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From:

Sent:

To:

Subject:

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Dear [Redacted]

In my capacity as a registered disabled person please find attached a reply to your department's consultation on the replacement of Disability Living Allowance with Personal Independence Payments for your perusal.

Kind Regards

[Redacted]

[Redacted]

Rec'd  
16/2/11

## CONSULTATION ON THE REPLACEMENT OF DISABILITY LIVING ALLOWANCE WITH PERSONAL INDEPENDENCE PAYMENT

### Abstract

I am replying to your consultation in my capacity as a registered disabled person.

The scope of the consultation is misrepresentative, the questions incomprehensive and the time scales a barrier.

The proposed changes contravene my Human Rights.

The proposed denial of mobility allowance for residential disabled is a contemporary socially engineered ghettoisation of the most vulnerable.

The societal ceilings of impairment aren't addressed in the consultation.

**Thank you for the opportunity to contribute to this consultation.**

## Response to DLA Questions

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

### Response

Given the diversity of disabled people in terms of age, gender, class, ethnicity, impairment, social deprivation and location, the bureaucratic, institutional, societal and systemic barriers preventing disabled people participating fully and actively in society are enormous.

A significant number of disabled people feel excluded from society, unable to lead meaningful and purposeful independent lives due to purposely or inadvertently restricted access to social housing, education, employment, goods and services, leisure facilities, events, buildings, societal and career impairment ceilings.

In addition to feelings of being excluded by society disabled people live in fear of bullying, victimisation, intimidation, hate crime as well as societal undermining, labelling and negative political and press discriminatory reporting all disabled people as "scroungers, cheats and a burden on the welfare state".

All this at a time when the recession recovery is weakening with negative growth, rising inflation, significant increases in indirect taxes, fuel, food, clothing, rents, heating and lighting costs, that together are perpetuating the widening of the extra cost gap of disability, whilst at the same time voluntary sector funding is being cut, employment opportunities are negligible and there is a postcode lottery for medical care and/or prescribed medication.

In addition to the aforementioned, as the barriers faced by disabled people are either caused by or result in their financial exclusion; this is why DLA is invaluable to so many disabled people.

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

### Response

The claim Disability Living Allowance is no longer fit for purpose may be over stated particularly with regard to self-assessment and therefore urge the retention of self-assessment applications.

The qualifying period should remain the same for those diagnosed with incurable disabilities as the new timescales may have a substantial adverse impact on new claimants.

An example of this is a spinal cord injured patient, discharged within four months of their accident - qualifies for DLA/PIP - but has a further two months before they can apply, which effectively stops them exercising their housing and care rights, whilst exacerbating their psychological and emotional wellbeing and institutional dependency.

The necessity for periodically reassessments for severely disabled (already assessed indefinite awards) in many cases may have a severe adverse impact as it would serve as a reminder of their disability and review of their static situation, particularly as there is no cure for severely mentally impaired, amputees, deaf/blind, haemodialysis, severely visually impaired, cerebral palsy, spinal cord injury, multiple sclerosis, etc.

There should continue to be the separation of mobility and the care components in the new allowance.

The allowance is not a benefit and therefore should not be combined with any Universal Credit proposals.

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

#### **Response**

The extra cost of disability is the amount of additional income a person with a disability would require - so as to achieve the same standard of living as a similar person without a disability - albeit problematic to assess, estimates range from £7.24 to £1,513 per week.

The calculation is problematic in so far as the main extra costs for a child, young adult, middle aged adult, pre-retirement aged adult, married, partner, parent or single person are complex (with many hidden costs) and varied and dependent upon other factors such as Gerontology, demographics and categorisation.

Albeit a conceptual definition of extra costs maybe subjective (goods and services required), comparative (goods and services used) equivalent (standard of living) the diverse grouping above incur many additional extra costs including support services inside/outside the home (dressing, bathing, toileting, cooking, eating, household chores), dietary needs, health services, transport, education, heating, disabled aids, repair and maintenance of disabled aids, sports and leisure activities.

However, the extra costs calculation for disabled people on the poverty line can be even more problematic as individuals substitute goods and services for cheaper alternatives or disregard them altogether as they cut back (heating use during winter) on actual activities (petrol costs of travel) to remain within budget constraints (buying from cheaper frozen food shops with its adverse impact on health/well-being).

The cut backs disabled people face because of their disability range from socialising, social interaction with friends and family, going shopping, going to the cinema, going to shows, going to events, hobbies, holidays and other activities of daily living.

As these activities produce a feel good-factor; build self-esteem, self-worth, meaning and purpose in life - as well as physical and psychological well-being that enable significant reductions in health care budgets, whilst at the same time facilitating a more active, inclusive and integrated UK society within the Governments own 2025 target.

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

#### **Response**

Any numerical reduction in the number of components to any allowance or benefit should make it simpler to understand but not necessarily easier to administer, particularly where there is a lack of clarity, a degree of complexity and poor objectivity all of which are characteristics evident in the two care rate proposal.

At present the middle band rate is approximately a 2.5 multiple of the lower band rate whilst the higher band rate is a 1.5 multiple of the middle band rate and approximately a 3.8 multiple of the lowest band rate.

A medium rate calculation between the middle and lower band rate components is approximately less than half the higher rate at £33.38 and based on the assumption the higher rate remains the same, those claimants mistakenly reclassified downwards will suffer a significantly greater cost of disability.

The claim assessments are to be objective, transparent, reflective, specific and targeted to individual needs neglects to state what assessment information – in accordance with natural justice – they will provide back to claimants?

Improved two-way communication would essentially allow claimants to make empowered decision-making judgements regarding changes in their condition, reporting them timelessly and accordingly whilst at the same time alleviating the need for periodic reviews.

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?***

**Response**

All assessments should be based on the principle of allowing the individual their human right to live a dignified, independent role in society.

As the effects of numerous conditions or impairments are extremely well documented in leading International Medical Journals then surely this, above all other considerations fully endorses the case for automatic allowance entitlement for certain conditions.

The idea of reviewing and reassessing individuals with medically registered conditions or impairments is preposterous just as viewing a wheelchair as part of an individual's ability rather than its essential use to get around.

As this could mean needs are assessed on an individual's ability in a wheelchair rather than the fact they need a wheelchair to undertake anything at all!

Indeed, the list of conditions or impairments resulting in automatic entitlement should be lengthened to simplify the process and make the system easier for everyone to understand.

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?***

**Response**

There are several evaluation tools available to measure Activities of Daily Living including the Katz and Lawton scales that cover self care, fundamental functioning and social interaction that are considered essential activities for everyday life.

Impairments are not only diverse but also multiple making essential activities of everyday living, time consuming with varying prioritisation on an individual basis, including but not exclusive to; personal hygiene, grooming, dressing, undressing, feeding, functional transfers, bowel and bladder control, medication, ambulation, housework, cooking, gardening, shopping, social activities, social interaction, exercise, relaxing, skin care, health care.....

Prioritising support on the basis of essential activities is undeniably flawed should it be functional assessment is based on the ability of a

disabled person to carry out essential activities, impacting their life chances and choices.

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

**Response**

The best way to ensure the assessments are appropriate, meaningful and provide a comprehensive account of individual fluctuating health conditions is to forge good relationship links between all parties involved in the process.

In the case of a spinal cord injury patient, they may have better knowledge as well as an 'uncanny ability' to interpret, diagnose and request medical or nursing attention for their physical ailments whilst at the same time fail to recognise psychological and/or emotional issues associated with their disability.

The psychological/emotional aspect of sustaining a spinal cord injury can present far greater challenges than adjusting to the physical aspects – "the wheelchair bit is the easy part, dealing with the associated complications is the difficult, challenging task"

In the immediate aftermath of spinal injury the individual is forced into considering their feelings about themselves, how and where they slot back into society whilst at the same time face significant challenges to their identity.

Therefore a sensitive and considerate approach to assessment must ensure contributions from numerous sources of expertise, take a comprehensive account of fluctuating and variable physical and psychological issues going forward. Because, even after effective rehabilitation, integration and return to meaningful living/employment, the psychological aspect of disability can be a ticking time-bomb just waiting!!

Additionally, periodic reassessment of spinal cord injured may only serve as a reminder about their incurable static physical condition and in doing so may only serve as a thrust towards negative thoughts concerning their plight with the knock-on psychological/emotional functioning and perceived further loss.

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?***

#### **Response**

In the case of a disabled spinal cord injured wheelchair-user the use of the wheelchair could be viewed as part of that person's ability rather than its essential function as a means of getting around. This could mean that a wheelchair user would be assessed on their ability in the wheelchair rather than the fact they need a wheelchair to undertake anything at all!

Although a puncture at work necessitated time out of the office; travel to and from a cycle repair shop, the time to repair plus the monetary cost of the repair – with the true cost to me of the puncture was sacrificing employment prospects as well as the need to divert budgeted expenditure to cover these hidden - true costs of disability!

The removal of employment barriers could effectively be impeded by unscrupulous employers applying the precedence set by this proposal.

The suitability, practicality, ownership, usage, cost and classification of personal aids makes it unrealistic, unfair and overly complicated to take a person's aids and adaptations into account when assessing their mobility.

Who decides what aids or adaptations is appropriate, the basic one or one of the more expensive ones? Is it the assessment officer, the person with the disability or some other bureaucrat?

As to whether the assessment should take into account aids and adaptations a disabled person could have is ambiguous and could have substantial adverse impact on those forced to substitute goods and services downwards!

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?***
  - ***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?***

#### **Response**

The claimant should be able to complete the claim form in a reasonable amount of time, questions must not overlap and the claimant must feel comfortable (questions not overly-intrusive) with what is being asked.

The claimant should receive one-to-one support where it is necessary for a claimant to negotiate the application/form.

The current online surveys by commercial organisations are a good indicator of how to gather the most relevant information whilst at the same time sustaining the interest of a diverse group of customers.

The effectiveness of any changes to the forms necessitates input from the end user and disabled people throughout the testing and identifying of the optimal point between user needs and information requirements.

The experience of disabled people and their potential input to the process of designing, implementing and providing information would be invaluable to coproduce a claim form and/or any public information on PIP.

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

**Response**

It is a recognised fact that people with severe disabilities have a lower health related quality of life than those in the general population and this could be contributed to the associated psychological functioning.

Whilst some impairments are degenerative others although not degenerative, only become manageable because the disabled person learns how to make institutionalised sacrifices.

The presence of mental health problems (anxiety, cognitive issues, consistent negative thoughts, out of proportion reactions to a problem) manifests itself in those groups with severe disabilities which can have a significant impact on the individual, their families, friends, colleagues and carers, so much so it is vital issues are addressed as early as possible.

How to capture such vital supporting evidence is challenging due to there hidden costs and most likely can best be provided by knowledgeable disabled associations, specialist consultants, therapists and psychologists specialising in disability.

In addition to the supporting evidence from professionals the timing of assessment evidence by the applicant is just as important and should take account of their status, age and whether they are newly or long term disabled.

It is claimed, social structures and environmental factors that serve to contextualise age and the life course are factors that can influence the timing, meaning and experience of disability. Spinal cord injury research indicates patients are better equipped to deal with a spinal cord injury at an early age compared to later in life's course.

Capturing supporting evidence of the social, psychological and biological aspects of aging, with limited activity and restrictive participation during life's course is essential to assess a disabled individual's ability and not just a periodic snapshot. In essence a clearer brighter image is what's needed!

The coalition government's commitment to measuring the 'nation's happiness factor' through a 'well being exercise' with questions on emotional health, social isolation, interpersonal relations and access to holidays, consumer goods and services may well be an ideal opportunity in collaboration with the DLA/PIP assessment exercise to actually gauge the well being and happiness of being disabled in modern day Britain!

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?***
  - ***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?***

#### **Response**

There are significant obstacles relating to face-to-face discussions with regard to location, travel, scheduling, health-care expertise as well as the hidden costs that make this policy highly inappropriate to pursue.

Societal barriers mean no location meets everyone's needs due to numerous factors including parking restrictions in town or poor transport links out of town. A disabled car owner recently had to turn back from a hospital appointment because they were unable to find a disabled parking space.

The scheduling of appointments can be horrendous for those with severe disabilities who struggle to cope with the fluctuating time it takes to complete some of the most basic everyday tasks, hence high non-attendance rates.

What happens if appointments are missed due to non-attendance?

The hidden costs are the psychological, stress related impact on the wellbeing of disabled person. A registered disabled man had his DLA care-component wrongly reviewed; he became depressed, stopped

eating, was hospitalised for a year and his death certificate stated malnutrition as the cause!

There is a considered concern that independent medical assessments will discriminate against those with complex, variable and/or hidden conditions which might not be fully appreciated by the assessor.

A disabled woman with a hidden stress condition resulting from her disability became depressed, stopped looking after herself, which led to both her legs being amputated (pressure sores) followed by her death shortly afterwards from associated complications from the amputation!

It is also considered highly unlikely that medical assessments would result in cost savings as assessment by independent medical officers would increase bureaucracy along with the additional costs of employing specialist medical officers, office rents and the legal and administration costs involved in legal challenges and appeals.

12. ***How should the reviews be carried out? For example:***
- ***What evidence and/or criteria should be used to set the frequency of reviews?***
  - ***Should there be different types of review depending on the needs of the individual and their impairment/condition?***

#### **Response**

The objectivity of any review is a balanced assessment of a claimant's past, present and future medical and psychological condition.

The process must be an open, transparent two-way relationship built on trust.

The process must be clear, concise and unambiguous with no hidden agendas.

The process must be two-way.

The process must provide more information than a fail/qualify reply.

The process must tell the claimant how to exercise their rights.

The rights to appeal, the right to information - Freedom of Information Act 2000, Data Protection Act 1998, Disability Equalities Act – the right to protection from the Disability Discrimination Act 1995 and the Human Rights Bill 1998.

The process must allow the claimant to know the level at what they were assessed: For example:

Higher Rate One – terminal illness

Higher Rate Two	–	permanent disabled / 24 hour care needs
Higher Rate Three	–	permanent disabled / medium care needs
Higher Rate Four	–	disabled / daily activity needs
Higher Rate Five	–	disabled / low care daily activity needs

The process can then develop review criteria for each banding (above) so claimants are clear about what specific changes they need to report.

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?***

#### Response

In the vast majority of cases the under reporting of changes can be contributed to a number of mitigating circumstances.

An insignificant change over a considerable period of time differs from a significant change over a short period of time with the latter being significantly less difficult to notice/identify and report.

There can be a tremendous demoralising impact on a disabled person's quality of life - when they hope - above everything else - that their condition is improving, only to be shattered when told otherwise by a specialist consultant, illusions of the mind! Thinking there has been a change when there hasn't - or there hasn't - when there has!

In regard to those with a spinal cord injury, autonomic dysreflexia or a urinary tract infection can have a significant impact on well-being, both over the short and longer term and therefore is almost impossible to accurately quantify the level of physical and/or psychological changes.

A wheelchair user may think the reason why they can no longer push themselves as far in their chair is down to weight gain, smoking, aging and/or just a lack of physical exercise when the real reason is a respiratory ailment, a secondary complication associated with their disability.

These examples hopefully demonstrate the complex nature of disability as well as providing an understanding as to why many changes are under reported as well as highlighting the potential administrative nightmare of over reporting with the need to clarify changes!

Improvements to encourage reporting of changes needs the person reporting the changes - having a better understanding and knowledge (two-way information agreement) of what to look for and how to identify reportable changes as well as how to report them.

By making the system as clear and transparent as possible with adequate support mechanisms in place for those with mental health or communication support needs this will, without doubt help improve compliance.

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?***

**Response**

The basic needs for a disabled person are the same physiological and safety needs (Maslow) for the able bodied, the only difference between the disabled and non-disabled is the cost of disability.

Whether PIP is a safety net or step up mechanism it should provide protection and security with advice and information on 'deficiency needs' with the aim of enabling esteem, parity, confidence and a route to purposeful, meaningful, fair and inclusive participation in society.

The types of helpful advice and information for claimants during the claims process are extensive and range from support services at home and outside the home, social services, care services, carer providers, day centres, rest homes, disability support organisations, local authority services, utility providers, tax offices, benefit/credit offices, pension credits, ombudsman, housing associations, advice shops, legal services/legal aid, counselling, trade unions, tribunal services, health services, transport, libraries, education, sports, leisure, jobcentre, motability and other similar disabled service/goods providers.

However, all of the above advice at once without doubt would be counter-productive and an information/administration overloaded nightmare.

The flow of information necessitates a much more targeted and systematic approach towards delivery as applicant's individual needs (Maslow's Hierarchical Needs) changes over time that breach societal impairment ceilings!

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?***

**Response**

I do not believe that people should be coerced into accessing support and advice for the following reasons:

Where the advice and support is appropriate and people are given sufficient information about how to access it, it is unlikely that they will need to be coerced into doing so.

Accessing advice and support can be a very difficult and stressful process for some people, particularly those with mental health problems and/or communication difficulties. People with conditions of this kind should not be discriminated against.

People may have good personal, moral or religious reasons for not accessing a particular form of advice and support and their decision should be respected.

It should be accepted that people do not enjoy having their ability to live independently curtailed and to suggest otherwise just cements the image that political discourse and the media are creating of disabled people being out for all they can get.

**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?***

**Response**

The funding of aids and adaptations for disabled people is sourced from their own savings, health boards, social services, district nursing services, charities, families, fund raising, legacies, donations, motability, churches, religious organisations, businesses and numerous others.

The Motability hire or lease of powered wheelchairs, scooters, adaptations and/or cars addresses the mobility needs for many disabled people over terms of up to five years - and they are considered exceptional because of their understanding and appreciation of the diverse needs of their customers.

The scheme is open to registered disabled in receipt of the Higher Rate Mobility Component of the Disability Living Allowance.

Consideration to allow Middle and Lower rate DLA holders' access to the Motability hires or lease scheme will enable greater mobility for all disabled!

It would also seem absolutely reasonable to allow the use of PIP to meet a one-off cost to fund an aid and/or adaptation as the alternative could have significant impact on their standard of living or force them into debt!

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 pass-porting arrangements?*

**Response**

The importance of DLA for accessing additional help or services cannot be underestimated although it is sometimes poorly communicated.

One area where pass-porting could be significantly improved regards access to Justice for the most vulnerable members of society.

The disabled face hate crime, harassment, victimisation, bullying, attacks or damage to their property or belongings just because they are disabled perpetuated further by the negative rhetoric from political discourse and media reporting of the 'DLA Welfare Burden' resulting in further discrimination and prejudice.

The disabled in employment or seeking employment can access employment support in the workplace if in receipt of the DLA albeit rather ineffectual when dealing with impairment glass ceilings!

For disabled people to participate and be more active in society a key objective of this consultation must be protection, disabled people need to know their rights, how to exercise their rights and (pass-porting) where to go to get the help and support they need!

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?*

**Response**

There would be many repercussions for disabled people and service provider if PIP was no longer a passport to other entitlements and services.

The repercussions could create significant disparities between disabled groups as well as within the same service provider industries, let alone considering the additional administrative paperwork and costs.

The best way to help the most vulnerable members of society is to make the process of accessing help, services and support as simple and user-friendly as possible which the right to passport other entitlements and services enables.

In keeping with the stated objectives of Universal Credit, a one-step process (passport) that potentially could enable the right support, at the right time, to the right people, with less bureaucracy!

Service providers and in particular utility service providers offer some of the most vulnerable disabled groups a number of concessions based on their entitlement to DLA that is easy to administer and process whilst getting the right help to those most in need!

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

**Response**

The stated Government objective to make the benefits system simpler and fairer together with a commitment to disability equality, human rights and independent living is contrary to the consultation proposals that will deny vulnerable disabled people participation, freedom, choice, dignity and inclusion in society.

The negative political rhetoric and inaccurate use of terminology developed by the independent living and disabled peoples' movements is so detrimental to inclusiveness the Government potentially risks undermining much of the movement's progress to date.

The haste and speed of the consultation is detrimental to participation and involvement of the vast majority of disabled people and shows little consideration to their additional needs and as such the consultation is fundamentally flawed in its objectivity!

The consultation neglects to address the methodology behind making the reductions in spending - is the objective to out-source the administration workload, pay staff and consultants bonus's or other detrimental incentives?

The comparison implied between people living in residential care homes and people who are in hospital is fundamentally misguided, offensive to disabled residents and based upon the incorrect presumption that **being disabled is the same as being ill**.

There is also real concern that the reforms will constitute a breach of the Human Rights Act 1998 with the changes denying thousands of disabled people equal access to private and family life as they will be unable to afford contact with their spouses, parents, children and friends.

Those who can no longer afford to attend their place of worship will be denied their human right to religious freedom!

There is concern the process will not adhere to set precedence developed and established over past reviews?

The DLA/PIP allowance should automatically passport awardees to winter fuel allowances, fuel VAT reductions and higher personal tax

allowances so as to help towards covering some of the additional costs of disability.