

received 2/12/11

402



DLA Reform Team
1st Floor
Caxton House
Tothill Street
London
SW1H 9NA

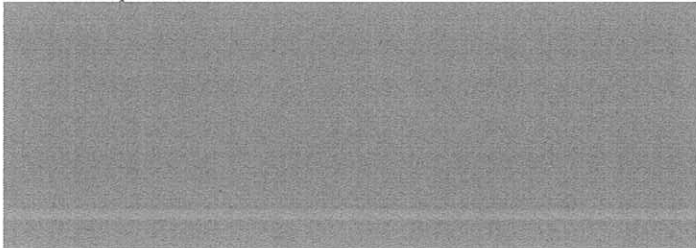
17 February 2011

Dear Team

Please find enclosed a copy of my response to the 2011 Consultation Document on DLA Reform. I have sent it by email today. I also sent a response on Monday 14 February, which was not finished. Please now discard that one, as this one answers the questions. I begin by going through the pages of the Document, and answer the Questions at the end.

I answer from the perspective of a Welfare Rights Advisor, a well trained volunteer, who represents clients at benefits appeals. I volunteer for Disability Rights Norfolk, from whom you will have received a response.

Yours sincerely





Feedback on Consultation Doc for PIP

17 February 2011

' Foreword 'allows people to work when they can and provides unconditional support to those who are unable to work" a non-means-tested cash benefit contributing to the extra costs incurred by disabled people'

paragraph 6 - if they want people to 'enjoy the advantages that an active working life can bring' the assessors need to understand the dangers of working for people with some conditions ie they must know the condition. And employers need to be willing (how come Seetec didn't want to give me a part time job unless it was min wage?)

Page 2, Purpose of the Consultation Document -PIP is to help 'people to remove the barriers they face to leading full and independent lives', but often the barriers come from other people, and disabled people get tired of fighting

Executive Summary

Page 3 no.3 - does the age limit take later retirement age into account, or do we all age at the same rate regardless of physical stresses?

page 3 no.5 - can we always know whether a condition is long term? Is 6 months long enough, and will there be annual reviews anyway? Most of the time people will need payment before they've been ill for a year.

Page 4 no.11 - sounds good. What information will be shared?

Page 5 - The need to reform Disability Living Allowance

Page 6 no.6 - to meet the additional costs arising from their impairment or health condition.. Who decides which costs these are?

page 6 no.8 - where does AA fit in now?

Page 10 no.19 -'There is evidence that people who receive DLA have lower work expectations. One reason for this appears to be that people fear they may have less money if they enter work.' What evidence? And they will have less money if they get IB/ESA too. The problem is people can't differentiate. And that employers are scared.

Page 11 no.4 (Our Approach to Reform) 'We are developing the new assessment in collaboration with a group of independent specialists in health, social care and disability, including disabled people.' DISCUSS!

Page 12 no.10 - mobility too? This also deals with my question above re retirement age.

Page 13 no.12 (a broader focus on disability) - does this mean one can be

penalised/rewarded for one's personality?

Page 13 no.13 - people's ability to budget will always vary, even within similar conditions.

Page 13 no.15 - expense? does that mean that if you are given aids to eg get to the toilet and use it, you may not have further personal expense?

Page 14 (question 4) - how does reducing the number of components help clients to understand them? I find that language is a problem. Few people know the difference between Motability and the Mobility Component, or between Carers Allowance and the Care Component.

Page 14 no.18 - so a temporary disability does not count? Disability incurs expense however short-lived.

Page 15 no.21 (question 5) - what about mobility? I've had clients in their 50s living in care homes (early onset Alzheimers) and they want to visit their children

Page 17 (Taking into Account Aids and Adaptions) no.27 - having a wheelchair is a responsibility: visits have to be made for maintenance, new cushions; it needs to be cleaned; flooring is restricted - carpet underlay is unsuitable, so the house is colder; housing restricts the type of chair - doorways, slopes; electric ones need charging daily - expensive; they chip paintwork

Page 17 no.28 - maybe people want more than the government will provide ie a better/sportier/colourful wheelchair, or they find some standard adaptations too ugly or institutional to live with. Will they be penalised for refusing them?

Page 17 no.29 - good, but assessors MUST listen to what the client says and allow them to change their mind - patience is required. Likewise, initial forms should be read properly. Would it not save money if Decision Makers were allocated a bit more time to consider applications thoroughly? Effects of disability on state of mind are important too.

Page 18 (question 9) no.30 - can anything be done about GPs charging for a letter of support, particularly when benefit is only payable after 6 months?

Page 19 no.33 'Circumstances' should not be related to perceived wealth of individual

Page 20 (Question 13) no.36 - this assumes willingness to comply.

Page 20 questions 14 & 15 - potentially invasive

Page 21 no.41 - being 65 is not a disability

Page 25 (A Passport to Other Support) no.4 - younger disabled people get cold too!

Page 25 no.7 (sharing information) - this may not always be in the applicant's favour, so all Departments' and agencies' assessments must be done properly or it isn't fair to interlink

Page 26 no.8 - Please see above. Also, please remember that staffing levels will be reduced in all care services, and corners may be cut unintentionally or simply through lack of time.

(Reassessing Existing Claimants 2.) Why is it to be working age people first? Surely that is irrelevant for this benefit.

Page 28 Religion/belief - what if someone refuses treatment on these grounds?

Disability - Regarding the impact of disability and not automatically assigning benefit for specific conditions, please bear in mind that the effects are well hidden by some people, and that costs and needs are similar whether or not the person appears to cope well.

Age - it can be cruel to be 'penalised' for having some money when a condition has struck in the 20s/30s and curtailed career progression.

Page 30 - Questions

1. Low expectations and self-esteem are sadly prevalent. Also, one can easily underestimate the effects of anger, and the effective bereavement caused by loss of or compromise to faculties.

Unfortunately, anything 'special' is prohibitively expensive, and difficult choices must be made, often by people least able to think clearly. Having said that, one barrier can be people making assumptions about what a disabled person can and cannot do/ does and does not want. The best thing is to ask them if possible.

2. DLA has a valuable function as an element of security.

3. They vary greatly, so the individual has to decide:

for some it is that to have a theatre seat where a care giver can come for free, and you can still see the whole stage, you have to buy the most expensive seats. One is free, yes, but the choice to buy two seats that add up to less than one at full price is not there; there is less and less free parking; taxis; prescriptions in England; food that is healthy but already prepared; equipment for sports, IT; driving adaptations; cleaning; equipment for blind/deaf people; clothing to accommodate disability; more frequent need to wash or replace clothes (not just incontinence but spillage)

4. I have given reasons why I don't think it will be easier to understand (see p 14). It will undoubtedly be easier to administer, and therefore cheaper, in that there will be fewer rules. Maybe levels of care are so complicated that two levels are not enough, just as two levels of mobility is a simplification. The danger of two rates is that borderline applicants are likely to be put on the lower rate as a matter of course.

5. Not all applicants have a firm diagnosis for various reasons eg neurological conditions are notoriously hard to diagnose. Their symptoms and accounts of them should be considered. Also, there are people who cannot accept that they will not get better, so a professional diagnosis can be all there is to go on.

6. Making judgements about what is essential, is for the individual to do.

7. Design questions that ask about repetition/stamina/fluctuation e.g. not just how far someone can walk with or without stops, but whether they could do that every day, or more than once a day, or at any time of day or night.

8. If the need is established, that's what should be taken into account. Adaptations can help, but don't remove the problem. If I have a wheelchair, I still cannot walk, and will develop arm/hand/neck problems. Wheelchair assessors say that once a person starts using an electric wheelchair all the time, they will start to lose function.

Prosthetic legs are notoriously problematic. Often pain caused to the stump means the

prosthesis cannot be used - but on paper the client has one.

Dialysis keeps you alive, but what quality of life is it when you feel ill for a day afterwards? Currently, if you go to the hospital unaccompanied, you don't qualify for DLA. Not fair when it could be 3 times a week, and people there with family or friends are getting some DLA.

9. The form may be easier if you followed the Inland Revenue model. The site often goes down, but the Self Assessment form has information boxes to click on by most questions, which is useful when they work. This could help applicants who cannot get an appointment with an advice agency but prefer to think about their answer rather than improvising in a telephone form fill.

Forms should be available in Braille, Moon, Makaton, various languages - whatever is needed.

10. Someone who knows them well - the GP doesn't see them at home, in fact home visits are rare. Good friends, occupational and physio therapists can be best, coupled with confirmation from the GP.

11. A benefit could be that the CLIENT has time to talk. Empathy is good, but not if the assessor's similar experience takes too much time or distracts from accurate statements.

A possible difficulty is that some people will not engage with anybody. That is the nature of their condition. A face-to-face discussion may not be feasible, and could cause anxiety all round. Similarly, a condition such as Aspergers is easily misunderstood. The applicant is likely to say they can do things that they actually get a lot of help with.

12. Reviews create great anxiety.

People with long-term conditions need long awards. Reviews should be infrequent, and maybe not at all if their condition is known only to get worse. A very simple check could be made infrequently to confirm they still have the condition, but the whole invasive questioning of the initial application is not always necessary.

13. If it will be easier, it will be very different so that one cannot make a comparison. There is a strong perception of the DWP as 'they' or 'them', not 'one of us'. Perhaps assessment and payment should be made by different bodies.

14. See question 9.

Also, what people often need is a general benefits check. DLA/PIP, as it is not income related, is rather different, and it is more a question of making the rules clear. Some people want to know whether it is worth applying, and of course an advisor cannot always tell, particularly over the phone. A very clear pamphlet may be useful. The facts about time limits for application and when payment might be made are essential. Also any passported benefits. Will all staff have the appropriate training for giving advice?

15. If it is available where they live and if extra time will be allowed for hard-pressed agencies to make appointments.

16. People currently spend their DLA as they need to. Social Services usually fund/provide aids and adaptation, maybe through a DFG (Disabled Facilities Grant). It isn't clear what you are proposing. If a 'one-off cost' payment would be in addition to regular payments it would be good - if not people could suffer. Also, the idea that somebody could apply for a one-off payment even if they do not receive PIP, is a good too. But does that

mean there is a move to close the usual channels?

17. they see themselves as 'the norm' when young. We have to make comparisons for them but listen.

18. Within the benefits system, not really unless you receive DLA - it is a benchmark against which need is assessed, so if you get it, you can get other premiums etc. High rate DLA qualifies you to apply for a Blue Badge. The main problem would be with Care: much hinges on an award of the Middle Rate e.g. Carers Allowance. Carers must not be abandoned, not only because they might give up (many people give up work to care and need some income) but because so many disabled people need them. The system as it is needs to be more generous to carers, and I am concerned that removing a middle rate could leave disabled people and their carers on the margins.

19. See above and 4. In addition, it means more forms to fill in. People do feel they are not believed if they have to prove their condition repeatedly, and revisiting the more painful aspects of their lives is disheartening.

20. -

21. Please see p 28 above.

LGBT applicants meet a good deal of bad attitudes, and this could make them guarded. They would have to talk about some very private issues.

22. -