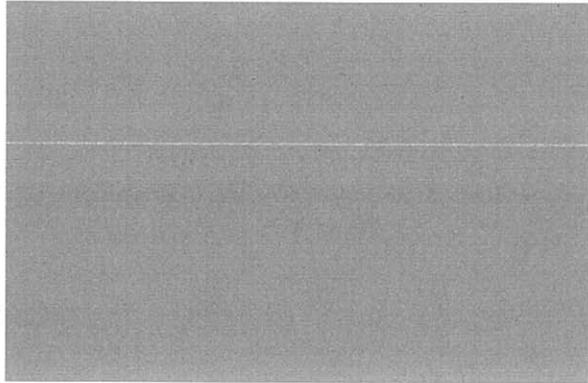


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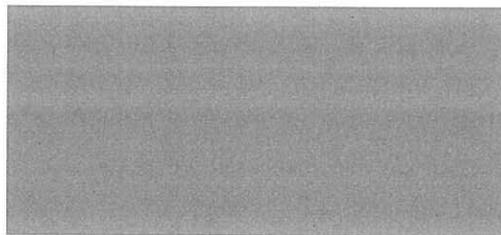


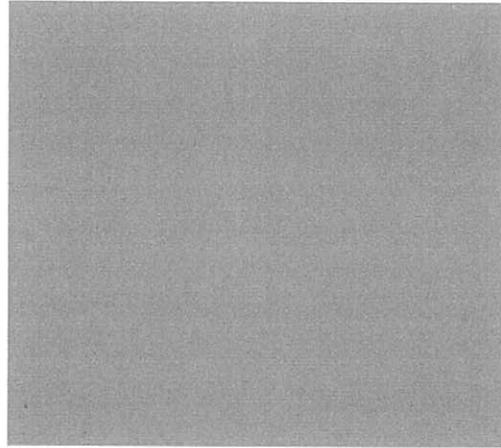
Dear sir/madam,

Please find enclosed a copy of my response to the Disability Living Allowance Reform Public consultation document.

I am responding as a disabled individual, suffering from multiple Scleriosis, and I hope that my views will be taken into account during this review.

Yours faithfully,





## **DISABILITY LIVING ALLOWANCE REFORM (D.W.P)**

### **(PUBLIC CONSULTATION)**

Q1

#### **PROBLEMS / BARRIERS**

-Transport: It is often difficult for a disabled person to access public transport, as he/she may not be able to walk as far as the nearest bus stop, or be able to step onto a bus or train. Walking more than a few yards can be difficult and painful. Public transport is not usually wheelchair-friendly.

- Mobility problems: There can be significant problems in gaining access to some buildings or areas, and a carer is often required to assist and accompany the disabled person.

- There can be a lack of disabled car parking spaces, and some public buildings are not easily accessible.

- Lack of finance: Many disabled people have low incomes, and exist either on state benefits or low-paid employment. The cost of running a car or using public transport is prohibitive, and so the Mobility component of D.L.A. is essential.

Q2

People who are put onto D.L.A. under age 65 should (as is the case now) remain on D.L.A. Care and Mobility beyond 65 if they satisfy the D.L.A. eligibility criteria.

They should not be transferred onto Attendance Allowance, which does not have a Mobility component.

Indefinite Period or Lifetime Awards of D.L.A. should remain as a period of award for life- long conditions, particularly for progressive incurable conditions such as Multiple Sclerosis.

**Q3**

**MAIN EXTRA COSTS:**

**a) Travel:**

It is often impossible to use public transport, due to the condition of the disabled person, who will need to use door-to-door transport, even for short journeys. A more mobile person could walk or use a bus. A car for most disabled people is essential.

**b) Food and Living Costs:**

It can be difficult to cook and prepare meals, therefore it can be necessary to buy ready meals, or at the very least to use prepared vegetables. This is always an extra cost.

**c) Prescription charges:**

Some people do not qualify for free prescriptions, and the costs of these can be high (some people can be having as many as ten or more items a month on prescription).

**d) Household Maintenance / Gardening:**

Disabled people very often cannot manage simple household maintenance tasks; decorating, gardening and other simple jobs that the average home handyman can do. Disabled people with mobility/balance problems (such as those caused by Multiple Sclerosis), will have to pay a tradesman to do these household maintenance tasks, or let their homes fall into disrepair.

**e) Heating / Lighting Costs:**

Heating costs are normally higher because the disabled person's lack of mobility means that heating needs to be on in the home more frequently. Also lighting appliances, as well as other household appliances, are used more often. Higher levels of water consumption are required, because of the need for more frequent washing of clothes and bedding, and indeed for personal hygiene.

**f) Accommodation Costs:**

Suitable one-level accommodation, such as a bungalow, is more expensive to buy or rent, and is difficult to obtain. The Disabled Facilities Grant is currently available, but will not cover the full cost of alterations. An extension may be built, providing ground floor facilities, but decorating and refurbishment costs are the responsibility of the disabled person.

#### Q4

Even if reducing from three rates to two does make the form simpler, it is very likely that people who are at present at the lower end of the scale will find that they are no longer eligible, as the entry bar will rise. This will mean great distress and increased poverty for this group of disabled people.

#### Q5

The group of conditions in Annex 1 should retain automatic entitlement as at present.

People with varying and fluctuating conditions, where they are recognised as permanent, progressive, chronic and incurable (for example Multiple Sclerosis) should incur an automatic entitlement to Middle Rate Care and Higher Rate Mobility, and be assessed for Higher Rate Care on an individual basis.

#### Q6

You should prioritise support to those least able to lead full and active lives by assessing their ability or lack of ability to get around, both indoors and outside the home; also their ability to socially interact with others, manage personal care and treatment needs (day and night), and access food and drink.

The most essential activities for everyday life are activities surrounding personal care (i.e. washing, dressing, toileting, personal hygiene. Also, the abilities to get up and down stairs; to get in and out of bed, and to prepare and cook a meal are essential. The applicant must be able to take medication safely as and when required.

#### Q7

In the case of variable and fluctuating conditions, those assessing the disabled person need to consider how the applicant copes on bad days, as well as on better ones. Also, whether the applicant is able to do a particular activity repeatedly or just once or twice needs to be considered. There is also a need to consider the longer term effects of an activity on a person's health. For example, an applicant may be able to walk 100 yards one day, but will suffer the adverse effects the following day.

There is an imperative requirement to listen to the opinion of the applicant's G.P. and consultant; and in the case of neurological conditions like Multiple Sclerosis, only persons with specialist knowledge of that condition should be making judgements about the applicant.

The applicant's G.P. or consultant can also advise on the condition of the applicant over a reasonable period of time.

#### Q8

A wheelchair-bound applicant should be assessed for mobility needs without their wheelchair (i.e. the wheelchair should be ignored for the purposes of the assessment).

A wheelchair-bound applicant is not mobile, and including the wheelchair in the assessment alters completely the results of any assessment of their capabilities. It can be impossible for the disabled person to transfer themselves in and out of the wheelchair without the help of a carer.

A manual wheelchair can only be used for a short distance outdoors, and if the disabled person lacks upper body strength, they will again need a carer.

The disabled person would also need the help of a strong, able-bodied carer to transfer both themselves and the wheelchair into and out of a car.

The assessment should only consider aids and adaptations the applicant already has, and not ones that might be available. (How is the assessor qualified to make this judgement?).

#### **Q9**

The form should be asking questions in user-friendly fashion, and should make use of examples to assist the applicant. There should be clear guidance notes as to what information is required and why.

To improve public awareness, information leaflets and posters should be displayed prominently in public libraries; post offices; community centres and doctors' surgeries- in fact, anywhere where people gather, to ensure that people are aware of the benefit and how to claim it.

Information should be available on the internet (for example on the DirectGov website), and there should be a T.V. campaign to highlight the benefit and target it towards eligible people. There should be an initial questionnaire on- line to assess basic eligibility.

#### **Q10**

Supporting evidence should come from the applicant's own G.P. and/or consultant, or from another health-care professional who is suitably qualified in the field of the applicant's illness. (It can never be acceptable to have a midwife assessing someone with a neurological illness, for example). The applicant's own G.P. or consultant will have a far greater understanding of their disability than a health-care official appointed by the D.W.P. The latter official will only have a relatively short time on which to base their findings.

#### **Q11**

The health-care professional may not have any expertise in the applicant's health condition (for example they may not fully understand a complex and variable neurological condition such as Multiple Sclerosis.

They may have a relatively short time-frame in which to evaluate an applicant's health condition, and this shortened time-frame would not be suitable for someone with a complex condition such as Multiple Sclerosis.

They may be target driven, with the underlying aim of reducing government expenditure on P.I.P. This could result in applicants for the benefit being denied benefit erroneously, or being wrongly assessed.

The applicant may not be given sufficient opportunity to voice his/her concerns, or to discuss the full effects of their illness.

The questions asked by the health care professional may not cover the applicant's full range of health problems (i.e. they may be using a computerised, standard list of questions which is difficult to apply to a variable illness such as Multiple Sclerosis.)

The health-care professional must have the applicant's G.P. and consultants' reports available at the time of assessment, to ensure that these are taken into account at the relevant time.

Applicants with fluctuating conditions such as Multiple Sclerosis might attend the assessment on a relatively good day, and so may be wrongly or inappropriately assessed.

Inappropriate circumstances would be in a situation where the applicant has a severe mental illness, or is diagnosed with a terminal illness.

#### **Q12**

The evidence should be provided by the appropriate healthcare professional, i.e. a consultant or specialist nurse. Persons with a diagnosed permanent, chronic illness should not be subject to reviews, as they can cause considerable stress. This should apply to people living with conditions of a varying nature such as Multiple Sclerosis.

#### **Q13**

With fluctuating conditions, improvements can be short-term, and the time-span of a change could result in benefits being reduced unnecessarily, at a time when employment is still unfeasible. By the time benefits are reduced, the condition could well have worsened again.

With Multiple Sclerosis, you cannot estimate the length or severity of variation, and the degree of disability can vary from day to day, or even from hour to hour.

Any assessment of someone with a variable / fluctuating condition must take full account of the level of disability on a "bad" day.

#### **Q14**

Advice and information should be readily available for people applying for any benefit (including P.I.P), but it should be on a voluntary basis, with the aim of providing positive help and advice as required.

#### **Q15**

There should be no requirement to access advice and support. This advice and support should be available on a voluntary basis to applicants who wish to take advantage of it.

The key features should be:

Voluntary help and advice: A positive approach by the adviser, so that the applicant is enabled to access any help that is available to them.

There is a danger that applicants for P.I.P. will be deterred from claiming this benefit and passed from pillar to post. The applicant will be discouraged by this process and give up trying to claim disability benefits.

There is also a danger of subjectivity, with different advisers applying different criteria to the definition of disability.

Also how much detailed knowledge would these advisers have on the various sources of help that applicants might be able to access?

#### **Q16**

Disabled people fund their aids and adaptations either wholly or partly through social services and the N.H.S.; self-fund, or apply for help from relevant charities (such as the Multiple Sclerosis Society or Motability). Some people may use a combination of the above to fund their aids and adaptations.

There could be an option to use P.I.P. to meet a one-off cost if this is in addition to ongoing P.I.P. support. If it replaces ongoing support, it is likely to plunge the applicant into increased levels of poverty. It must be a voluntary option chosen by the applicant (for example, an applicant for P.I.P.

might be in full-time employment, and choose the option of an upfront, one-off payment in preference to a regular weekly/monthly benefit.)

#### **Q17**

Not answered

#### **Q18**

D.L.A. is extremely useful as a passport to additional help and support, such as access to the Warm Front scheme and the Blue Badge scheme. This passport must be allowed to continue under any revised scheme. The close links with Motability must also be maintained.

#### **Q19**

Disabled people would be extremely disadvantaged and impoverished if it was not possible for P.I.P. to be used as a passport to other benefits and services, and service providers would be inconvenienced and forced to apply different criteria when assessing levels of disability.

There is no reason why P.I.P. should not be used as a passport to other benefits and services in the same way that D.L.A. is.

#### **Q20**

The present system for direct payments from Social Services runs fairly and objectively.

It is extremely concerning that the underlying thrust behind the Personal Independence Payment unfortunately appears to be to cut the benefit budget. If a disabled applicant was (re)assessed for P.I.P., and turned down for this benefit or had it reduced, this could potentially set off a chain of

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unfortunate events that could lead to other vital benefits being similarly reduced or withdrawn (for example, Direct Payments for Adult Social Care, Blue Badge eligibility or Carers Allowance).

The overall effect would be in this case to create potentially extreme impoverishment and disadvantage.

#### Q21

The impact that these proposals could have on the different equality groups is likely to be negative. It is not made clear in the proposals how the new benefit will be "better focused on helping disabled people to lead independent lives", or "provide an opportunity to promote equality of opportunity to those least likely to lead full and active lives". In the *Executive Summary* at the beginning of this consultation document, there is an admission that the "rising caseload and expenditure (of the present system of D.L.A. payments) is unsustainable", and unfortunately, there does seem to be a cynical, cost-cutting exercise at the very heart of this consultation.

The question must be clearly posited: How exactly will this new benefit enable disabled people to lead "full and active lives"? Also, how will it promote independence, or equality of opportunity? The Disabilities Discrimination Act and the recent Equalities Legislation already exist to protect the employment rights of disabled people and their carers. Reducing and cutting disability benefits such as D.L.A. /P.I.P. will limit the lives of disabled people and their carers significantly, and will, in many cases, result in an increased level of dependency on the state. For example, if a reduced D.L.A./ P.I.P. award results in a lower rate of Mobility Allowance being paid, the disabled person will lose their entitlement to a Motability lease car. In my own case, I am unable to walk as far as the nearest bus stop, or to access public transport. Therefore, if I did not qualify for a Motability lease car, I would be housebound. It is difficult to understand how this situation would either increase my independence and "equality of opportunity", or my job readiness.

Another concern is that disabled people "with lesser barriers to leading independent lives" will receive a lower rate of support. Yet these people have already been assessed as needing a certain level of support under D.L.A. regulations – they have already had to satisfy stringent conditions to qualify for D.L.A., and it seems unjust and inequitable to reduce their benefit now. Although it is commendable to "focus support on those with greatest needs", this particular group will not in fact see any increase in their disability benefits under these new proposals.

Certain conditions which are permanent, progressive and incurable (including Multiple Sclerosis), should involve an automatic entitlement to benefit. There seems little point in regular reviews of such cases, as there is no cure, and no effective rehabilitation. Regular reviews, therefore, would not be cost effective, and would cause unnecessary stress to the disabled person. In some cases, they could be the cause of a significant worsening of the symptoms. In the case of Multiple Sclerosis, stress, and the physical exertion involved in attending regular reviews, are indeed extremely likely to cause a relapse or a worsening of symptoms.

It is also very concerning that the consultation document suggests that the new proposed benefit may "remove a barrier to working for some disabled people, promoting equality of opportunity", and may improve understanding "that support is available both in and out of work". Present recipients of D.L.A. already understand that this is a benefit which can be paid "both in and out of

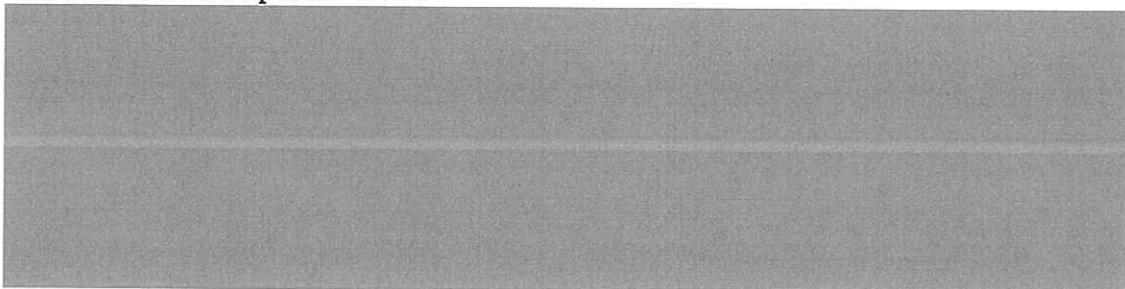
work". The present system of paying disability benefits such as D.L.A. is not in itself a barrier to finding or keeping work. Rather, it is the nature of the disability itself, and the lack of realistic employment opportunities, which form the barriers. Many disabled people are genuinely unable to work, and would be severely disadvantaged in a repressed job market. As a civilised nation, we should be protecting these people, and enabling them to receive their full entitlement of disability benefits, not attempting to cut these benefits, and justify our actions under the umbrella of "equality of opportunity".

Factors to be considered when developing this policy should include the physical, mental and emotional well-being of the disabled people affected by the policy (in particular, those people currently in receipt of D.L.A.). No-one currently in receipt of the benefit should have the benefit arbitrarily withdrawn or reduced. Lifetime or indefinite awards already in existence should be allowed to continue. Disabled people suffering from chronic, permanent, progressive illnesses should not be subjected to unnecessary regular reviews. There should be an independent appeals process, not linked in any way to the private healthcare company conducting the assessments, and applicants should be able to provide evidence concerning the nature and extent of their disability from their own doctor or medical consultant.

#### **Q22**

This consultation document has obviously aroused many serious concerns about the future of D.L.A., and the introduction of P.I.P. These concerns have not been fully and properly addressed in the consultation document, and there remains the over-riding concern that the needs of severely disabled people have been summarily sacrificed in a savage cost-cutting exercise. I would therefore ask that the concerns raised be addressed and responded to by the government in a detailed and freely accessible response. I personally would like to read this response, as I am sure would other disabled people affected by the issues raised.

#### **Consultation Response from:**



**I am responding to this consultation as an individual. I am disabled, suffering from Secondary Progressive Multiple Sclerosis.**