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T: [Redacted]

E: [Redacted]

DLA Reform Team  
1<sup>st</sup> Floor, Caxton House  
Tothill Street  
LONDON  
SW1H 9NA

23 December 2010

Dear Sir/Madam

Please find enclosed my considered response to your consultation document.

I am very interested in contributing to the development of DLA Reform and I have my own strongly held ideas about how disabled people should be supported. If there are any opportunities to become involved in focus groups or other types of consultation then I would like to be given the chance to contribute my views.

I am disabled and have been in receipt of DLA continuously since 1998. I use a wheelchair and, until recently, I was employed on a full-time basis by a central government agency.

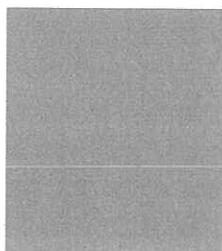
Thank you for this opportunity to submit my views.

Yours Faithfully

[Redacted signature block containing three lines of blacked-out text]

## Disability Living Allowance (DLA) Reform consultation response

**Respondent:**



**23 December 2010**

### **Question 1:**

There is still a huge amount of work to do before our physical environment is accessible to all on an equal basis. Not all trains and buses have space for wheelchair-users. Where there are accessible buses, with the exception of London, it is by no means certain that a particular bus service at a specific time will be accessible, so it is still difficult to travel independently if one uses a wheelchair.

Attitudinal barriers prevent the full inclusion of disabled people in society. Despite the fact that 10 years have passed since accessible buses were first introduced, many bus drivers still refuse to operate equipment fitted to the vehicle and humiliate disabled passengers, especially wheelchair-users, who insist on their rights. Disability hate incidents are the daily experience of disabled people and this makes many fearful of venturing out.

Disabled people who work face a woeful lack of understanding from employers about the need for reasonable adjustments, often delaying their introduction until the next financial cycle or objecting to their introduction for health and safety reasons until it becomes impossible for the disabled employee to do their job and they are forced to resign. This has happened to me. Access To Work is far too slow to respond to changes in disabled workers' job roles and the expectations that people generally have about the capabilities of disabled workers is so low that this affects the self-confidence of disabled people and limits the extent of their employability even further.

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### Question 3:

Transport costs because of unreliable or discriminatory public transport policies and practices or the need to hire a taxi or employ a driver. Medical equipment costs because the NHS refuses to contribute to clinical elements of a person's Social Services assessment. Nursing costs because District Nurses refuse to treat patients who receive a social care direct payment or personal budget (this has happened to me and my immediate neighbour). Incontinence aids because the NHS refuses to supply certain types of incontinence product. Additional laundry costs because of incontinence. Additional diet-related costs due to allergies, clinically necessary food restrictions. Employment costs for a personal assistant (PA) or home help to deal with domestic chores, shopping etc. Assistive technology to prevent or reduce the need to employ a PA.

### Question 4:

There should be a "minimum income guarantee" for every citizen, regardless of age, but with an expectation that those of working age should be employed and therefore earn more than the minimum. The specific rates could contain a disability element and grants could be made available in addition to this minimum to cover the purchase and maintenance of specified items of equipment such as an electric wheelchair.

A disadvantage of having two rates is that it could stigmatise either group. People who qualify for the higher rate might not claim it for fear they would lose their current award.

### Question 5:

All claims should be dealt with equally and there should be no automatic entitlements. However, there should be a "fast track" process for severely disabled and terminally ill people, as well as people who are reapplying without a change in circumstances (if confirmed by their GP).

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### Question 6:

By integrating PIP with other funding sources, such as a Social Services direct payments or personal budget. Aim to have entitlement linked to a Person Centred Plan (PCP), which expresses the disabled person's views and choices about how they want to live their life.

Activities essential to everyday life should be defined relatively broadly and include bathing, dressing, eating and drinking, working, playing, family life and being a private individual. A holistic view of the person's life should guide the assessment but PIP should not necessarily be used to fund every activity if these are being met or should be met by other public sources on a contractual or statutory basis.

### Question 7:

Entitlement should not be based upon a "snapshot" medical examination but include a comprehensive assessment of ability based upon talking to the claimant about the way they live their life and what they would like to change for the better or need more help to do.

### Question 8:

**SHORT ANSWER:** No, an assessment of someone's ability should not take into account any aids and adaptations they use. However, a person's need for aids and adaptations should be taken into account when determining the **level** of benefit awarded. This is because there are costs associated with their initial purchase and ongoing maintenance which are additional to those incurred by able-bodied people. Awards should disregard a person's need for aids and adaptations only where the equipment has been (or should be) provided and maintained by other public agencies (e.g. the NHS) as part of a contractual or statutory obligation.

**BACKGROUND:** I use an electric wheelchair, which was initially bought with DLA and is now maintained using my DLA. I needed to buy an electric

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wheelchair because, although assessed as needing one by the NHS, I am a low priority. This is because the NHS wheelchair service operates on a medical model, with wheelchairs prescribed on the basis of clinical need alone. The NHS takes no account of the family circumstances of wheelchair-users (I live alone and have to employ someone to push me around when my electric wheelchair is unavailable) or the social value of getting out and about.

The prescription of wheelchairs by the NHS is therefore out of step with the social model of disability, which underpins DLA/PIP. If the NHS were to buy and maintain electric wheelchairs for everyone who needs one for social, employment or other non-clinical purposes then this would involve a tremendous cost which would dwarf the amount of money saved by removing the element of choice that existing DLA recipients have in deciding how best to address their mobility problems.

Some choose to use their DLA mobility component on taxis; some on a railcard for a companion; some on a wheelchair or electric scooter, and others hand the money over to Motability and receive an adapted or converted vehicle. Following the logic in the consultation document, it could be argued that the availability of taxis, trains and cars could be used as a reason for removing the DLA mobility component altogether! The purpose of DLA is to meet the **additional** costs that disabled people face when getting out and about. In my view, ***the decision about how best to use DLA to help one get out and about should be left with the individual citizen and there should be no prejudice shown against any particular choice.***

For people, like myself, who are unable to use a self-propelled wheelchair, the purchase and maintenance of an electric wheelchair is the best way to overcome the difficulties that impaired mobility creates in getting out and about.

There are other pieces of equipment that indirectly provide savings for the public purse overall. For example, I have an electrically adjustable bed. This prevents the need for two people to get me in and out of bed. With the assistance provided by the bed, I can make do with only one helper. However, there is a real danger that a perverse incentive will be created, whereby disabled people dispose of or refuse to purchase equipment because they fear a loss of income. ***This will only shift costs to elsewhere in the public sector.*** Using the example of my bed; if I were to get rid of it in order to maintain my

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level of income, then I would have to ask the Council to reassess my personal budget because two people would then have to help me in and out of bed. There may well also be a need, from a health and safety point of view, for a hoist to be fitted, which would also have to be paid for by the Council.

Furthermore, even if people decide to use their own money to buy equipment, **there is a huge premium on disability-related products and incredible rates of depreciation.** It is not unusual for an electric wheelchair to lose up to 20% of its value in the first year and insurers will not cover wheelchairs that are over six years old. Therefore, a wheelchair-user needs to replace their wheelchair on a maximum 6-year cycle. The market for disability products is not very big and this means that purchase prices are high. Irresponsible procurement procedures by the NHS and Councils has also artificially inflated prices for disabled shoppers. **Until there is a degree of equalisation between disability related products and similar products for the general population, there will be a need to help disabled people buy assistive equipment.** This has started to happen with electric scooters but, unlike wheelchairs, these are not medical devices.

Many aids and adaptations require maintenance and, eventually, renewal. Failing to recognise this fact of life in the benefits system will eventually lead to disabled people using faulty, poorly maintained equipment that is a danger to themselves and others. One consequence of this is that they will be denied access to buses and trains (secondary legislation requires such devices to be kept in safe working order). Disabled people should continue to have access to sufficient funds to keep their equipment in a safe and serviceable condition. This is even more important now that so many of us employ our own staff using a personal budget. Any accident causing harm to an employee would be the responsibility of the disabled employer and prosecution could follow.

There is no legal obligation for registered social landlords (RSL) to provide aids and adaptations, although most do. At present, disabled tenants can often make an arrangement to share the cost of adaptations, with the tenant using DLA as their contribution. However, with increasing financial pressure, RSL may refuse to subsidise the cost of making changes such as fitting paddle type taps, adapting a kitchen or removing a bath to create a wet room. Without access to alternative resources, many disabled people will continue to have their needs unmet in this regard. Once again, the Council may need to step in

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to ensure these adaptations are provided in order to safeguard the disabled person.

If the provision and maintenance of aids and adaptations around the home were to be made a statutory obligation of RSLs (and all other landlords) towards their disabled tenants, then I would not object to receiving a lower rate of DLA/PIP.

### **Question 10:**

Testimony of a PA. Submitting a video diary showing how the person gets out and about, including any barriers they face. Accepting other assessment documents, including a recent PCP.

### **Question 11:**

The healthcare professional may not be truly independent, which is essential for public confidence. People with chronic conditions which do not change for many years should be fast-tracked without the need for an interview, unless they want to have one, as long as their GP supports this choice and confirms that there has been no notifiable change of circumstances.

### **Question 12:**

One of the most distressing things for people with chronic, progressive and/or incurable conditions is to be called in for regular medical reviews. In my view, it is important to establish at the start of each claim what the general prognosis is. GPs should be given an enhanced role here because people generally feel more comfortable going to see their GP than someone they do not know. In my experience DWP doctors are not always truly independent and I have personal experience of one such doctor falsifying my responses during an assessment. Following my complaint, that doctor resigned but the point is that there must be a better way of treating all claimants fairly but, at the same time, ensuring that claimant fraud is minimised or even eliminated entirely. It is in everyone's interest to ensure that the system is fair and works as it is meant to.

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There are special rules for terminally ill people but one of the cruellest parts of the existing system is that people, like myself, with chronic pain conditions are often treated very poorly. To be blunt, although someone with terminal cancer will likely endure severe pain, their suffering will be ended by an early death. For those of us with chronic, incurable pain conditions (in my case fibromyalgia) we have to endure levels of pain similar to some cancers but for decades rather than a few weeks or months.

Against this background, establishing a likely prognosis for 1, 2, 5 or 10 years ahead at the start of a claim will help to ensure that reviews are done at an appropriate time and in a way that ensures that people who are unlikely to improve are allowed to live their lives and manage their conditions without unnecessary worry and intrusion.

***I would like to see the introduction of a range of statutory review periods.***

For example, a prognosis study review<sup>1</sup> for patients with ME (Myalgic Encephalopathy) calculated a median untreated patient full recovery rate of 5%, and the median improvement rate at approximately 40% compared to pre morbid status. So, 95% of patients are going to be suffering symptoms for the rest of their lives and up to 60% will see no improvement over time. Does this limited capacity for recovery justify annual medical checks? There is a legal requirement for people to inform the DWP if their condition improves and an enhanced role for the GP should help to pick this up quickly. For many conditions like ME, if someone is going to improve then it happens within the first few years following diagnosis. Review periods should therefore increase if the evidence submitted by the GP shows that someone has not improved.

The situation also becomes far more complicated when there are co-morbid conditions. For example, I have osteoarthritis as well as fibromyalgia. This excludes me from the only available treatment in my area. Consequently, I have seen no improvement in my condition in the last 15 years.

If someone is of working age, they may well also be claiming Employment and Support Allowance (ESA). What this reform should ensure is that claimants of both ESA and PIP do not have to attend separate medicals. The aim of both

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<sup>1</sup> Cairns R, Hotopf M (2005). "A systematic review describing the prognosis of chronic fatigue syndrome". *Occupational medicine (Oxford, England)* 55 (1): 20-31.



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systems is to ensure that people who are capable of work are encouraged to remain or become active. ***Any differences between the two assessments should be ironed out and there should be a shared assessment and review system for both benefits.***

For someone (again, like myself) who has been placed in the ESA support group, there should not be a requirement to also be examined for PIP. Wherever possible, the review dates for both ESA and PIP awards should be aligned, preventing the need for duplication of effort on the part of the DWP and the claimant. Once more, an enhanced role for the GP would help to reduce the need for separate medical assessments. ***There should be a "fast track" review for people with chronic health conditions, where they and their GP tick a "no change" box on the review form.*** In order to prevent fraud, a small sample of those who have ticked the "no change" box could nevertheless be called in for an interview.

### Questions 14 to 16:

An enhanced role for the GP would help here. Requiring a claimant to be registered with a GP and requiring the GP's meaningful involvement in the process would help to reduce fraud. The development of personal budgets is also necessary. Councils who support people to write a Person-Centred Plan (PCP) should ensure that all appropriate funding sources are included in the plan. The PCP could be an important tool in ensuring that public money is used in the most cost-effective way but also in a manner that best supports the individual's needs and choices.

I would make the point again that **taking account of capital expenditure on aids and adaptations is not enough.** For example, wheelchairs need regular maintenance and replacement after about 6 years due to insurance restrictions, so even if a capital payment could be made by the Council or the NHS, PIP may be needed in order to cover necessary revenue costs.

### Questions 18 and 19:

Removing the "passport" element of a DLA award would make it necessary to make separate applications for things such as a Blue Badge, increasing bureaucracy and cost. Consideration ought also to be given to making

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placement in the 4 support group of ESA a passport to the lowest entitlement of PIP, or to an exemption from review for the period of the ESA award, following the expiration of which, the two awards share a common review process.

### Question 20:

ESA (especially where the individual has been placed in the support group); PCP (prepared as part of a Social Services personal budget); housing benefit; council tax benefit; blue badge scheme; NHS continuing care; NHS direct payment; landlord-funded aids and adaptations; Motability; Access To Work.

END

Respondent: [REDACTED]