

8<sup>th</sup> February, 2011.

My name is [REDACTED] legal advocate for my younger sister [REDACTED] since the death of both of my parents. She is a 43 year old woman with quadriplegic cerebral palsy and moderate learning difficulties and is in full time residential care. She is totally dependant on others for all her needs and currently receives the full DLA award. You know now why I am writing to you.

I am sure you have read the response 'Don't Limit Mobility' to the proposed changes to this award. It could have been written with my sister in mind. In reality there simply is no 'double funding'. If this allowance is taken away from her she will have £18 to pay for everything outside her bed, board and care. £18 to pay for clothes, treats, holidays. She comes to my home for a day every week, a 50 mile round trip to enjoy a day with her family. It is the highlight of the week for us all, we are close and this will have to stop or be severely limited. As I am a teacher she has a short break with us every school holiday and although I do not take money from her the DLA covers the transport costs. She has suffered from depression and is on long term anti-depressants. She has started to eat again and becoming healthier in mind and body. If all she has to look forward to is to stay in and watch TV all day with the odd trip to the park I fear for her well being.

In your proposal you talk about simplification of the system. A welcome outcome as long as it is not over simplification and targets a narrow group and loses those who are truly in need. You talk about assessment but no criteria for assessment has been made known and who will do that assessment? I am not worried about this as I am sure my sister would qualify for the award if she was not in residential care. The last issue of fairness I do take issue with. I too want it to be fair but to take the DLA away from everyone in residential care is a travesty. They will NOT be able to lead 'full and active independent lives' as your document promises to ensure. You will be creating the exact opposite of that for the most vulnerable members of our society.

Part of me thinks what you are proposing just can't be true. It is beyond my comprehension that anyone would think it to be appropriate and justifiable. I have read that a society can be judged on how it takes care of its most vulnerable members. Can you and your government stand up to that judgement if you follow through with this? Does it not go against all of the legislation set down to ensure equality for people with disabilities? It will be a huge step backwards. Do you really want to put your names to this?

Yours,

[REDACTED]

## DLA Reforms Meetings: 3<sup>rd</sup> & 4<sup>th</sup> February 2011

### Question 1

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

So many - social attitudes  
- Physical access to places including appropriate and readily available transport.  
- Appropriate support and care  
- Lack of finance & mobility, access ends very expensive, facilities for disabled people always the most expensive  
Long term support from their families and advocates - pressure on those families.

### Notes:

The new benefit will continue to have:

- No means test and not taxable; it doesn't matter whether you are in full/part time employment or unable to work
- People will be able to spend the money the way they want to and will not be held to account
- Fast track for terminal illness

### Question 2

Is there anything else about DLA that should stay the same?

Will the assessment take into account the low level of income people in residential care paid by state have (people with severe and profound disabilities) - currently £18-20 per week for all but their bed and board. This has to buy toiletries, clothing, 'meals', recreational activities, holidays and breaks.  
I would welcome a means test, these people may be very poor.

### Question 3

What are the main extra costs that disabled people face?

Specialised transport - currently met by DLA  
Aids and equipment  
Telling more leisure time  
→ Blue badge abuse, unsafe pavements including cars inconsiderately parked.

#### Question 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?
- What, if any, disadvantages or problems could having two rates per component cause?

Difficult to say without seeing the forms and knowing the assessment.

May not take all needs into account, catch those who may be entitled

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#### Notes:

The new payments will only be made after a qualifying period. It is likely that a person would have had to have a condition for 6 months before becoming eligible for an assessment and the condition would be expected to last for a further 6 months (so 12 months in total).

The consultation is looking at the difficulties some people have with assessments when they have a fluctuating conditions that can worsen at times.

People with terminal illnesses will still be fast tracked through the assessment process and may in some cases still be automatically entitled to claim.

Currently, DLA is paid due to the condition or impairment and not based on how it might affect a person. The reforms will amend this to ensure the assessment takes into account the impact the condition has on an individual.

#### 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?

Claims should be based on the needs of the individual.

### Notes:

At the moment, if you enter hospital or a care home, the entitlement to the care component stops after 28 days.

The reforms propose that the mobility component should also be discontinued unless a person pays for their own care. It is planned to make this change in 2012.

### Question 6

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

The assessment should take into account the current way these people spend their lives and at least pledge to maintain the current activities and hopefully provide opportunities to further enhance their lives as their needs and interests change. If mobility component is taken away, these people may never be able to leave their homes and have few 'treats' let alone pursue an interest. £18-20 per week will not cover very much given current use in prices.

Do not take DLA away from these people or at least ensure they have ~~equi~~ funds under another name.

### Notes:

The DLA assessment looks at what a person cannot do and not what they could do if given more support. It is a very negative view of a person's life.

Future assessments will be based on a broader, more objective measurement of the impact of a person's health conditions or impairment on everyday activities.

### Question 7

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

Regular assessments may be necessary - but this would be unwelcome and costly.

**Notes:**

At the moment only aids such as prosthetic (false) limbs are taken into account when making an assessment.

In the future, the assessment will look at other aids such as wheelchairs and take into account how these aids are used successfully.

**Question 8**

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?

Aids, adaptation are costly. Everyone should have what they need to ensure their safety is secure. You may end up spending more than you do now.

**Notes:**

Disabled people have said the claim form for DLA is too long and complex is looks at their impairments and health conditions in a negative way.

**Question 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?
- 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?

Do NOT KNOW  
I would welcome a simpler format but simpler does not always mean better or include all it should.

### Notes:

The assessment process will need face to face meetings with an independent healthcare professional (a doctor or occupational therapist). There will be an opportunity for extra evidence from your own GP or social worker.

People with a terminal illness or complex conditions may be excluded from these types of assessment.

### Question 10

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

Person themselves, those who know them well and care for them. May need back up of medical evidence

### Question 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?
- 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?

Do health care professionals know the person well?

Care must be taken not to focus too much on someone's physical abilities or indeed learning difficulties. You must consider the change in lifestyle and limiting opportunities might mean for the wellbeing of those concerned esp people in long term care



### Notes:

One of the major changes being considered will recognise a person's changing needs over time. A regular review of people using the new Personal Independence Payment will ensure a person's needs are being met appropriately.

These reviews might involve gathering evidence from various sources, including self-report forms, information from relevant professionals who support the individual and face to face or telephone discussions.

### 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?

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..... DIFFICULT TO SAY - REGULAR WILL BE  
..... COSTLY - WHO WILL DECIDE ON WHAT  
..... IS APPROPRIATE FREQUENCY  
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### 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?

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..... MAKING SURE PEOPLE ARE NOT FRIGHTENED  
..... BY THE OUTCOMES OF BEING HONEST  
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**Notes:**

It is possible that the assessment process will include an element of information, advice and guidance around the options available to them.

It may become necessary for this to become a compulsory part of the assessment process.

**Question 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?

..... IT WILL DEPEND ON THE ABILITIES AND  
..... RESOURCES OF THOSE APPLYING.  
..... SOCIAL SERVICES, ADVOCATES ETC COULD  
..... BE OVERUN WITH PEOPLE ASKING FOR ADVICE  
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**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?

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**Question 16**

How do people currently fund their aids and adaptations? Should there be an option to use PIP's to meet one-off cost?

..... SOCIAL SERVICES  
..... FAMILY CONTRIBUTION  
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**Notes:**

It is recognised that disabled children and adult's needs can be very different.

**Question 17**

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

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**Notes:**

People receiving DLA at present are also sometimes eligible for other benefits that are means tested.

It is recognised that it is important for many people that they do not have to be reassessed for all benefits and this makes it easier for them to apply.

**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?

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**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?

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### 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?

[illegible]

### Question 21

What impact could our proposals have on the different equality groups and what else should be considered in developing the policy?

[illegible]

### Question 22

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

IT HAS BEEN DIFFICULT FOR ME TO COMMENT  
ON SOME OF THESE QUESTIONS.

PLEASE FIND ATTACHED MY RESPONSE TO THE PROPOSAL TO TAKE AWAY DLA FOR THOSE IN RESIDENTIAL CARE.

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## Optional

Name:.....

Address:...

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Telephone: