not cheap to run and often the Motability vehicle is the only one available to the whole family. DWP must ensure its impact assessment covers the affect of this policy change on disabled people and carers (for example) unable to rejoin family and/or stay in work due to the loss of vehicles.

DWP must work with the Department of Health and hospital trusts to ensure this issue is fully costed, including the need for greater accessible hospital transport provision.

If the proposal goes ahead, one recommendation could be to lose the 28-day linking rule that currently exists for DLA (DLA Regs; reg 10(5)), that treats two stays in hospital separated by 28 days or less as a single period. This could help limit the impact for some disabled people.

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**Reassessment process issues (Chapter 5)**

We are very concerned that the plans for reassessment could still erect barriers to compliance that are: avoidable; more expensive; and will deny disabled people access to support.

We believe that it is both possible and necessary for the claims process to be made more efficient for existing DLA claimants.

We object strongly to the following aspects of the process:
• the "opt in" process for PIP for those claimants who already receive DLA, particularly for those currently receiving lifetime awards;
• splitting the claim form into two parts; and
• setting a time-limit of just four weeks for disabled people to respond.

All of these risk generating additional hurdles for claimants that may cause people with high needs to drop out of the process.

DWP research suggests 56% of DLA recipients have four or more health conditions/impairments and – in this context – the emphasis should be on an automatic system of supporting people to make a new claim. Being excluded through failing to conform to a new process will invoke scepticism amongst DLA recipients that a new claim for PIP is genuinely being sought by DWP – and will dampen disabled people’s expectations of being able to access PIP.

It seems unlikely DWP will be directly providing a new support service to ensure disabled people are able to understand the new systems and processes in detail. We believe the pressure on advice agencies and charities will be massive in timeframes in which we are not always able to support disabled people. Many people will need to make an appointment to discuss the process with an advisor, then a further meeting to fill in the claim form accurately. This could create an additional burden on already-stretched advisory services, causing real problems for advice agencies and prevent disabled people accessing support. DWP must adequately resource independent advice agencies to support disabled people through the process.

We also believe that four weeks is an unrealistic time scale in which to expect people to get the support that they may need to complete each part of the form and gather the necessary additional evidence (as appropriate).

We hope to hear from DWP the information on the modelling of the number of claimants who will drop out of the claim process as a result to these barriers².

We believe that the costs of the bureaucratic paper chase involved in asking people to apply and using a two part claim form should also be avoided by sending both parts of the claim form together. Forms could be pre-populated where possible, asking individuals to verify information (reducing assessment bureaucracy).

We also believe that the time-limit for returning application forms should be extended to 12 weeks, as in the current DLA application process.

² DWP agreed to provide this information at a DBC meeting on 30th May 2012.
DWP should also build in additional safeguards for people unable to comply with the PIP claims process, including taking a broad view of what constitutes ‘good reason’ for lack of compliance. DWP must consider a claimant’s ability to access the information provided, seek and receive appropriate support and advice where required, and presence – or lack of – at their registered address (due to hospital inpatient care for example). We believe these issues would all qualify as ‘Reasonable Adjustments’ under the Equality Act.

Finally, we welcome statements from DWP spokespeople indicating that they will make efforts to ensure that claimants will not go through PIP and ESA reassessments very close together. We would welcome a commitment from DWP to ensure that the claimant journeys will be kept separate, to ensure no-one is faced with the stress and confusion of going through two different reassessment processes within a short time period.

**Award durations and reviews (Chapter 6)**

We urge DWP to consult in detail on the guidance regarding award durations. It is vital that people with long-term conditions or impairments which are unlikely to change over time receive appropriately long-term awards, and are not subject to unnecessary, costly and stressful reassessments.

It is very concerning that DWP states that all PIP awards will be reviewed at ‘appropriate intervals’. For people who have a long-term degenerative and incurable condition or impairment and who are receiving the highest DLA rates, we believe that a long-term award with appropriately limited (or no) review would be a better system – limiting costs to government and stress to individuals. At the most, reviews for these claimants should be ‘light-touch’.

DWP should also engage with DBC member organisations and disabled people to develop guidance as to what level or review would be appropriate, and what would constitute ‘appropriate intervals’ in between reviews.

**Residence/absence (Chapter 8)**

We are concerned at the change from needing to have spent six out of the past twelve months in Great Britain under current DLA rules, to spending a minimum of two out of three years in the country for PIP. We are also concerned about plans to decrease the allowable temporary absence period from 26 to just four weeks. It would seem especially difficult to justify this change for someone moving from one part of the UK to another (i.e. from
Northern Ireland to England, Scotland or Wales) to be affected by the rules around GB presence and we would welcome clarification on this issue.

Moreover a four week absence limit seems draconian, especially for people who may want to be undertaking extended holidays and visiting family abroad while they are able to travel when well – or for recuperation and rehabilitation purposes to help manage a health condition for example. DWP provide no figures to rationalise these proposals and we would welcome further explanation for this restricted travel ability for disabled people.

Refugees, people granted humanitarian protection and those granted discretionary leave to remain in the UK following an asylum claim are entitled to all mainstream benefits, including DLA. But this group could be considerably disadvantaged by the current proposals.

Considerable effort is made by Jobcentre Plus to help this group of refugees make the transition to mainstream support, as there is a high risk of homelessness and destitution once asylum support stops.

It can be anticipated that many refugees will need to claim PIP. However, the proposed new rules around the habitual residence test, past presence test and temporary absence may undermine support.

When the habitual residence test is applied for other benefits, it is clear that refugees are exempt. We believe this must also be made clear for disabled refugees seeking PIP support.

In addition, there should be a clear exemption from the past presence test. Although many refugees will have already been present in Great Britain for two of the past three years while waiting for a decision, some will not. People who have a claim compelling enough to be granted a ‘rapid decision’ may well be more likely to have significant support needs related to the physical and mental impact of persecution.

Finally, we are concerned about the impact that the temporary absence rule will have on this group. Refugees and people granted humanitarian protection may have stayed many years in Great Britain while their asylum claim was decided. Once granted leave to remain they will have access to travel documents for the first time. For many people, a first priority will be to visit children and other family members. This may be in a safe location near to their home country, or in another country where relatives have sought asylum. The claimant may exceed their temporary absence period (four weeks) but should not be forced to choose between their right to family reunion and the support needed to help manage the additional costs of living as a disabled person.
Inadequate assessment of impact (Chapter 9)

We are very concerned that the Government approach to abolishing DLA for disabled people of ‘working age’ (16-64 years of age) risks being implemented without adequate assessment of the potential impact on disabled people, families and overall government expenditure. This is despite the legal obligation on DWP to ensure policy promotes the equality of opportunity of disabled people and other disadvantaged groups (including carers).

It is particularly the case that policies which disproportionately affect disabled people or other disadvantaged groups must be properly assessed for their impact. The abolition of working-age DLA and the creation of a far less significant system of support under PIP is a clear example of where it is essential DWP analyses and understands the impact fully.

We believe that the DWP plans to remove eligibility for support for 500,000 disabled people will undermine disabled people and carer’s equality of opportunity and heighten poverty, disadvantage and inequality. This is particularly worrying given the reduction in support from councils and other measures disproportionately affecting disabled people and carers.

The impact assessment suggests the net effect on carers is neutral. But Carers UK dispute this suggestion. DWP acknowledges that 500,000 disabled people will lose eligibility for PIP, but ignores the equivalent necessitation in a rise of informal support from carers for the same disabled people made ineligible for PIP.

The proposed, limited assessment criteria risk significantly disadvantaging disabled people and their families – even people with the highest levels of need. DWP estimates that over a quarter of a million (280,000) disabled people will lose eligibility for high rate DLA mobility payments (or ‘enhanced’ PIP mobility payments). DWP must assess where this significant group of disabled people with high needs will turn for alternative support. With 300,000 carers already unable to participate in the economy it is essential DWP ensures the UK economic inactivity rate caused by informal care provision does not increase further.

This ‘cumulative effect’ of retracting support for disabled people and carers was highlighted by the recent Equality and Human Rights Commission.

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3 The 300,000 figure is based on LSE research analysed by Age UK and Carers UK. See: http://www.carersuk.org/newsroom/item/2617-care-in-crisis-more-than-53-billion-wiped-from-the-economy
investigation\(^4\) and the Joint Committee on Human Rights’ inquiry into the UK Government’s implementation of disabled people’s right to independent living\(^5\). Across Government the provision of adequate impact assessments has been shown to be weak.

In DWP, where policies directly affect millions of disabled people and carers on a daily basis, it is even more pertinent that assessments are thorough.

But we are yet to see an adequate assessment from DWP as to how the potential impact of cumulative Government welfare proposals will affect disabled people’s lives. We are particularly concerned at the narrow nature of the assessment for the PIP assessment plans. We recommend DWP fully analyse plans again and ensure a thorough equality impact assessment is provided on the assessment in particular before draft regulations are provided.

We are particularly keen for DWP to produce an impact assessment that considers whether people with any specific condition or impairment group will be especially disadvantaged by the changes and what measures the Department has taken to help mitigate the impact.

In order to better help understand the Government’s rationale for proposed differences between current DLA rules and PIP regulations, it would also have been useful to have an explanation of the savings and/or other issues considered by DWP.

The consultation is threadbare on the evidence or justification for some significant changes (including for linking rules). We would expect to see a cost-benefit analysis and other rationale for the decision and are disappointed information has not been shared.

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**Involving disabled people and DBC members in developing the assessment**

We are concerned that the assessment has been devised by a very limited group of ‘health professionals’ and without adequate input and involvement of disabled people. We do not consider simple attendance of organisations at meetings as adequate ‘involvement’. We have emphasised the need for DWP to ensure our recommendations are included in plans to ensure involvement delivers outcomes.


However, we are concerned that recommendations and suggestions from the assessment group’s disabled representatives and beyond are not being built into plans and cannot be clearly identified in the current proposals.

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