

Rec'd 31/1/11

088 Con. Res. W:

Formal Response to the DLA Consultation Questions

1. ***What are the problems or barriers that prevent disabled people participating in society and leading independent, full and active lives?*** My son has autism. The biggest barrier to him leading an independent life is that, since he cannot understand the unwritten rules of our society he needs to have someone with him at all times in case something goes wrong. He will not understand what has gone wrong or why and cannot formulate an alternative plan to deal with the unexpected. He still has tantrums like a 2 year old when he gets frustrated or confused. As he is 16, nearly 6 foot tall and 11 stone, this is dangerous and frightening for all witnessing it and for him. When buying adaptations, anything with the word 'disabled' attached to it is usually at least three times as expensive as it would be normally. Everything costs more when you have a disability – from having to boil wash and tumble dry laundry because your asthma is so bad you need to kill the dust mites and then cannot hang the washing outside to dry because it will collect air borne pollen and dust, to buying adaptations to be able to lead as fulfilling a life as possible.
2. .
3. ***What are the main extra costs that disabled people face?*** As mentioned above, everything costs more – you need to pay for an extra long stay in the most expensive car parks because they are the ones closest to the shops and it takes you longer to get about; electricity bills are higher as you need to keep the house clean - extra vacuuming, laundry needs to be done more frequently and at higher temperature, tumble dryers need to be used more often; mobility aids are expensive; adaptations to the home; companions; staying at home more because you cannot get out to work; convenience meals because cooking is difficult. Until it happens to you, it is difficult to imagine how the little extras add up and become a significant money problem.
4. ***Two components of PIP:*** The problem I face with filling in the DLA and I see no reason why the PIP will be any different is that it seems to concentrate on physical disabilities, both severe and those that come with age e.g. arthritis. My son can make a cup of tea – if everything is there, but cannot cope if the milk is off or there is no milk or tea bags – or it is loose tea instead of bags or there is a power cut. These sorts of issues are just as disabling as not being able to walk in their own way and it is very difficult to capture these disabling factors on the current DLA form. There is too much emphasis on personal care – can you go to the toilet unaided? While these are very important issues, disability in today's society is a much wider issue.
5. .
6. .
7. .
8. ***Should the assessment take into account any aids and adaptations they use?*** I was under the impression that DLA was to help you buy the aids and adaptations you need so they shouldn't be taken into account when assessing ability, you should be assessing peoples abilities without any additional help, then assess what aids and adaptations they need and how this will affect how much help they need to finance the purchase and upkeep of such aids and adaptations.
9. .

10. **Whose is best placed to provide clear assessment of ability?** Parents and carers; work colleagues; school teachers i.e. people who they spend their days and nights with should be asked and their input should be given as much weight as the medical professionals involved.
11. **Face-to-face discussions with health care professionals.** Many disabled people do not have regular contact with health care professionals – you have a very limited view of disabled people if you think that they do – and so these discussions would seem to be a waste of time, money and resources for many people. Also in my own situation, my son will not talk to his regular doctor and so it is very unlikely he would co-operate with an unknown one. He has autism – and people with autism cannot take part in such discussions, they do not have the mental ability to reflect, or the social ability to take part in such a discussion, even if they wanted to. They would not understand why they were being asked to take part in such a stressful situation.
12. .
13. .
14. .
15. .
16. .
17. **Assessing children:** Help parents understand that they can claim the benefit and trust them to know their children best. Professionals need to help tease out the relevant details.
18. .
19. .
20. .
21. **Considerations in developing the policy?** Talk to the Carers. We save you a lot of money, and have a lot of knowledge and experience no other group of professionals have. WE are also the ones who pick up the pieces when it all goes wrong. Link up disability policies etc with Carers' policies. Remember that you now have a legal obligation under the Autism Act 2009 to those on the spectrum, not just to the more traditionally disabled.
22. **Anything else?** I am very concerned about the idea of removing mobility allowance for those who live in residential care. A lot of people with autism and learning difficulties do live in residential care homes or supported living but are able to be quite active in their community this seems to be a backwards step in helping them to lead fulfilling lives – having jobs and taking part in leisure activities especially as they quite often need a companion with them to keep them safe and may be unable to use public transport because of the stress involved. It seems at odds with current Governmental thinking on enabling those with a disability to take as full a part in our society as they can. Many people with disabilities contribute to The Big Society by working for little or no pay or in a variety of charities especially Charity Shops and they will be unable to do this without the mobility portion of DLA helping to pay for their additional costs. This will become exaggerated with many Councils, including my own (a Conservative run one) cutting subsidies for public transport, and indeed many bus routes that disabled people rely on.

