

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?

The problems that prevent our disabled son [redacted] are multifaceted, he is severely mentally & physically handicapped. eg. that is far more than having learning disabilities, he cannot walk, he cannot propel himself in a wheelchair or anything else. he cannot dress himself, wash, comb his hair, take himself to the toilet, he is doubly incontinent. He requires help & assistance day & night in his care home. He is epileptic and the only means of him going out to Ed Centre or for holidays, trips home is through the use of the homes minibus and driver plus escort. It requires the help of a care worker or others all the time.

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?

The DLA should stay the same, but rise automatically with the rise in cost of living which never goes down. When [redacted] is having his assessment as his DLA we as parents should be advised with the date of this so we can be present at the assessment to speak on his behalf. We hope to receive a letter in advance to inform us. He will expect to have a team of professional people to speak also in defence of [redacted] mental/physical disabilities & impairments. If DLA is removed it would mean an end to his life & be like imprisonment to him.

Question 3

What are the main extra costs that disabled people face?

The main extra costs for [redacted] is that the new PIP could be higher or lower dependent upon where they put the bar for his future. They may alter the criteria and give a lower allowance which wouldn't adequately cover his present status. In this type of situation there must be a thorough examination of all aspects of [redacted] life both physical/mental & present status & the prognosis for his future wellbeing. Extra costs are buying, replacing chairs (wheelchairs) only equipment which he uses to make him more mobile. Use & payment out of his funds for minibus use daily & at weekends, charges for minicab use, repairs to vehicles & chairs etc.

#### Question 4

The new benefit will have two rates for each component:

- Q5 a
- Will having two rates per component make the benefit easier to understand and administer, while ensuring appropriate levels of support?
- Q5 b
- What, if any, disadvantages or problems could having two rates per component cause?

No, it will not, but the individual person with Learning Disabilities will have to be assessed with properly educated professionals all at the same time, a team's holistic approach to make certain that the outcome is not greatly flawed. Only the trained people like those who work with [redacted] Staff, managers, Social Worker, Key Worker, Senior Nurse, Advocate, Parents, Psychologist/psychiatrist can full assess [redacted]

#### 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?

The DKA should make a built in fund so that disabled people can have the help of an Advocacy Agency to be present with them after the 6 to 12 month qualifying period, as they should be given strong support to apply again for the new PIP. In these cases it is illegal to have people who are not qualified and I suspect this might happen as 2 corners might be cut to avoid further expense.

### 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

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

(b) We prioritise support by having an individual personal programme or plan for each resident living in our home in the community at [redacted]. This is the care already. Support is given according to their plan, by care staff getting them to dress themselves, wash, bathe, shave, eat meals, mingle socially in home take them shopping, walking if they can - most need help with this toileting, going out to centres, cinemas, parties, Birthdays to surgery, dentist, hairdressers etc, using muckton at school, going to the pub for lunch, interacting with each other & teachers, Education

### 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?

For example if a resident (disabled & learning difficulties) also get epileptic fits & they increase they should look carefully at the amount of medication given, do the tests for this rather than get the resident to hold & drink a cup of tea by himself. They will have to have in very carefully to all the residents' complaints, listen & observe carefully all that might not be normal at any one day or time. Movements of the body should be watched when a resident is not cooperating with a task as they might have a secondary condition of the limbs like arthritis or fluid & not be able to move as easily as previously. As the residents get older so too will they suffer from ageing conditions. I believe in the use of physiotherapists to help residents.

### 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?

- (a) You can only tell if the person is eligible for the use of an aid in their own home or having home of over 6 months the condition doesn't go away or improve (they couldn't put on an Act) It's a heart to put him in bath.....
- (b) [redacted] already has aids a toilet seat which is raised to make standing up after use easy & also sitting down more comfortable. He has an electric wheelchair but always has to have someone to operate it for him, also has the ongoing use of the minibus or taxi. Uses a special "stay safe" dinner plate with food ring.

### Notes:

Disabled people have said the claim form for DLA is too long and complex it 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?

- a) Since Britain is multi ethnic, make sure all the forms are done in the various languages with larger print for those with reading difficulties. Do not use jargon ever. Use notes form before or question to help explain. Advise the person if they are having difficulty to get in touch with DHA Dept, or an Advocate, a close friend, a retired teacher. Someone from the C.A.B.A. (volunteers) a Social worker...
- b) Use The Council's Newsletter which goes to every home in the Borough; use of T.V. radio chat shows. A short talk on T.V. in an evening slot so people are home to hear it



## 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?

The supporting evidence should be a plan or I.P.P. and individual Personal Programme sent in to the prison or (Team professionals) before the date of Assessment. The signed Report from that Care Plan following the 1st 6 months after then a report from the 12 monthly review to assess how the resident responded to any new treatments. This should give a good idea of what is going on & if learning or betterment is taking place. A School or Centre Report should also be made available for this Assessment. Best placed are teachers, Social workers, Key workers Advocates Managers, Psychologists & GPs. Parents

## 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?

Some disabled people are not in a position to do face to face, due to more disability/impairment, but face to face is the what must, because you can see the persons handicaps / disabilities. Our son [redacted] is like this. Ideally we as parents would like a team of qualified professionals to do the Assessment face to face with parents eg ourselves present & other professionals should be in form of the date / time well in advance so they have had time to consider all [redacted] impairments physical / mental and write a report on him. Normally he is assessed twice yearly by a Learning Disabilities team of which one person is from the outside community. [redacted] mobility allowance has never been challenged yet. [redacted] is always present at this conference. Withdrawing his mobility allowance would limit his life very severely.

### 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:

- Q51 • What evidence and/or criteria should be used to set the frequency of reviews?
- Q52 yes, • Should there be different types of review depending on the needs of the individual and their impairment/condition?

*On a measuring scale of the disability of the person and also his/her abilities. The reviews should be yearly with a follow up. They should be less or more often according to the assessors.*

### 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?

*The assessment will come from the Care Home Domicile by the designated Care providers which will include parents.*

### 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?

They will need all information on what PIPs covers. They will need to be told the difference between on what it was based on in the first DLA & what the new benefit PIP is based on (positives). They need to know about the variation of pay on different levels, some of the levels may be changed.

### 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?

Yes, there should be. It should take the form of being able to get another trusted professional in the field of special needs to help them fill in the form or give details.

The finished Assessment Report should be made available to the appropriate people for comment.

Avoid unprofessional people. There should be a line on the final Report (Assessment) concerning any grievance procedure or objections to be taken.

### 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?

a) Dementia funds their Aids through the mobility Allowance.

b) Not quite sure of this one, part of P.I.P. could be put into place for maintenance & upgrading.

**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?

N/A

**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?

DLA has been most important in helping the disabled to get other services or entitlements as it helps pay for things which they need.

**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?

They would lose the benefits they receive if it were withdrawn. Victor would lose his home mobility, education training, social life, Church, days out, trips, visits to parents, friends, clubs, holidays, service trips to GPs, dentist, hairdressers, Barber and set back any positive training previously done by the Home/School Staff.



### 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?

851 Social Care and Health Care should be combined into one assessment so that the whole life of that special needs person is assessed altogether and if necessary sharing of information with only the agreement of DWP and next of kin also parents/guardians.

### Question 21

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

852 I think they will have great difficulty in understanding the ins and outs of this new proposal of the PIP.

851 It should not be a negative policy on what can't do (work) taking away from him will not help. This is a duplicity question, it's a juxtaposition.

### Question 22

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

Yes, I was got mixed up in people's minds with the cut backs from local government cuts and against the cut back from government and the new grammatical changes in the wording of government policy. Also carried forward too quickly without proper advertisement and notification and difficulties for disabled people to understand.

### Optional