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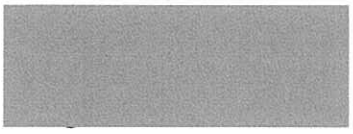
9 February 2011

Dear Sir or Madam

Disability Living Allowance Reform – Public Consultation

Please find enclosed my response to the above Public Consultation Document.

Yours faithfully,



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Disability Living Allowance Reform – Consultation Document Response

The Consultation document states that the current DLA benefit provides no opportunity to review awards. This is incorrect, as claimants are required to notify DWP of any changes in their condition and DWP have the option of requiring a claimant to undergo a further assessment, by an independent doctor, should they feel this change in circumstance deems it appropriate.

The document makes no reference that one of the aims of changing the DLA benefit, to the Personal Independent Payment, is to reduce the current costs by 20%. This aim will have an overriding impact on the scheme.

On page 33 (item 3 of the Consultation Document) it states that:

> *3. The Government Code of Practice on Consultation recommends a minimum 12-week consultation period for public consultations, unless there are good reasons for a limited consultation period. In this case, we are consulting on general principles only. We intend to further consult on specific details as these are developed, and therefore our Minister has agreed that a limited consultation is appropriate.*

Having now waded through the document, several times, it does not appear that the public are being consulted on "general principles only". This impression is reinforced in the intention to introduce changes to the way some elements of the benefit will be implemented, linked to the Comprehensive Spending Review, which are scheduled to come into effect as early as 2012.

The Consultation period is much shorter than other similar Consultations have been and, as much of the Consultation period fell over the Christmas and New Year holidays, it is likely that this will prevent the maximum involvement of the disabled community, recipients of the DLA and other interested parties.

The length and complexity of the Consultation document, added to the reduced Consultation period, is detrimental to the needs of those likely to be in receipt of the benefit.

The Consultation document is quite vague, in some areas, and provides little indication of what the Personal Independent Payment form will contain. This lack of detail will inevitably diminish the ability of responders to achieve a successful outcome of the Consultation.

The intention to move away from 'automatic entitlement based on specific impairments' is likely to reduce benefit to many claimants erroneously. The level of benefit will be dependant on individual assessments and, as these assessments will be carried out by many assessors, whose opinions will be subjective, it will be impossible to achieve the desired result to "*...help to remove differences in treatment which can currently arise depending on an individual's impairment or whether an award is made on a fixed or indefinite basis*". It is likely that the changes considered will exacerbate the inequality of the system.

The Consultation Document states that one aim of the new scheme is to promote "*equality of opportunity*". Equality of opportunity will only be attained by strengthening the legislation, which supposedly reduces discrimination towards disabled people, and in pursuing those who

discriminate against disabled people. Reducing the benefits of some claimants would appear to be un-connected with this aim.

The Consultation Documents states that the Personal Independent Payment "*will remain a benefit focused on helping people to meet the additional costs arising from their impairment or health condition*". Even a tenuous link to employment will remove this stated aim.

If some disabled people are unaware that the existing DLA, and its proposed cheaper replacement is available to those in work, as well as the unemployed, it would be a simple matter to launch an advertising campaign to rectify this. Reducing the benefits of some claimants would appear to be un-connected with this aim.

If the Personal Independent Payment benefit is to remain a non-means tested payment, an analysis by income distribution would seem a futile exercise, in understanding the impact of the proposals. It is obvious that those with a higher income will be less affected, by a reduction in benefit, than those on a lower income. This is particularly relevant when considering withdrawing benefit, for those on low income, during Hospital or Care Home stays.

Q1 What are the problems or barriers that prevent disabled people participating in society leading independent, full and active lives?

- Inadequately drafted legislation. The DDA's use of the word **'reasonable'** when referring to adjustments that Employers, Service Providers etc., are required to take into account, when considering provision to disabled people, defeats much of the intention of the Act. This word is used to ignore/get around much of the DDA legislation.

- Lack of finances. Disabled people have a much lower level of disposable income, compared to non-disabled people.

- Lack of provision in access to services, including medication and medical services.

Q2 Is there anything else about Disability Living Allowance (DLA) that should stay the same?

All of it, with the exception of allowing someone to receive benefit without having first undergone an examination by an independent medical professional.

Q3 What are the main extra costs that disabled people face?

Heating, Transport, Housing, Clothing, Food, Furnishings, Care, Employment, Education, Social and Spiritual outings etc.

Q4 The new benefit will have two rates for each component:

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

(a) Not necessarily – especially if the 'qualifying conditions' are too narrowly defined. It is likely that many disabled claimants will be under rated and fall short of appropriate levels of support.

(b) Some disabled people are likely to receive a lower level of benefit. They may substantially exceed the lower rate level of need, but still not qualify for the upper rate. It will depend on how the rules are drawn up and, as this is still to be quantified; it is not possible to provide a full answer to this question.

Q5 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?

The benefit should be determined by the need of the individual. Some conditions/impairments would seem likely to meet an 'automatic' qualifying standard, especially if they have previously been judge so to do, by an independent medical assessment.

Q6 How do we prioritise support to those people least able to live full and active lives? Which activities are most essential for everyday life?

(a) Support could be based on a points system e.g. each assessment task could attract the same number of points. The need of help with three or more tasks could achieve the number of points needed to secure the highest level of benefit.

(b) Personal Care (Bathing, Washing Hair, Dressing, taking Medication, Getting in and out of bed, Help during the day/night), Walking **Unaided**, Ability to prepare a Cooked Meal Independently, Ability to carry out everyday tasks safely and independently.

Q7 How can we best ensure that the new assessment appropriately takes account of variable and fluctuating conditions?

The assessments **should only** be conducted by medical professionals **trained in disability needs.** Many health care professionals have little or no comprehension of the needs of disabled people. Ironically, this can also apply to staff working in Pain Management Clinics.

The '**better**' days are difficult to predict and, even when they occur, the disabled person is likely to suffer a detrimental level of ability to someone who is non-disabled. Tiredness, following '**acute**' periods of some conditions is debilitating and, even if symptoms have lessened, the disabled person may still not be capable of pursuing and maintaining 'normal' activities.

(For the reasons stated above, there should be no link established between employment and the DLA/PIP, which should continue to be a non-means tested benefit. If someone has a fluctuating chronic, long-term condition, they will be unlikely to have access to employment and the social activities non-disabled persons enjoy.)

Q8 Should the assessment of a disabled person's ability take into account any aids and adaptations they use?

- What aids and adaptations should be included?
- 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 Disability Living Allowance reform 31?

Aids should only be taken into account to negate the need of further medical assessments. For instance, if a disabled person is incapable of walking the required distance without the aid, to qualify for DLA/PIP, they should receive the benefit, or if they have previously been awarded the benefit on an 'indefinite' basis.

(a) Anyone requiring the use, on a permanent basis, of Walking sticks, frames, wheelchairs etc. (These aids are not always able to be used e.g. some theatres require a wheelchair/wheeler user to leave their aid in the lobby and they are then assisted to a seat. They then have to wait to be assisted from the seat, either by a carer or member of staff. If a disabled person is dependant on an aid, they should be deemed 'not able' when calculating benefit, as they would be incapable of performing the task, in the absence of such an aid.)

Some buses/trains are still inaccessible to disabled people, even when they have aids at their disposal. So are some shops, offices, churches, courts of law etc. To assume that someone using these aids has the same full access, as the non-disabled, is unfounded and incorrect.

(b) This question is dependant on the determination of (a). If the use of an aid allowed for benefit to be withdrawn/reduced, the obvious conclusion is that disabled people were being punished for helping themselves.

One could also ask if child benefits should be withdrawn for subsequent children or whether extra payment should be withheld from someone who has achieved an older age.

Q9 How could we improve the process of applying for the benefit for individuals and make it a more positive experience? For example:

- How could we make the claim form easier to fill in?
- How can we improve information about the new benefit so that people are clear about what it is for and who is likely to qualify?

The questions on the form need to be clear, concise and transparent.

(a) They should not be devised as a means of reducing the benefit bill, but as a measure to determine to true needs of disabled people and should be available in ways which make them accessible to people with additional needs i.e. large print, Braille, etc.

(b) Ministers and Government Spokespersons should be fully briefed about all of the details of the new scheme and their answers need to be consistent. Too often the public are told a new piece of legislation means one thing, only for this to be're-**defined**' in subsequent interviews/press releases etc. Publicity, on a par with Stop Smoking campaigns, might be considered.

Q10 What supporting evidence will help provide a clear assessment of ability and who is best placed to provide this?

Medical reports, which have already been provided by an independent medical examiner, for existing DLA claimants, independent reports for new claimants, or an independent report from a Consultant, who is familiar with the patient/claimant's condition, if the claimant has given permission for the information to be divulged.

Q11 An important part of the new process is likely to be a face-to-face discussion with a healthcare professional.

- What benefits or difficulties might this bring?
- 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?

(a) Many claimants will suffer anxiety at the prospect of such an assessment.

(b) It would be inappropriate for an interview to be conducted, at either location, if:

i. the claimant does not have the opportunity of having a carer/advocate present;

ii. the sex of the Assessor does not meet the requirements of the claimant or,

iii. the claimant's health prohibits them from receiving a fair hearing.

Q12 How the reviews should 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?

(a) The criteria for repeat interviews should be dependant on the claimant's condition being **likely** to have improved. If the claimant is suffering from a chronic, long term or degenerative condition, it would be unreasonable to require the claimant to submit to further assessments for a period of less than 3 years. This reviewing process should have an end point, if the claimant's benefit has previously been awarded on an 'indefinite' basis. The response to Q10 would cover this point.

(b) If the claimant's condition has deteriorated, from when last assessed, they should not be required to undergo further physical examinations. The claimant should not be required to undergo any examination which could exacerbate their condition i.e. pressurising claimants, with skeletal conditions, to undertake exercises they have notified as painful, or unmanageable, because of their impairment.

Claimants with learning difficulties must always have an advocate to represent them. This will need special arrangements to be in place, in the case of physical examinations, to preserve the claimant's dignity.

Q13 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?

A declaration form could be sent out, with each notification of change of benefit, to the claimant. This should be accompanied by a s.a.e. and the claimant (or representative) could be required to sign and return the form, in order to continue receiving benefit. There would need to be a reminder system in place, to allow for postal discrepancies.

Q14 What types of advice and information are people applying for Personal Independence Personal Independence Payment likely to need and would it be helpful to provide this as part of the benefit claiming process?

Access to other 'passport' benefits could be supplied with the Personal Independence Payment pack and providing them, as part of the benefit claiming process, would seem sensible.

Q15 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?

No potential claimant, of any group, should be 'required' to access advice and support. This would negate the premise of this being a Personal 'Independence' Payment. It would be useful if telephone/helpline numbers, of voluntary advisory groups, such as the CAB, translation services etc., were provided to claimants with the claim forms. If the benefit is clearly set out, transparent and effectively advertised, claimants will access it.

Claimants should be provided with a complete copy of their assessment, in case they have a need to seek advice in contesting a decision. They should also not be required to sign a record of their assessment, without having first been furnished with a copy for them to consider and to seek advice on, should they wish to do so.

Q16 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?

Maria Miller MP, Parliamentary Under Secretary of State and Minister for Disabled People, stated, in the Consultation document, that "*We are steadfast in our support for the principles of DLA, as non-means-tested cash benefit contributing to the extra costs incurred by disabled people.*" If this is so, how disabled people use/spend their Personal Independence Payment should be entirely at their own discretion. They are best placed to decide how the application of the payment affords them maximum benefit.

Q17 What are the key differences that we should take into account when assessing children?

Children (**and people with learning difficulties**) should not be subjected to long or onerous assessments. A greater weight to GPs', and other health care professionals', reports could be given in these cases. An independent assessor should have very strict criteria when assessing such claimants. Those criteria should be fully disclosed to the claimant, and their representatives, prior to any assessments. The assessor should be required to take on board, and record, any additional information a child's, or claimant with learning difficulties, representative offers at the assessment.

Q18 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?

DLA has been fundamental in providing disabled people with access to other services or entitlements. These benefits could be improved if a list of 'passport services' were included with the claim pack and also with entitlement statements.

Q19 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 32 Chapter 5 Questions?

If the Personal Independence Payment does not provide a passporting service, claimants will have to undertake further assessments, to access entitlements, and many would feel unable to face further assessments. This would leave many disabled people more vulnerable, than they are at present, and would not fulfil the stated aims of the proposed changes. or making the PIP a passporting benefit would increase bureaucracy, denied claimants entitlements and, in turn, greatly increase administration costs.

One change, which should be considered, is that when a claimant has their DLA withdrawn, a scheme should be in place to allow the continuation of the Motability contract, until they have had the chance to appeal the decision. The immediate withdrawal of this facility in effect renders many claimants immobile and, in some cases, unemployable.

Q20 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?

The assessment for DLA has, in the past, been rigorous. Any claimant, who has been deemed to have qualified for the DLA, should automatically qualify for other payments.

Government bodies/local authorities should have access to information which records if someone is in receipt of a particular benefit. **(This information should not include details of medical conditions, as access could be wide ranging.)** If someone is in receipt of a particular benefit, which could automatically entitle them to other/linked benefits. This would reduce costs and distress to claimants.

Q21 What impact could our proposals have on the different equality groups (our initial assessment of which is on page 28) and what else should be considered in developing the policy?

If DLA/PIP is advertised, literature clearly set out and easily obtained, and in the previously identified formats, there should be no issue of deleterious impact to any equality group.

Q22 Is there anything else you would like to tell us about the proposals in this public consultation?

Additional comments relating to specific Items

Pg. 19 (Item 21) – People who can afford to pay for their own Private Care Home/Hospital stay often receive an enhanced standard of care than those who cannot. It will be completely unfair if those people will **also continue to receive the benefit**, which will be withdrawn from the poorer members of the community. Not all Hospital/Care Home stays will result in the Institution making 'reasonable adjustment' for a disabled person's stay. The withdrawal of benefit, from non-self-funding claimants, will prevent them from meeting the additional costs arising from their impairment or health condition in such circumstances. E.g. the withdrawal of higher rate mobility component, to a non-self-funding Care Home resident, who can no longer afford to hire a taxi, will prevent them from maintaining contacts with family and friends, practising the religious beliefs, etc. whereas a self-funding claimant will continue to receive their benefit, even though they are financially able to self-fund the hire of the taxi. This proposal will punish some claimants, merely for being less affluent. In such circumstances, the stated aims of the proposed legislation are not met.

Pg. 21 – **Taking into account Aids** – Does the proposal intend that if you **must** use a walking stick/walker/wheelchair to walk and get around, you could be denied benefit, as these will **'enable'** you, whereas someone who doesn't need them to get around could receive benefit? This would be perverse and could put claimants at risk. The intention of the proposed change is unclear.