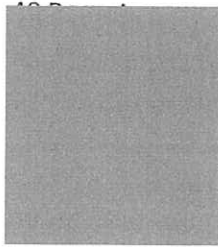


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DLA Reform Team

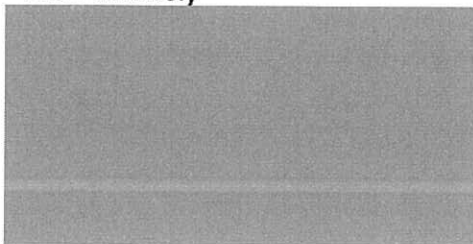
1st Floor
Caxton House
Tothill Street
London
SW1H 9NA

February 8th 2011

Dear Sir

I am enclosing my response to the consultation on the reform of DLA. I am the mother of an adult son with severe learning disability. My responses also reflect my experience over many years of working as a volunteer with local disabled children's charities and my current experience as a member of the local Learning Disability Partnership Board and as a trustee of two national disability charities.

Yours sincerely



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

The attitudes of society, although changing, still present significant barriers to most disabled people. People with physical disabilities will continue to find the built environment a major barrier for a long time to come. Low, disposable income is a barrier to participation for many disabled people.

2. Is there anything else about Disability Living Allowance (DLA) that should stay the same?

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

Extra costs relating to care/support and mobility are already acknowledged. A major expense for many disabled people - those with both physical and learning disability - is excessive wear and tear on clothing, household goods and, in many cases, on the fabric of their home. Many also have additional expenses relating to specialist or extra equipment and fuel bills. Many learning disabled people do not understand the value of money or are unable to budget; this inevitably leads to increased costs.

4. The new benefit will have two rates for each component:

- Will having two rates per component make the benefit easier to understand and administer, while ensuring appropriate levels of support?

Agree that 2 levels will make the benefit easier to understand and administer; appropriate levels of support is a much more complex issue. The benefit rightly, covers people with a very wide range and variety of needs. For those with the greatest needs it usually forms part of a bigger package of support. For the more able it might be the only extra support that they get.

- What, if any, disadvantages or problems could having two rates per component cause?

If the assessment process is genuinely going to form part of a wider assessment of the support needs of the disabled person then there may be sufficient scope for flexibility, but with only two rates there is a danger of people being 'pigeon-holed'. There may be less incentive for people to work towards achieving greater independence if the outcome is that they lose the benefit altogether.

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?

I agree with the principle that all claims should be based on the needs and circumstances of the individual applying. However the point at which many significant disabilities become apparent is often at birth or in the first couple of years of life. At this point parents are often in shock and struggling to come to terms with their child's disability. I think it would be appropriate to award DLA to severely disabled children on the say-so of the paediatrician or consultant involved, rather than the parents, who might be in denial, having to go through the application process.

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

Those least able should be known to Social and/or Health Services and be currently receiving the higher or middle rate care component.

Most essential activities include personal care - toileting, washing, dressing; food preparation, shopping, managing money, maintaining a home (eg laundry, cleaning), managing medication, being safe inside and outside the home, being able to access and move around the community. So, to remove the mobility component from people living in residential provision, as is proposed, will have a devastating impact on their ability to access the wider community. There is no chance, in current circumstances, that funding local authorities will replace that money.

7. How can we best ensure that the new assessment appropriately takes account of variable and fluctuating conditions?

If a person's condition varies from day to day, the assessment must take account of the worst situation. If a person's condition varies over time, this should be taken account of by periodic re-assessment. If a person's condition is such that change is unlikely, then they should be required to confirm, at intervals, that their condition has not significantly changed, and otherwise only be re-assessed at transition (18?).

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?

The assessment should take account of aids and adaptations that a disabled person uses, in the context of their ability to use them and their safety. The assessment could take into account aids and adaptations that might support greater independence in the context of a wider assessment of support needs. The person's ability to fund aids and adaptations should be taken into account and funding provided from some public source.

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?

I have no suggestions for making it a more positive experience - all I know is that almost everyone finds completing the form a very negative experience. I hope others have some ideas! See also response to question 5.

- 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?

Health and Social Care professionals have an important role here. I am aware of families with a severely disabled child who have not learned of DLA until their child is a teenager. This is particularly true of families from minority communities. An advertising campaign making it clear that DLA is an entitlement for disabled people that will not affect their other benefits might be a good idea.

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

GPs should be able to give relevant medical information but will probably not know most people well enough to know how their disability affects their life. The appropriate supporting evidence will come from a wide variety of sources and vary from person to person. In the case of children it is most likely to be the parent. Some adults will be able to provide supporting evidence themselves but many will not. There shouldn't be restrictions on who can provide supporting evidence.

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?

Children and many adults with learning disability may find this difficult. Some would find talking to a stranger difficult or impossible. (People on the autistic spectrum?) Others would not understand the questions or the context of the questions. (My own adult son would probably answer 'yes' to every question asked).

- 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?

There are many people who currently receive DLA for whom it must be very obvious that the benefit should continue. I do not see that there is anything to be gained from reviewing their entitlement. On the other hand it might cause anxiety to them and/or their carers. It would also be a waste of public money.

12. How should the reviews be carried out? For example:

- What evidence and/or criteria should be used to set the frequency of reviews?

Some people have clearly identified life-long disabilities. Where this is identified as having a significant, on-going impact on their ability to lead a normal life reviews should only be necessary if their condition or situation changes, probably for the worse.

- Should there be different types of review depending on the needs of the individual and their impairment/condition?

A review of DLA for someone with a life-long impairment should only be by letter asking for confirmation that there has been no significant change.

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?

Maybe a periodic letter asking for confirmation that there have been no significant changes could be sent out.

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?

Many people do not access their full benefit entitlement because of the complexity of the benefits system and/or the lack of competent advice. Many adults are currently experiencing significant cuts in the support they receive from Adult Social Care. A positive, supportive review of all the support received would be helpful; anything less would not be.

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?

16. How do disabled people currently fund their aids and adaptations? Should there be an option to use Personal Independence Payment to meet a one-off cost?

Most aids and adaptations should be available as a right. I think it is scandalous that, in a wealthy, developed country, disabled people have to fund-raise to get basic necessities such as powered wheelchairs. Delays in accessing aids and adaptations supplied from health and/or social care authorities is also an issue.

17. What are the key differences that we should take into account when assessing children?

The point at which many significant disabilities become apparent is often at birth or in the first couple of years of life. At this point parents are often in shock and struggling to come to terms with their child's disability. I think it would be appropriate to award DLA to severely disabled children on the say-so of the paediatrician or consultant involved, rather than the parents, who might be in denial, having to go through the application process.

Babies and young children, whether disabled or not, are dependent upon adults so different criteria need to be in place. The impact on families of the arrival of a disabled child can be severe, and needs to be recognised. Many families break up under the strain. The criteria need to acknowledge the role of the family.

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?

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?

This would cause duplication of assessments, more bureaucracy and, probably confusion for disabled people.

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?

This is a difficult question. Sharing information, on the face of it, speeds things up and saves duplication. If this is to happen, it will have to be seen as secure and done with individual consent.

21. What impact could our proposals have on the different equality groups (our initial assessment of which is on page 28) and what else should be considered in developing the policy?

In my experience people from minority communities are less likely to be in receipt of DLA because of lack of information and/or cultural attitudes to disability. The benefit needs to be well advertised within those communities.

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

I am very concerned at the possible impact of removing the benefit from vulnerable and isolated people who live independently. I am thinking particularly of those with moderate learning disability and/or mental health problems. It is vital that benefit is not removed without a thorough review of their circumstances and level of support.