

Received 21/2/11

421

(Sorry about cutting bottom off!)

Comments for the Consultation Process with regard to Governmental proposed changes to Disability Living Allowance Benefit-presented in Question & Answer form.

Question 1

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

Lack of Mobility.

Inaccessibility of places.

Lack of a carer if you need one.

Social isolation.

Dependency on others.

Low income – sometimes lifelong - unable to build up a pension because of inability to work) The prejudice & stigma attached to both visible and invisible disabilities, leads to unreal expectations equals either too high or too low - from both employers or others making success at a job application or interview for example impossible in many cases.

Depression & mental ill health are difficult enough to cope with conditions in themselves but the extra stress caused by a physical disability often leads to - depression and breakdown.

E.g. Form filling, problems in the system of claiming together with pain & sometimes lack of mobility or social isolation, can all further contribute to mental health difficulties.

School separation - many disabled children are separated from others in mainstream schools or because they have to attend special schools - this does not help with social integration or stigma.

Hospitalisation and medical appointments as well as the follow up from them, often take up a great deal of time and energy. This prevents regular commitments either to social or work activities.

Question 2

Is there anything about DLA that should stay the same?

Keep DLA name as it is well known

We agree that DLA / PIPs should not be means tested or taxed and it is most important that the choice of how it is spent also remains.

Applications for PIPs should continue to be based on the claimants own Doctors and Consultants medical advice or from information gathered from other health workers or from the wider community e.g. friends and carers.

Entitlement should remain automatic for terminal disease and also for certain other conditions e.g. blindness, hearing disability, M.S. Muscular Dystrophy.

Keeping the different levels for care and mobility is essential - and adding to them by one level to the mobility component highly desirable.

Awards should continue to be assessed and administered by Central Government, retaining the standard levels of payment at regular monthly intervals. These awards should increase annually to keep pace with the increase in the cost of living.

Responsibility to advise the administering department should remain with the client.

Easy continued free access to an information line for help with filling out forms and guidance through the application process and forms should continue to be available in different languages.

Retention of the Motobility scheme-which could be widened to include other forms of transport.

The higher rates of awards should continue to act as a gateway to other benefits, e.g. Blue Badge Scheme, Council Tax rebate and free bus passes.

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

DLA is a LIFELINE to people claiming it. Without DLA or reducing it, will mean people will no longer be able to cope with their lives and it will cause further mental health issues and suicides.

Extra heating and lighting costs, as disabled people are often at home more both in the day and evening.

Special diets and nutritional needs e.g. diabetes, vitamin B or D deficiency. Food and drug Intolerances.

Provision of suitable transport, e.g. the cost of purchase and running of a car including any necessary adaptations-this might mean using the Motobility scheme or for others being able to have a free bus pass rather than having to pay to take more bus rides. Taxis are costly and often do not have ramps. Taxis with ramp adaptations are often not easily available.

Disabled people often benefit from having extra therapies and these can act as a way of "keeping going" or/and maintaining mobility e.g. physiotherapy, osteopathy, massage, gentle exercise /hydrotherapy etc. However, because of the health problem concerned the person is likely to need more of these therapies and sometimes they will be ongoing - all of which increases cost.

The extra cost of paying for a carer, cleaning, gardening, changing a light bulb, decorating, D.I.Y. and the many odd jobs that cannot be carried out by somebody with a disability e.g. moving heavy items, changing the curtains, going into the loft as well as other household shopping, ironing, washing and for example.

Paying for either ongoing physical care or ad hoc personal care during or after illness or after periods of hospitalisation.

Clothing suitable for people with a range of different disabilities, can include front opening or Velcro fastenings, plastic protective coverings or special footwear and hose.

Personal care supplies e.g. incontinence pads, nappies and special creams for skin suppleness and to prevent bedsores.

The cost of home adaptations e.g. having an extra room or W.C. added on the ground floor or having a shower or wet room installed. In addition there may also be the high cost involved in moving to a ground floor flat, bungalow or sheltered accommodation.

There are extra costs incurred from wear and tear on the home and furniture or bedding e.g. more frequent washing of sheets, clothing as well as wheelchair damage to floors and walls. It follows that special flooring and adapted furniture/furnishings are also sometimes required

Holidays-there are extra costs for disabled needs e.g. transport and accommodation.
Prescription costs are likely to be greater because more prescriptions are often required for complex health conditions. Medicines and Supplements of vitamins and minerals for those who have intolerances to chemical drugs.
Extra cost should be considered for those people living alone with a disability.

Question 4

The new benefit will have two rates for each component (currently there are two rates for the mobility component and three rates for the care component). Will having two rates per component make the benefit easier to understand and administer, while ensuring appropriate levels of support? And, what, if any, disadvantages or problems could having two rates per component cause?

There should be three levels for mobility and care so that a person can work to improve their health, so as to go to the next level down, thereby reducing dependency. To have just two levels would represent too big a gap and act as a disincentive to work towards this reduction. A three level system should not imply that being on one level for one component, would automatically mean that you would be on the same level for the other component. It is also very important to note that in a two level system, not everybody would be able to be fitted into either of the two levels because of the varying symptoms and health conditions.

It follows that it is also important to be able to move to a higher level/rate if symptoms increase.

A three level system is in line with an Occupational Therapist type assessment- a pre-completed O/T assessment could then be used (with the claimants agreement) as a major part of any applicants award assessment, or obviate the need for one altogether-therefore reducing time and cost.

Question 5

Should some health conditions or impairments mean an automatic entitlement to benefit, or should all claims be based on needs and circumstances of the individual applying?

Entitlement should remain automatic for terminal disease and also for certain other conditions e.g. blindness, hearing disability, M.S. and Muscular Dystrophy.

Entitlement needs to be on the grounds of disability alone-as that in itself always causes problems and difficulties in life. Other circumstances should not be taken into account, either those of a support or financial nature- i.e. awards should not be means tested.

Special entitlement should be acknowledged for those people living alone with a disability.

Question 6

How should the Government prioritise support to people least able to live full and active lives? Which activities are most essential for everyday life?

It should be accepted that many disabled people will never be able to live full and active lives. That said suitable housing and shelter with secure tenure and

adequate income are pre-requisites for activities which are essential for everyday life.

These are:- Being able to have a properly cooked meal regularly, being able to sleep well and regularly and feel safe at home, being able to keep self, home and clothes clean, to have social contact and activities - hobbies, interests, visiting relations/friends – being able to go out of home, having a telephone and computer for communication, and a radio and TV for company and accessible entertainment purposes.

Being able to keep a pet or a working animal e.g. a guide dog

Questions 7 & 10

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

By allowing the claimant to use supporting evidence for their application for example using medical information from their GP or Consultant, and reports or social & community evidence e.g. from carers, friends or diaries-of symptoms or medical appointments.

By allowing the evidence of employers, teachers/ complimentary therapists, social services, Occupational Therapists in the assessment process, but ensuring that the clients worst days and times be taken into consideration.

It would be helpful if the forms were less repetitious and of shorter length, also-benefits advice should be easily available, either face to face or on a free telephone line. The process should also have shorter waiting times

The assessment process should be carried out by a team of regularly employed doctors or nurses-part of a team within a Government department, and doctors should not be brought in on an ad hoc basis as is at present the case.

Appeals and tribunals should be made less formal and easier to access.

Question 8

Should the assessment of a disabled person's ability take into account any aids and adaptations they use? If so, what aids and adaptations should be included? And should the assessment only take into account aids and adaptations the person already has or should it consider those that the person might be eligible for and can easily obtain?

No, aids and adaptations should ever be taken into account for an awards assessment. Because aids and adaptations often take a great deal of extra time and energy to use - therefore it would be unfair to see someone using a wheel chair for example as mobile in the usual sense

Question 9

How could the Government improve the process of applying for the benefit for individuals and make it a more positive experience? For example, how could the Government make the claim form easier to fill in? And, how can the Government improve information about the new benefit so that people are clear about what it is for and who is likely to qualify?

It would be helpful if the forms were less repetitious and of shorter length, also-benefits advice should be easily available, either face to face or on a free telephone line. The process should have shorter waiting times.

Tribunals should be less formal

There should be leaflets/forms at all GP Surgeries social work Departments and Post Offices.

Put information about the new benefit on TV and Radio before and when it is first introduced, and then as part of an ongoing information service.

Train GPs and hospital Doctors, as well as other health professionals to mention this benefit.

Assessing doctors should never turn up without warning.

Accept the extra difficulties experienced by people living on their own.

Question 10

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

By allowing the claimant to use supporting evidence for their application for example using medical information from their GP or Consultant, Alternate and Complimentary therapists reports, and reports and social/community, diaries-of symptoms or medical appointments.

By allowing the evidence of employers, teachers/ complimentary therapists, social services, Occupational Therapists into the assessment process, but ensuring that the clients worst days and times be taken into consideration.

Question 11

An important part of the new process is likely to be a face to face discussion with a health care professional. (What if any) benefits or difficulties might this bring?

A doctor should be used where complex cases are involved, nurses and other professionals e.g. O/T could be used for less complex cases providing they were given adequate training with regard to the nature and difficulties caused by disability.

An assessment would probably take over an hour, or in some cases more time and second appointments needs to be allocated for more complex or distressing cases.

Carers-or an advocate, or supportive person should be allowed to be present at an interview.

This would help as claimants cant necessarily articulate very easily.

A translator or signer may also be necessary.

Cultural needs should always be taken into account.

There should be a choice of where the interview should be held-at home or in an office-but if in an office it should not be up flights of stairs unless there is a lift.

The cost of a taxi or other form of transport should also be provided.

These sessions should be as informal as possible to take account of peoples pain, stress and anxiety-and should not be about ticking or filling in a pro forma. Nor should the claimant feel that they are on trial.

Question 12

And are there any circumstances in which it may be inappropriate to require a face-to-face meeting with a health care professional-either in an individuals own home or another location?

Yes-the following would be circumstances in which a face-to-face interview would be inappropriate. If someone is terminally ill or in hospital, or is unable to communicate for themselves.

Some religions don't allow women to speak to males for example.

It is not appropriate to interview a young child regarding a claim, this would have to be done by an adult responsible for their care.

Similarly, an adult with learning difficulties for example might either need to have an appropriate adult present to answer the questions and/or represent them.

Question 13

How should the reviews be carried out? For example what evidence and/or criteria should be used to set the frequency of reviews? And, should there be different types of review depending on the needs of the individual and their impairment/condition?

The terminally ill should not be re-assessed.

The claimant should be allowed to report if they are feeling better or worse, this is a matter of personal responsibility.

Reviews should be variable-someone who has a serious condition e.g. Multiple Sclerosis should not be reviewed unless they request it, but claimants with other conditions might be reviewed after a standard period, or again if they request it.

Extra consideration from those people living on their own with a disability.

Question 14

The system for personal Independence Payment (the new name for DLA the Government has proposed) will be easier for individuals to understand, so the Government expects people to be able to identify and report changes in their needs. How can the Government encourage people to report changes in circumstances?

Don't change the name of DLA as it is well known.

The claimant should be allowed to report if they are feeling better or worse, this is a matter of personal responsibility-a telephone help line should be free ,and easy to access in order to do this.

It should be recognised and acknowledged that some claimants would have difficulty in reporting a change in their circumstances-because of their condition e.g. bi-polar or other mental health conditions especially, but not exclusively. In such cases perhaps a box could be ticked on the application form asking if they wish to be sent a pro forma at intervals to help them to do this. **THERE SHOULD HOWEVER BE NO QUESTION OF PROSECUTION IF SOMEONE FAILS TO REPORT AN IMPROVEMENT BECAUSE OF THE ABOVE.**

Question 15

What types of advice and information are people applying for PIP likely to need

and would it be helpful to provide this as part of the benefit claiming process?

Yes, it would be helpful to have advice and information about the application process, this could include:- a leaflet with every application form, explaining the whole application process and saying how to contact a free help line who would say where to get advice, or give advice and help to fill the application form in

Questions 16

Could some form of requirement to access advice and support, where appropriate, help encourage 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?

A leaflet and application form should be available in all Gp surgeries Social Workers Departments Post Offices and noted on all communications from Government, e.g. at the end of a tax return form- Put on the such forms - do you need a DLA or other benefit application form? or include a leaflet about the benefit with the forms

THERE SHOULD BE NO REQUIREMENT OR COERSION to take or agree to a medical opinion on how to treat a claimants disability or other health condition as this infringes personal freedom, and the right to treat any health problems in the way an individual may choose.

Question 17

How do disabled people currently fund their aids and adaptations?

By grants from the Local Authority for housing adaptations

Social Services – Occupational Therapist provision

Motability

Hospital loan

Own savings

Charitable loans

Question 18

Should there be an option to use personal PIP (the new DLA) to meet a one off cost?

Yes, there should be provision for one off costs under the new PIP scheme for large expenditures e.g. requirement to move house, computers or a costly item to help with disability such as a mobility scooter, but not instead of or included as part of an award, it should be over and above any regular payments.

Question 19

The Government might also use the new assessment for children. What are the key difficulties the Government should take into account when assessing children?

It is not appropriate to interview a young child regarding a claim, this would have to be done by an adult responsible for their care.

Schooling – special needs children often have extra cost.e.g.aids at a mainstream school or the cost of special schooling e.g. transport to and from school for the child, but also for the family to visit if the school is residential.

Personal care supplies and needs e.g. nappies, rubber gloves, transport, relief care and special diets.

Question 20

How important or useful has DLA been at getting disabled people access to other

services or entitlements? Are there things the Government could do to improve the "passporting" arrangements? And 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?

PIP would be most important to disabled people as a gateway to other services and benefits:

- 1) High rates of mobility awards should equal a free bus pass and a Blue badge entitlement. Special consideration for a Blue Badge should be given to people living alone.

Higher award rates should equal automatic access to council tax discount.

These gateway benefits should be put on the DLA/PIPs information leaflet.

The above keep people mobile, independent and also help with mental health- it follows that without them people would become more dependent and isolated.

Question 21

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?

When a claimant applies for sickness type benefits information could be shared (but only with claimants agreement.) it could go towards a DLA application.

The reverse would also be true.

Question 22

What impact could the Government proposals have on the different equality groups (disability, age, ethnicity, gender, sexuality, and faith/religion) and what else should be considered in developing the policy?

A monetary award could help a disabled person to be ,and feel more integrated into the local community.

Help with the costs of schooling – special needs children often have extra costs.

eg.aids at a mainstream school or the cost of special schooling e.g. transport to and from school for the child-this could help integrate disabled children more into the educational process.

With face-to-face interviews there should be a choice of male or female interviewers for reasons of ethnicity and religion.

Cultural, religious and gender differences should also be taken into account to help alleviate the problems of minority groupings.

The forms should be in other languages and a translator should be provided where necessary.

Question 23

Is there anything else you would like to tell the Government about its plans?

An advocate should always be allowed to help with assessments and reviews etc.

No one should be coerced take medical treatment or advice etc this is an important issue with regards to personal freedom and erodes the individuals right to treat their condition in the way they feel best including the use of complimentary therapies.

PIP should not be administered by a Local Authority, but continue to be administered by Central Government and awarded on grounds of disability only, and not in any way means tested.

There should be three levels of award for both mobility and care. Keeping the different levels for care and mobility is essential-and adding to them by one level to the mobility component highly desirable.

DLA represents a real lifeline to many people-it is the difference between having self respect (or not) and between having a reasonable lifestyle and level of mental health rather than having to live on a very low income for long periods. It stops claimants being dependent on others and also on Government provided services.

This independence end would continue on the condition that a claimant would have the freedom to spend the money as they would choose-it treats people with the respect and dignity that they should have. It keeps costs to the authorities down especially with regards to mental health, as having a physical disability and all that that entails can easily cause mental ill health and breakdown. Extra stress can be caused from dealing with forms, hospital situations and the illness or disability in itself.

Allowing one off payments under the new PIP's scheme for items of large expenditure would help with financial stress and long term low income issues, but should not be instead of or included in an ongoing award. Receipts should be provided by a claimant after the purchase of the item in question.

A claimant in a care home should not be deprived of financial assistance to get out and about, as this is really important for the maintenance of mental health, and having a full and active lifestyle.

Plans already announced to remove the mobility component from residential care residents - when there is virtually NO overlap of funding by Social Services - condemns such severely disabled people to further exclusion from society and probably breaches their human rights.

The most wasteful (in terms of public funds) proposal by far is to greatly increase unnecessary DWP healthcare assessments.

The emphasis on these so-called "objective" assessments contradicts the Government's Personalisation Agenda, which encourages self-assessment.

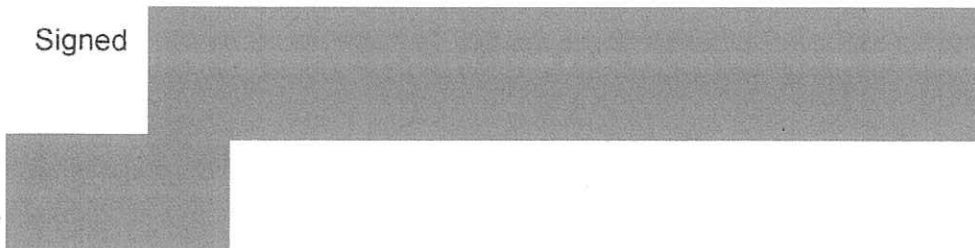
This consultation is (a) rushed and (b) short on examples and therefore clarity.

PIP's should continue after age 65 for everyone-this would save on the cost of changing to Attendance Allowance for example.

Applications and assessments for Pip's should not be processed by private companies, but instead continue to be administered by Central Government, and to take into consideration the claimants choice of supporting evidence.

Claimants of DLA who have been given lifelong awards should not have to be reviewed- there is good reason for the awards.

Signed

A large rectangular area of the document is redacted with a solid grey block, covering the signature and any associated text or date.

