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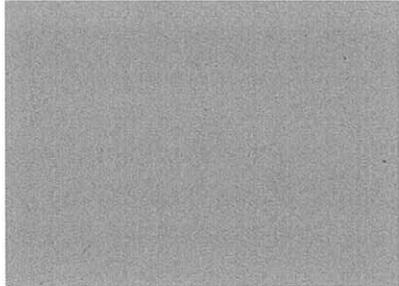
Rec'd  
31/1/11

  
26<sup>th</sup> January 2011

Dear Sir or Madam,

Enclosed please find my own responses to the Disability Living Allowance consultation document.

Yours faithfully,



## DWP consultation questions

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

Lack of funds.

Lack of suitable aids and adaptations.

The built environment.

Reductions in social care since Care in the Community was first introduced. First billed as 'quality of life for disabled people' and all areas of individual life were covered for a range of disabilities. This is now reduced to provision for only the most severely disabled people.

Lack of regular physiotherapy. People with limited mobility need physiotherapy on a regular basis to increase mobility, health and life quality. This is not provided.

Attitudes towards disabled people in the work place and society in general. This is reinforced by poor attitudes towards social care of the disabled and the elderly.

Having completed the questionnaire and read the consultation document, this legislation will be one of the biggest barriers to disabled people leading fully active lives.

Independence, as a concept, is defined differently in relation to disabled people, than for people without disabilities.

There are proposals here which would create an interpretation of independence for disabled people. Then, if they were perceived to have achieved this state of 'independence', one of the supports by which they are assisted to control their lives, the DLA benefit, will be removed or cut.

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

Continue to pay people a mobility allowance when in residential homes. No residential homes have either the staff or the transport to allow individuals free or spontaneous access to the community.

Increasing numbers of people in residential homes are getting cars with their mobility allowance and then only needed family or staff members to drive.

The current format for DLA does not seem as dysfunctional as this document suggests. The cost of making changes in order to achieve a 20% reduction suggests that in practice much more cuts must be made to meet the overall cost.

This will adversely affect the quality of life of many disabled people.

**3. What are the main extra costs that disabled people face?**

Aids and adaptation. Support needs not covered by social services provision. For all but most severely disabled people, this means all support needs. Support staff will not do housework, such as hoovering, ironing, cleaning or even washing soiled sheets and clothing.

Transport needs, buses are not all accessible until 2020 and the rural routes are the last to be updated, taxis are expensive and possibly unreliable. Car adaptations are expensive and access by wheelchair vehicles, to drive, or as passenger very costly.

Extra washing and clothing costs.

Extra heating costs.

**4. 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?**

The problems with administration have always been very much due to lack of adequate staff training in the identification of differing types of ability and disability.

That such a high percentage of refused claims have always gone ahead after the appeals process suggests that staff are not interpreting the initial claim forms adequately. The appeals process itself must be very costly to run. Changing to two rates for the benefit will not solve the above problem.

If, as your document suggests, people have not understood the differences between living and mobility costs, or indeed, the principles of the DLA itself I would suggest that this is due to errors in explanation and presentation of the benefit on first application.

**• What, if any, disadvantages or problems could having two rates per component cause?**

By comparison with other benefits DLA is clear and understandable, people are able to see what rates are available, claim, be assessed and then know exactly what to expect in payment.

Since we have no idea of any changed criteria for the proposed rates it can be assumed that the lower level applicants will fail to qualify.

It would be interesting to know how many people would not qualify for the benefit under the changes to two rates.

Given that social services have withdrawn support to many people with disabilities, unless they are unable to get out of bed unaided and have no suitable family member, narrowing the DLA eligibility by reducing the rates would leave a potentially large number of people without the means to cope with daily life.

**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?**

It would seem to be a waste of time and money to keep reassessing static physical conditions that are constant in their effect on the individual.

A compromise would be that certain impairments mean less regular assessments. Assessment is a distressing and worrying event for individuals who know that they have a constantly deteriorating condition, but have no faith that the form they complete will be interpreted in a manner which ensures continuation of benefit. Individuals become more ill through worry that they will not be able to cope financially.

**6. How do we prioritise support to those people least able to live full and active lives?**

The level of payment, the accuracy of the assessments through good staff training and availability of support to apply would ensure that disabled people gained benefit appropriately. A better awareness and understanding of the benefit amongst support and associated services to encourage individuals to apply.

**Which activities are most essential for everyday life?**

This question would be better reversed. The policy makers, if not disabled, are likely to have 'full and active lives'. Which of their daily activities do they think disabled people should NOT have access to?

Activities which constitute 'everyday life' are down to individual choice, the DLA allows people to make these choices.

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I have a list of the activities which a national charity provided for its care at home clients in 1994. Only a small fraction of these would be covered by support staff today.

Life is sustained by food, water and some degree of warmth.

If an individual is given support which covers only a narrow interpretation of 'essential' activities they would have a very limited life. Quality of life includes access to the full range of social and domestic activities, so that people can be a part of the community, in good physical and mental health, exploring their own potential.

Whilst the process of application should not be too cumbersome, it also needs to cover a range of activities which reflect the above.

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

Determine what is meant by 'variable and fluctuating' in relation to impairments.

People whose condition can vary considerably within a matter of days should not be penalised for an assessment taken on a 'good' day. The fact that they have managed to get to the assessment, or appointment with the doctor can be evidence of a non representative day, they would have cancelled the appointment on a 'bad' day.

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

The efficacy of any aid used by an individual depends on that person's ability to use the aid. This varies greatly for the same aid.

The danger is that the provision of an aid will be seen as a medical cure, that the person is then able to function as well as someone without the disability.

**• What aids and adaptations should be included?**

I do not think any aids should be taken into account in assessment.

**• 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?**

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There are very few aids that can be obtained easily. Costs are extremely high, communication devices are available that would assist tens of thousands of people, yet very few use them and support staff are often unaware of their existence.

When first introduced the wheelchair voucher covered the entire cost of the wheelchair assessed as most suitable for individual needs. Now this has been severely reduced and involves at least 50% of cost to be paid by the individual. Many costly aids are outside of the NHS or government provision.

9. 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?

Make sure that there is assistance to complete the form and this is readily available and advertised.

Gathering accurate information from any group of people is difficult, to simplify the procedure too much will result in poor decisions.

The form is of necessity about the functions a person cannot perform; otherwise they would not be applying for DLA.

People are often not describing a true reflection of their capabilities; they want to be upbeat or not seen as 'whinging'. These cases are some of the ones using the appeals process.

• 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?

Clear use of media.

Despite there being low uptake of many benefits in the past only the fact has been publicised, not a subsequent campaign to inform the general public.

Disabled people have, so far, had limited channels through which to learn about the benefits to which they are entitled. This can be as chancy as word of mouth.

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

The individuals themselves are usually the best authority on their condition. Although medical records are becoming more centralised many disabled people have more than one condition, more than one specialist, and more than one hospital. The individual's GP practice increasingly collates this information, but it still has to be interpreted into effects, preferably by someone who knows the person.

Using staff without appropriate training can result in assumption based on their own understanding of a condition. Using General Practitioners to visit can result in rushed, cursory assessments based on lack of time.

A true snapshot would involve feedback from all the healthcare professionals involved. This in addition to the form filled in by the disabled person. An on going, constantly updated document to which the individual has access and the chance to comment.

**11. 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?**

Travel to be assessed, if necessary.

Communication difficulties, if the disabled person does not have the means to fully express themselves they are likely to be incorrectly assessed.

Adequate and suitable training is needed for the professionals doing the assessment.

The effect of the stress involved on the person being assessed may result in their not giving all the facts.

This process would be more effective if there was adequate indication of what might be expected in advance.

**• 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?**

Communication difficulties, as above – written forms may be more suitable.

If the face –to-face is carried by out by someone who does not understand the person's condition or complexity of conditions

It may be inappropriate where dependence is placed on this meeting without checking other sources of information. For example, someone may forget to state aspects of their condition, or conditions themselves, through absent-mindedness, stress, or confusion.

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

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

Evidence from as many sources as possible, collated by people who are trained to interpret such information.

The starting point should still be the individual's own responses. The form at present can be filled in over a period of time, ensuring that the full range of effects is listed. As in Q 11, a face to face meeting is very likely to result in omissions.

In the past disabled people have not been encouraged to self report negative changes in their own conditions, only improvements. Re assessment may result in an inappropriate down grading and people are frightened to use the system.

There certain static conditions such as paraplegia, which are not going to change over time. However, over time paraplegia negatively affects other parts of the body and its function.

The degenerative nature of conditions such as Multiple Sclerosis means that although there will be no improvement regular assessment ensures the individual is receiving the correct rate of benefit.

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

Yes, there should.

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?

As above in Q12. Individual's having trust in the system may help, but this is not a short term solution.

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

Information is power; people cannot have too much information on how to claim benefits. The sources of information have been problematic in the past.

Not all disabled people have access to the internet, citizen's advice, or even regularly read a newspaper.

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?

This is a catch 22 situation - as mentioned above, many aids are prohibitively expensive, or require the individual to partly fund these themselves. Without adequate funds or savings they are unable to do so.

Saving up to buy an aid would result in loss of means tested benefits. Without the benefits they cannot afford the aids.

Putting a requirement on disabled people to have certain aids as a requirement would result in more individuals below the poverty line and unable to access community life.

More research could be done into the present quality of life of many disabled people and how many situations breach the current Human Rights legislation.

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?

If this is an additional payment to meet needs for aids and adaptations it would be excellent, but expensive.

To have to use this payment to fund aids and adaptations would mean people going without support in other aspects of their lives.

To absolutely dictate where disabled people spend their PIP is to negate the notion of individual choice. Choice is an important word, not featured strongly in this consultation document.

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

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?

DLA has been important in allowing access to other entitlements where;

- a) the person has been able to access information about the entitlement and
- b) where application for the service/entitlement has been easy to complete.

Information for other entitlements should be available through a variety of media and professional services. As an example, the disabled person, who is housebound, without access to a computer or newspapers should still be able to get the information.

Application for passported entitlements requires a copy of the DLA letter of award to be sent by post. For most people this is easy, in the above example the person may not be able to get a photocopy, write a letter, or even get to the post.

More is required in identifying people who may not easily claim and giving them both information and practical assistance.

Haring information between authorities, with permission, would certainly help with some of the above issues. If the system were proactive, it would identify those entitlements not currently applied.

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?

Greater isolation and poorer quality of life.

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?

Minimising bureaucracy is laudable, but not if it results in disabled people relying on one possibly flawed assessment.

An assessment for Local Authority social care may be made in between DLA/PIP assessments and provide a more up to date picture of individual circumstances. Reliance on an out of date assessment may result in the person not getting the support they need.

Any assessment system needs to be backed up with an accessible system to contest decisions.

Points 9 & 10 are very positively worded. It would be interesting to see concrete proposals for practice in this very topical and essential area of social support.

Support in the home for elderly, like other disabled home support, can be a post code lottery, and not tailored to individual needs due to lack of funding.

21. 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?

Focussing on those disabled people with greater need, at the expense of those with needs assessed as lesser, will result in an underclass of disabled people, unable to exercise their human rights, in terms of accessing community, family life, or even basic life needs.

There is often inequality between disabled people with different conditions or impairments.

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

There could be more evidence of research into how disabled people live and cope with life and finances at present.

This benefit is designed to increase quality of life and choices for disabled people. It has enhanced the lives of many disabled people; research needs to be done into the more positive aspects of the benefit, which would inform the prospect of possible negative effects of any changes.

Despite all the current measures, many disabled people's lives are untenable, without the ability to get out of the house for any reason, without being able to afford what constitute the necessities of basic life, neglected as to their physical support.

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Whilst person centred assessments can be seen as a positive procedure, some of the suggestions in the document appear designed with cost cutting in mind, rather than an increase in quality of life.

There is a need to exclude benefit fraud, such reports reflect badly on disabled people as a whole and encourage negative attitudes. Measures taken to ensure this should not result in genuinely disabled people in need being penalised for the fraudsters.