

DLA Reform Team  
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9 February 2011

Dear Sirs

**DLA Reform – Public Consultation document dated December 2010 (Consultation Document)**

I respond as a parent to 2 adults, both of whom are disabled due to mental retardation and behaviour patterns associated with autism (ASD). One receives the higher Care and Mobility rate, the other the Middle Care rate and Lower Mobility rate.

This response is written with the incurable mentally handicapped (MH) in mind.

I am very pleased to see that those with the greatest need will be awarded the greatest support and that PIP will be paid only to those with a long term disability.

My biggest concern with the Consultation Document is that, apart from Annex 1, there is no mention of the MH. There are references to claimants completed forms, face to face discussions, aids and adaption's, leading full, active and independent lives, all of which could be relevant to the physically handicapped (PH), but not the MH. They cannot do these things, one of my children basically needs 24/7 personal care simply in order to exist. I sincerely hope that the new PIP will take due account of the MH.

Leading on from this, in the past I have always felt that the DLA Claim Form is designed with the PH in mind and is difficult to answer questions and get over the issues/problems the MH encounter/need support for. However it was good to see that the mobility component is to be defined as ability to get around independently not ability to walk.

Often the MH have incurable disabilities and are unemployable, thus without a wage their income is non-existent without benefits like DLA. Contributing to things like the household budget and meeting the additional needs created by their disabilities are important but not easy to put over in a form. Again I sincerely hope that this is taken into account with PIP, but I was encouraged to see the commitment to provide unconditional support to those unable to work, that it will continue to be a non-means tested benefit and support will be targeted at those disabled people who face the greatest challenges to leading independent lives.

I would question the need for those already granted permanent DLA to have to be re-assessed for PIP. I would also propose that that once a grant has been awarded, for those who have a permanent disability, there should not be a periodic review. Again that places additional burden on the parent/carer.

It is important that disabled people be free to spend the money in the way they want to and not have to account for expenditure. For the MH this would place yet another burden on the parent/carer in managing that.

My responses to some of the questions in Section 5 of the Consultation Document are detailed below.

Question No.

1. Being unable to speak, have no safety awareness, requiring 24 hour personal care, a lack of understanding by the public, not having the mental capacity, being unemployable, to name a few examples.

2. (a) The automatic passport to other benefits, (b) The Motability Scheme, (c) Not having to re apply/being subject to periodic review if a person has a permanent disability (i.e. situation is not going to change unlike where it could for example with a person having suffered a stroke, as per the example in section 17 of chapter 2.) One of my children cannot get around on his own, interact with others, manage personal care, buy food, prepare food (25 of chapter 2 refers) or plan a journey, make a journey on his own, understand and communicate with others (26 of chapter 2 refers) and never will be able to. Such disabled should not have to re apply/be subject to periodic reviews.

3. It is difficult to explain all the extra costs incurred by the disability – the fact that a disabled person may be unemployable means they do not have a wage but they need income to live – but is that “an extra cost”? In our situation my wife cannot work because of her carer responsibilities to our children – so she is also not bringing in a wage – again that places a financial burden on us – but is that an “extra cost”? In our case travel costs are definitely extra – that is why we find the Motability Scheme so good.

4. Seems reasonable that those facing the biggest hurdles be granted the higher benefit. This is very subjective so having 2 rates instead of 3 should make things easier.

5. Yes it should. Those whose disability is permanent should be granted automatic entitlement to PIP at the highest rates.

6. Grant a permanent award to those already on permanent award on DLA. 24/7 support to be able to live – feeding, dressing, bathing, toileting, transporting

7. It must be acknowledged that for some there will never be variable and fluctuating conditions – profoundly mentally handicapped will always need 24/7 support.

8. Access to the Motability scheme must stay. It is a great scheme.

9. Including questions that relate to the MH. Don't forget that in the majority of cases it will be the carer/parent of the MH that will have to complete the form on behalf the MH person – those will not be able to respond themselves. Yes the Form could be made easier. If a professional (such as a hospital consultant, educational psychologist) can verify a person's life long disability surely that should be sufficient evidence of a claimant's disability?

Regarding the content of the current form - one example relates to mobility. Naturally the PH encounter difficulties but it is more difficult to explain the mobility issues facing the MH. Often they can walk – however their mobility is actually very restricted because they cannot be anywhere on their own because of a lack of safety awareness or lack of intelligence to access their destination.

Rather than asking specific questions – ask the claimant to detail what help and support they need.

10. GP's/hospital/Social Services/support provider's reports/carer.
11. In my experience most profoundly MH would have no understanding or be able to participate in a face to face discussion.
12. There should not be periodic review for those severely MH whose disability is lifelong. The disabled and their parent/carers need to have the security of knowing they have funding in place and that it is not going to be removed or reduced.
13. The MH will not understand the system – that will be for the parent/carer to do. For those that can – impose fines/remove funding if they do not report changes.
- 14.
- 15.
16. I believe the disabled should be free to spend their benefit as they wish (or how their parent/carer feels is best for the claimant) and use the PIP for purchase of aids and adaption's as necessary.
- 17.
18. Extremely important and should not be removed. It removes a burden and thus eases strain on the parent/carer not to have to complete more forms/provide justifications in order to access other benefits.
19. Increase stress for the carer and increase the administrative burden. It would mean more time and effort for parent/carer of the MH in completing forms, answering questions.
- 20.
- 21.
22. Just to re-iterate my concerns that the needs and requirements of the MH should be considered and that such people rely of their parent/carer for support and cannot give their views themselves. Also repeated reviews for funding is both time consuming and stressful to parent/carer, hence our view that permanent awards be granted for those with obvious lifelong disabilities.

MH often cannot exercise choice and control over their lives – but it is imperative that they should not be penalised financially because of it.

Yours sincerely

