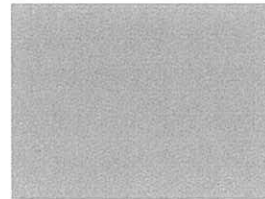


Rec'd

4/2/11



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

Dear Sir/Madam,

**Response to DLA Consultation Exercise**

I do not disagree with the concept that it is time to reconsider DLA – especially because of the dramatic increase in the number of people claiming the benefit and the huge cost of funding the scheme. With resources being limited it is important that available resources are targeted towards the people with the greatest need.

I am disabled as a result of having suffered from Multiple Sclerosis (MS) for nearly 20 years. MS is a variable condition and people can suffer a whole range of different symptoms and I am not sure that all neurologists/medical practitioners fully understand the effects of this condition – let alone non-professional staff that operate a rigid tick box system which will determine whether or not an applicant qualifies for financial support. This is my central concern regarding the mooted changes for reassessing applicants for this new benefit.

**Specifically, my responses to the 22 questions are as follows:**

1. There are 2 main barriers – physical and attitudinal. The physical barriers are fairly obvious and transport features very strongly. People with physical/mobility disabilities can have great difficulty getting out of their home. They may be dependent upon using a wheelchair and if they do not have their own transport would be reliant upon public transport. In many parts of the country local buses are not accessible to disabled people and the same applies to many taxis. Local dial-a-ride schemes can be helpful but there are usually a number of restrictions on the times when they operate, the journeys they can undertake and they are quite expensive. They do not operate in all areas.  
Attitudinal issues can have a very negative impact on the lives of people with disabilities – especially with people who have learning difficulties. It should not be assumed that the Equalities Act has put a stop to unlawful discrimination!
2. DLA should remain as a non-means tested allowance which is paid to people who have significant and a chronic disability. The whole purpose of the allowance should remain as a means to ensure that disabled people can live as independently as possible. It is a recognition that living with a disability is much more expensive than life for able-bodied people. With a disability your choices are often limited and if you want something you will very likely have to pay more. For these reasons I think that it is very unfair to contemplate removing the benefit for those people who live in care homes. This is not the same as being in

hospital. The proposal to remove DLA has the potential of destroying the right to live as independently as possible (see para 6 for more detail).

3.
  - a) Transport – inability to use free public transport, the cost of hiring a taxi, the cost of having to use a larger car which is capable of carrying an electric wheelchair, the extra cost of vehicle conversions, the cost of purchasing mobility equipment – wheelchairs, electric scooters, rollators etc – the cost of insuring this equipment and maintenance costs.
  - b) Carer's costs – the extra cost of paying for a carer's travelling and hotel costs – their wages if the carer is not a volunteer.
  - c) Laundry costs – a disabled person may have incontinence issues to consider.
  - d) A disabled person will be more dependent on their partner and this will have an effect on the living expenses of the couple. For example – prior to my disability I would do routine maintenance jobs in the house. I am now completely dependent upon my wife. I cannot even change a light bulb because that requires standing on a stool or step ladder. There are many situations when I have to employ a professional person to do a simple job that my disability prevents me from doing.
  - e) Treatment for my disability. My condition requires me to undergo weekly physiotherapy. This is not available under the NHS. I have travelling costs + the cost of this treatment. There are also opportunity costs when my wife has to accompany me to these sessions. She chooses not to work so that she can care for me. My condition is unpredictable. On some days it is more debilitating and I need more assistance.
  - f) The huge cost of home adaptations. I have recently had to adapt my home and garden to cater for my disabilities. This was extremely costly. I now live downstairs. I had to have an extension built to provide a downstairs bedroom and bathroom. All the doors had to be widened. The entrances had to be low-threshold. Steps had to be replaced with ramps.
  - g) Purchase of disability aids. Disability aids can improve the lifestyle of people with disabilities but these can be costly because they are manufactured for a relatively small market. The price of simple items can be extraordinarily high.
4. I have no firm opinion on whether or not to reduce from 3 levels to just 2. If this will simplify the procedure then I am happy to see the abandonment of the lower level.
5. Automatic entitlement seems a little arbitrary. I am very much in favour of looking at each case on its merits. I am very much against a tick box culture. There is a big danger that if you do not ask the right questions you will not get the right answers – especially if the person making the decision on the application does not have a full professional knowledge of the condition in question. Anecdotal evidence from disabled people suggests strongly that recent decisions on disability benefit have been very unfairly decided on a tick box culture.
6. It is a fact of life that money can, to a large extent, minimise some of the debilitating and limiting effects of disability. The converse is true. Poor people bear the full brunt of the effects of disability and life can be very harsh as a consequence. A disabled person may be dependent upon either their partner or a carer to help them out of bed, to get washed, to get dressed and to help them prepare meals and eat. Without some support people with disabilities may be forced into 24 hour care homes prematurely. Sometimes only a minimal amount of support will prevent that person becoming a much greater expense on society. Aside from this very basic level of care help is often needed to allow a disabled person to get out of their home and interact with society in general. In many cases disabled people will not have access to public transport, notwithstanding the fact that buses theoretically offer free travel. Instead, they will be dependent upon

private adapted transport and if this cannot be afforded then the person could be a prisoner in their own home! In summary, it will be essential to determine whether a person can perform the basic functions of living in their own home and whether they have the capability of getting out of their homes and meeting other people in society. **I am very much against the proposal to suspend benefit if a person is in a care home. I think it is a mistake to assume that being in a care home is the same as being in hospital. They are totally different situations. It is probably fair and reasonable to suspend DLA entitlement while a person is in hospital because that person is receiving professional care in exactly the same way as a person who is able-bodied. However, the situation is different in a care home. The resident should still be able to expect to lead a reasonably normal life and to be able to enjoy going out and mixing with people in society – whether in the home or outside. They will need to purchase mobility aids to make their life easier. It should not be assumed that these will be supplied by the care home. They still have the right to make their own decisions about how to live independently.**

7. Mistakes in assessment will be much more likely if assessors are not properly qualified or if they have not received adequate training. This is especially the case with variable and fluctuating medical conditions like MS. When tick box questions are used there has to be a box for general comments outside of the specific questions asked. Consultations should be made with various societies which represent people with certain significant medical conditions – such as MS or cerebral palsy.
8. This is a hugely problematical area. There are all sorts of misconceptions about what may or may not be available on the NHS. This problem is exacerbated by the post code lottery of where you live. In some localities there may be no problem in getting a manual NHS wheelchair – in other areas the waiting list and other obstacles may mean that patients have to purchase their own chairs. Many disabled people prefer to buy their own because of the bureaucracy, waiting time and limited choice that is available within the NHS. Wheelchairs are often either too heavy to transport or have other design limitations. Most mobility aids are very expensive and it is a lottery if you can get such devices funded by the NHS. I know of one person who took over 2 years to persuade the Health Authority to fund a £6000 wheelchair. 'Never again', was her concluding view. It was not worth the stress and aggravation.

There is a suggestion in the consultation leaflet that where someone has already had the foresight to privately fund an aid to their disability that this should be held against them in their application for DLA. Such a proposition would be manifestly unfair. If a person has reduced the effects of their disability by privately purchasing a mobility aid then it is right and proper that this should be considered in a DLA application but any reduction of benefit should be compensated with a return of monies equal to the cost of purchasing and maintaining the device in question. It would be wrong to assume that such a person is not in need of financial assistance because they have already bought the product. The purchase may have been made as a result of a loan or from extending a mortgage or by suffering financial hardship as a consequence of this extra expense. From a practical point of view it may be easier to disregard private purchases of mobility equipment. This is especially the case when someone has converted their home to adapt for their disability. **Is the State going to punish those who have had the foresight to try to make their lives easier before they become more disabled?**

9. There is a view that the current form has duplicated questions. Whether or not this is done to reduce fraud is perhaps debatable. I have a feeling that if people are going to be dishonest they will do so irrespective of whether duplicated questions are asked. Unfortunately, there are no simple answers to these problems and ultimately it will require some independent evidence from a properly qualified and experienced adjudicator. It should surely be possible to devise a system that is capable of checking whether or not the claim is valid? The forms should be written in plain English, or other languages, giving the applicant the opportunity to expand on their answer – especially where a tick box system is used.
10. There is a danger that supporting evidence from the patient's doctor or consultant could compromise the doctor/patient relationship. However, it will be necessary to confirm that a person has a given medical condition. The effects of that condition on a person's lifestyle will need to be verified by an independent professional – possibly a doctor/physiotherapist or occupational therapist – all of whom will need additional training.
11. This is obviously necessary and beneficial with the proviso that the professional person has knowledge and understanding of the relevant condition. It should not be automatically assumed that just because the person is a doctor that they will have an understanding of all illnesses. I have met many doctors who don't really have sufficient knowledge about MS! If there is the slightest doubt about the veracity of a person's application then a face to face interview will be essential. If a person is unable to attend an 'assessment interview' then that person should be seen at their home. There may be advantages in doing this because it may help to verify the legitimacy of the claim – especially where expensive adaptations have been made to make life easier for the person in question.
12. Each case needs to be reviewed on its merits. If a person has a chronic condition for many years it is highly unlikely that they will get better or improve – in reality there are very, very few cases where Lazarus arises from his bed! I say this from the recent experience of a colleague who was severely disabled as a result of having suffered from MS for a number of years – steadily getting worse all the time. At a recent assessment she was seen by a medical professional and the concluding report was that she was showing improvement and in his view would be able to go back to work in about 18 months' time. This comment was totally inaccurate, defying both logic and medical knowledge. The evaluator obviously had little or no knowledge of MS. However, there are clearly many medical conditions where it is logical and reasonable to expect some improvement and these will need to be reviewed on a reasonably regular basis.
13. Claimants should be divided into 2 categories – those whose conditions could improve and those which will not. By doing this, more resources could be allocated towards the former category and it may be possible to liaise directly with the NHS in order to check whether or not a patient was responding to treatment.
14. I can only really speak for my situation. I attend an MS Therapy Centre once a week. I pay to attend this Centre. I also belong to the MS Resource Centre Charity and receive a bi-monthly magazine. The combination of these 2 charities plus researching my illness on the Internet provides me with a wealth of information about how to best manage my condition. I do not expect the Government to help me any more with information about my condition. I am grateful for the financial support and independence that DLA gives to me.
15. I think that it may be difficult for people who have unusual and rare conditions to get the support that they probably deserve. They will not have large national charities to refer to and they will also have the added problem of trying to

- convince the administrators of DLA that they have a genuine debilitating condition. I think that in these situations I would hope that the person's doctor or consultant could give the necessary advice and make them aware of DLA.
16. I am very fortunate in that my disability came late in my working life. I have the cushioning of a good occupational pension. However, many of my colleagues are in much less fortunate positions and some are bordering on the poverty line. Without DLA their independence and living standards will be severely compromised. Adaptations to the home are probably the single most costly items of expense followed closely by the need for mobility aids, private transport, vehicle conversions, electric wheelchairs and scooters. Motability schemes are a great help to many people with disabilities because a single costly expense is deferred over 3 years using the mobility component of DLA. It could be beneficial to have a similar scheme in place in relation to DLA care payments.
  17. I have no knowledge of this area.
  18. Aside from my Blue Badge I do not claim for any other entitlements.
  19. I would have to go through a more detailed assessment to get my Blue Badge every 3 years. Furthermore, currently my adapted motor car is eligible to be taxed as a disabled vehicle. This in turn provides certain exemptions for car parking and toll charges.
  20. There are probably some assessment issues common to both DLA and the capacity to work. However, it would be wrong to assume that a person who qualifies for DLA would be incapable of work.
  21. No comment.
  22. The devil will be in the detail. The success or otherwise of this new scheme will be dependent upon whether or not fair, objective tests can be devised to legitimate claimants from the sizeable minority who are abusing the system. There will also be dangers that incorrect assumptions will be made about disabled people's entitlement to services and benefits. For many genuinely disabled people the necessary disability equipment, such as electric wheelchairs, is not available and they have to be privately funded. Furthermore, disabled people do not necessarily claim many benefits to which they have an entitlement.

This reply represents my own views on the matter. However, I believe that my views are representative of many disabled people, especially those who suffer from MS. I have regular contact with disabled people both from an MS Resource Group that I attend and from having worked on a local access group for the last 11 years. I sincerely hope that the Government will take notice of the views of disabled people and that meaningful consultation is applied.

Yours sincerely,

