

## Disability Living Allowance reform consultation – email responses 201 to 400

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| EM201             | 14-Jan-11     | <p>I am not only a disabled person who relies on the DLA to help me to meet the addition costs involved in leading an independent life but I am also an employee of a charity that helps young people who are disabled and their families.</p> <p>*I was not born disabled, I became disabled in 2005 following an accident at home. I am in constant pain and have been told by specialists that my condition will not improve and will, likely, become worse with time.</p> <p>*I live in a remote area and require an automatic car in order to work. My DLA has helped to pay for this car and to keep it running. Without the DLA I would be unable to afford the upkeep of my car and would, therefore, be unable to work and have to claim unemployment benefits and suffer severe depression due to my loss of independence.</p> <p>*I am worried about the proposal to change the DLA to the PIP with a compulsory medical assessment.*</p> <p>Throughout the last 5 years I have received physiotherapy to help me to walk more correctly and cognitive behaviour therapy for the depression that I have suffered from due to the sudden loss of independence in my life and being told that I will be in pain every day of my life.</p> <p>*To the outside observer I look no different than anybody else. This is because over the last 5 years I have learnt to hide my constant pain from others in order to be perceived as 'normal'. I have good days when the pain is minimal and my emotional state is good, and I have bad days when the pain makes it unbearable to walk and my emotional state suffers.</p> <p>*I am worried that having a one-off medical assessment in one day would not reflect the true impact that my disability has on my ability to lead an independent life. I also worry that this would be the case for other people currently receiving DLA.</p> <p>*I want to work and contribute to society but, without DLA, I would not be able to keep my job and would probably feel so low that I would begin contemplating suicide (this is how I felt before I got my job at [REDACTED]).</p> <p>*These are difficult times financially but I don't think that this is the way to save money when so much is wasted elsewhere. At this rate, prisoners will have more human rights than disabled people!</p> <p>*Thank you for taking the time to listen to my concerns.*</p> |
| EM202             | 14-Jan-11     | <p>My family and I have been watching, with growing trepidation, the news of disability benefits reform. I suffer from many ailments including MS, Epilepsy, Osteo-arthritis, Lupus, and more. When DLA was formed from the long defunct Mobility Allowance, it took me over 12 months to be accepted, mainly because the staff did not understand the medical terms. Both my husband and my son are also disabled and, to be frank, we are all terrified by the suggested reform, due to so many losing their badly needed benefit and being too frightened to fight for it. I am due for an operation which involves the surgeon drilling into my vertebra and scraping away excess matter. The outcome could mean the difference between slight mobility or none. The same options apply if I don't have the operation.</p>   |
| EM203             | 14-Jan-11     | <p>I have read the DLA reform consultation document with interest and would like to make the following comments. Although I am the manager of a charity, these comments are made by myself as an individual.</p> <p>*Whilst agreeing that work is beneficial in terms of self esteem, income, social inclusion and being less of a 'burden to the state', it is possible for some but out of the question for many. My concern, I am sure in accordance with many other thousands of people, is that the aim of this reform is fundamentally to cut costs at the expense of vulnerable people.</p>   |

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|                   |               | <p>*I have a disability myself, although I do not claim DLA, and continue to work albeit with the help of relatively minor adjustments made available through the 'Access to Work' scheme. My wife however does claim DLA and is unable to work. Having been in receipt of this benefit for some time she did attempt to return to paid employment under her own initiative, not through any external pressure, but this was unsuccessful and resulted in deterioration of her health for some considerable time. By the second day of her employment, I had to return from a work meeting 45 miles from my home in order to collect her and take her home because of her desire to try and return to work.</p> <p>*</p> <p>My point here through my own experience, which for some time was managing projects supporting people with disabilities into employment, is that people with a strong work ethic do wish to work and do indeed make attempts to do so, despite risking their own health and well being in doing so. To put pressure on people to do so if in a fragile state of health will most certainly result in worsening health and increased stresses.*</p> <p>Your document states that "...advice from an independent healthcare professional should be an important part of the new process". In my wife's case, she has already been assessed by a number of qualified doctors in addition to several specialists and consultants. Will the remit of the 'independent healthcare professional' be to provide an objective appraisal of the patient's health condition, or to remove as many people as possible from the benefit? Also, what qualification will these 'professionals' have? A Practice Manager is, after all, a healthcare professional, but hardly qualified to offer information which potentially could differ from that of doctors who specialise in particular health conditions. *</p> <p>I trust that feedback such as this is what you are aiming to solicit through this consultation. I would also like to comment that the consultation period for a reform of such magnitude, albeit legal, does seem short. Thank you for your kind attention to this response.</p> |
| EM204             | 14-Jan-11     | <p>1. a) Transport - I live on a main road in Merseyside but there is no suitable form of public transport I could use to go out. I am a wheelchair user that cannot walk outside unaided, and I need my car or a taxi to attend hospital appointments and shop for food. Without DLA mobility allowance I would be a prisoner in my house.</p> <p>*</p> <p>b) Help with personal care - I cannot look after myself properly, or even prepare a cooked meal, without some help from others, and could not manage without the care element of DLA.</p> <p>*</p> <p>2. Those who sufferer from medical conditions that will never change should not be re-assessed, but there are too many people with "bad backs" who are capable of working, but choose not to.</p> <p>*</p> <p>3. a) Transport - as above*</p> <p>b) Buying equipment to help 'normal' life, such as bath lifts, walkers, wheelchairs, small table-top ovens to reduce the need for bending.*</p> <p>c) Any item made specifically for the "disabled". For instance, a hand-held GPS system to enable the visually impaired to travel independently costs a minimum of £500.</p> <p>*</p> <p>4. No, having two rates per component will only confuse most disabled and elderly. It is more likely to dissuade those that genuinely need it from attempting to claim.*</p> <p>If it's absolutely necessary, then four separate rates would be easier to understand and administer.</p> <p>*</p> <p>5. Yes. a) life-long conditions that prevent a normal life should be given automatic entitlement, such as the blind, Down's Syndrome, autism, Asperger's Syndrome, Cerebral Palsy, Motor Neurone disease, chronic</p>  |

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|                   |               | <p>kidney disease, etc.<br/>*</p> <p>b) anyone diagnosed with dementia severe enough to prevents a normal life<br/>*</p> <p>6. a) good personal care that does not remove dignity.<br/>*</p> <p>b) good healthy and regular meals, with help to eat it where necessary<br/>*</p> <p>c) access to good medical care<br/>*</p> <p>d) access to friends and family, and others who care.<br/>*</p> <p>7. Difficult, but perhaps a regular GP's assessment [like a quarterly sick note] for those people?<br/>*</p> <p>8. No. A wheelchair is no substitute for working legs! *<br/>Should the assessment only take into account aids and adaptations...?*<br/>No, the assessment should not take aids and adaptations into account. It's hardly "normal" to stagger around on sticks, or use a guide dog to get about.<br/>*</p> <p>9. Keep the language basic and allow plenty of room for explanation from the individual.*<br/>How can we improve information....? *<br/>Posters in GP and hospital waiting rooms as that's somewhere that all disable people go.<br/>*</p> <p>10. The consultant or GP that makes the diagnosis.<br/>*</p> <p>11. My experience of the healthcare professionals who are appointed by the DWP locally has been very bad. In one case the person did not speak good enough English to understand my responses. Many disabled people cannot express themselves well in a face-to-face situation with a stranger where they can do so in writing or with their Consultant or GP.<br/>*</p> <p>12. There should be reviews for conditions which can and do improve either spontaneously or following treatment, such as bad backs, mental breakdown, anxiety, depression, phobias, heart attack, stroke, etc.<br/>*</p> <p>13. By prosecuting more of those people who are cheating the system and publicising the cases better.<br/>*</p> <p>14. As part of the benefit claiming process:<br/>*a) they need to know if their condition automatically qualifies for the benefit<br/>*b) they need a free telephone number [or fully-manned online one-to-one live contact] with good support staff who can answer their questions - and who knows who to pass the individual on to if they don't know the answer!<br/>*c) they need to know that they will not be abandoned by "the system" so long as they genuinely need help.<br/>* 15. No, there should be no requirement. If people believe that they can manage without the financial help of the state they should be allowed to do so. There should only be a requirement when their lack of action affects a vulnerable dependent.<br/>* 16. The local authority installed hand rails to make the steps into my bungalow safe, and I have two "bed leavers" which are on load from them. Everything else I have had to purchase myself using my DLA - mobility scooter, walkers with wheels and other mobility aids, bath lift, kitchen aids, magnifying lamps, my Talking Book machine, etc., etc.<br/>* 17. Children are not expected to be independent, but they do have the right to as normal a life as possible.<br/>* 18. The only ones I can think of are a blue badge for parking, and free use of the Mersey Tunnels. I'm not one for trying to claim more than I need.</p> |

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|                   |               | <p>* 19. If the Personal Independent Payment didn't give access to the Blue Badge or free Mersey Tunnel it would be very serious for me and I would imagine most other disabled people who have to travel through it to hospital appointments on a regular basis.</p> <p>* 20. I find the whole system baffling, and my only plea is that the government should NOT had over sensitive information to local authorities. Here in the [REDACTED] our Adult Social Services are embroiled in one of the biggest scandals Merseyside has ever known and are not to be trusted.</p> <p>* 21. In my opinion it is discriminatory for the government to make life more difficult for disabled people. We have enough problems already, and most of us don't have the money to make life easier.</p> <p>* 22. Is there anything else you would like to tell us about the proposals in this public consultation?</p>   |
| EM205             | 14-Jan-11     | <p>as i full time carer to my disabled mother who has many health problems, i think this change is very unfair as it is targeting the sick and disabled. my mother needs her money to lead a near enough normal life and the money she gets helps to do this and keeps her car going. as a carer i do 36 hours + a week and see her 24/7 and watch her struggle with her conditions which is heartbreaking. i would urge the government to leave the change alone as it will hurt so many disabled people and could lead to them killing them selfs as i have been reading as they can not cope. thank you</p>   |
| EM206             | 14-Jan-11     | <p>Dear Roger,</p> <p>*As we agreed, I am enclosing some views, comments and suggestions I have in relation to the reform of DLA into PIP. The comments are from my experiences of the benefit rather than a detailed review of the proposal. I have split my comments into relevant sections to make them easier to understand. *</p> <p>Background - It is clear that many charities, disability organisations and disabled individuals are crying foul in terms of the reforms without really understanding DLA and the reasons for reform. The reality is that disability has radically changed in the last 20 years in terms of the changes in social policy, attitudes, stigma and barriers. It has also changed from something where people with minor impairments were ashamed to be a part of into a 'Jeremy Kyle' fashion accessory.</p> <p>*</p> <p>Labels - In terms of the benefit's advantages, it has been argued there 2 groups. The first group are clearly and obviously disabled in any way it is defined and they see DLA as a core financial benefit which they are entitled to by simple logic. While the media and others may raise fears, they are safe. Also, the benefit plays a very little part in their daily identity as they are known as disabled in any activity they perform.</p> <p>*</p> <p>For the second group, DLA is a key component in their validation of their disability because they may have often called hidden impairments. The DDA and the presumed benefits of disability has moved their response from fear and stigma to frustration at the fact not everyone recognises them as disabled and having assumed rights to these services. This is why so many people appeal again and again.</p> <p>*</p> <p>Another issue is that DLA is currently the most recognise form of written proof of disability and therefore many organisations use it inappropriately as a gatekeeper to so-called Disability Discrimination Act services despite the definitions of disability being very different. This has further pushed the desire to gain DLA as a gateway to other services.</p> <p>*</p> <p>It is therefore useful to include a formal recognition of minor impairment as a legal status which may not warrant financial benefit. This may reduce the appeals process as people maintain their legal status.</p> <p>*</p> |

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|                   |               | <p>Assessment Process - I agree that the assessment should include evidence and/or face to face interviews. The reality is there is a manner to fill in the current forms using the right terms to always gain the benefit whatever level of impairment without being deceitful.</p> <p>*The main problem with the assessment process is assuming the eligibility is 50 points to gain high rate, for people with significant impairments which affects a majority of their function, they may gain a score of 500. The reform therefore only relates to the people with lesser impairments.</p> <p>*I believe as well as providing medical evidence, new technology evidence should be permissible like facebook profiles and youtube videos. These should be considered in terms of consistency so if someone points you to one youtube video, you would examine other videos from the user and so on. This would avoid a reliance in acted out videos to fake impairment.</p> <p>*I feel assessment should also include the outcomes such as education and work which I explain more in the next section.</p> <p>*Activities and Outcomes - In terms of the activities which may be defined as a part of independent living, it is important that the predetermined outcomes used as culturally relevant to a modern society and a benefit that covers multiple generations. Therefore if one of the tasks is preparing a hot drink, it assumes that they drink tea or coffee and that their social or family role includes preparing hot drinks. Therefore if they have no awareness of the task, their answers will be estimated and most likely in their favour. It is important that applicants have an opportunity to put down their own outcomes which are important to them and which the impairment causes and demonstrates difficulty.</p> <p>*I strongly feel it is no longer acceptable for people to gain benefits solely because they have impairments but they need to demonstrate how the payments made will assist them in fulfilling their outcomes as active citizens.</p> <p>*Future Development - I would personally like to scrap DLA and merge it with all other social care funding streams including ILF, Direct Payments, Access to Work and Personal Health budgets into a single Universal Personal Independent Payment which is assessed locally on national criteria which fits into an enablement and empowerment agenda.</p> <p>*I hope you find this useful and helpful. I would be keen in getting involved on any committees dealing with the reform as an independent and experienced 'user' as I feel many so-called user organisations have a doom and gloom agenda to reinforce dependency for their job security as opposed to fairly representing the best interests of disabled people. I look forward to your response.</p> |
| EM207             | 14-Jan-11     | <p>I have spent my working life caring for others as a nurse. I now have multiple sclerosis and can no longer work. My husband has been at work for over 40 years and is still having to work so that we can survive. We are just one family in a multitude of households who include a person with a disability. *</p> <p>I believe that the cost of implementing these changes will outweigh any savings made. In the process those who are disabled will be made more ill with the stress of the whole process and will just end up eventually on a higher level of benefit.*</p> <p>Why not instead save money by not repeatedly screening those with severe illness and abolishing the sham of ATOS health assessments? Why not rely on the patient's own doctor's reports? ATOS are just acting as dishonest loss adjusters.*</p> <p>My last home assessment was made by an Indian man called [REDACTED] He did not seem to be medically qualified to me, just 'poked' me in three different places. On a previous medical assessment I had asked for the person's GMC number and was given an incorrect number. Why would this have been necessary if they were a credible doctor?</p>  |

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| EM208             | 14-Jan-11     | <p>I currently receive DLA mobility high rate and lower rate care. I use this to lease a car to enable myself and children to get out and for myself to attend university. my son has autism and has elective mutism` often not even speaking to teachers. I really want to highlight that not all disability is always visible and how will this be assessed. leave the system as it is but rehabilitate those who can then work such as addicts</p>   |
| EM209             | 14-Jan-11     | <p>As an individual, currently in receipt of Low Rate Care and Low Rate Mobility DLA, I should like to submit my comments.</p> <p>* 1. Firstly, the government, in its proposals, makes no mention of the true reason for the proposed reform which, quite simply, is to save money by reducing or removing disability payments from a substantial number of claimants. I would call for the Government to be completely transparent about this rather than dishonestly stating that the reason for the reform is to help disabled people.</p> <p>* 2. The Disability Discrimination Act and The Equality Act make it quite clear that any action which discriminates against disabled people (as defined in the Acts) is illegal. There can be no doubt that removing payments from people who have previously been deemed entitled to them is acting directly against the interests of those people and there can also be no doubt that any person currently in receipt of DLA, is classified as disabled in UK and EU legislation. If the Government goes ahead with such proposals, it faces a very real risk of legal challenge.</p> <p>* 3. The present system, although far from perfect, does allow disabled people a certain degree of security as awards are made for a known period, either for a set period or "indefinitely." It has been stated that DLA is to help with the additional costs due to a disability rather than regarded as income, but the truth is that it <u>is</u> income and, an award made indefinitely by HM Government should be regarded as secure. Many people rely on this income to pay for essentials like mortgages. In my own situation, my wife cares for me full time, although she has not been deemed eligible for carers' allowance. She is therefore unable to follow any employment and has no income whatsoever. My DLA helps to go a small way to redress this problem.</p> <p>* 4. There is a common misconception that DLA recipients also automatically receive many other benefits such as Housing Benefit, Council Tax Rebate. ... Not true! I have a small occupational pension and so do not qualify for any means tested benefits. Despite my disabilities, I still have to fully pay for all such services.</p> <p>* 5. Any changes to the present system <u>must</u> be implemented in a manner which does not result in severe financial hardship to DLA recipients.</p> <p>* 6. The Government's repeated theme of insisting that all must be forced into work has a distinctly Dickensian feel to it. " Is the treadmill not still in operation? Are the workhouses still open?"</p> <p>* 7. Above all, The weak, sick and disabled must not be targetted just because they are seen as a soft target, unable to fight for themselves. No fair and civilised society should stand by and see money taken from such a vulnerable group whilst, at the same time, allowing the abomination of multi-million pound bonuses for the bosses of public funded companies. All we ask is a just and fair society.</p> <p>* I hope that my comments will go some way to show the feelings of a fairly typical DLA claimant. Best regards,</p> |

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| EM210             | 14-Jan-11     | <p>Once again another political party is targeting the disabled and elderly. Not once in the consultation paper does it say how much the new benefits are going to be.</p> <p>*The criteria you propose are totally wrong and I feel in some cases, against our human rights. You say that with aids and adaptations this will be taken into consideration when reviewing people with disabilities. The way this has been worded is that as far as you as a government are concerned if you have those aids then you don't need the benefits! This also applies to people who are in wheelchairs. That is discrimination at it's worst. We need these benefits to survive. The mobility money goes towards the cost of either a mobility car, the upkeep of a private car or using taxis etc. The care component goes towards using carers, cleaners, special diets etc, which all takes extra money. You are doing your best to take all this away from us and I for one totally disagree with what you are trying to do in its present format.</p> <p>*Yes there needs to be change to the benefits system but not at the cost of disabled people and the elderly who very often can't fight for themselves. *</p> <p>Try working harder at benefit fraud and those that are caught make them pay all the money back and given them harsher sentences. There is more fraud in the benefits system than people who genuinely are ill and disabled.*</p> <p>You are causing so much stress and worry for people with disabilities. You have no idea what it is like having to live on limited income and having to watch every penny. We are just surviving and if you take any more money away from us we will be under the poverty line.</p> <p>*I shall be writing to my own MP to tell him what I think of these so called proposals and urge him to vote against these policies.</p> |
| EM211             | 14-Jan-11     | <p>Hi I am writing this as a parent of a deaf/ HoH child. I have great concerns about the reform.</p> <p>*How will my child and other HoH children be assessed? My child receives DLA middle rate care at the moment , this money helps us a great deal with petrol/transport to attending hearing appointments, special</p> <p>*educational groups and to attend NDCS weekends. My daughter will need hearing aids all her life, so that will be all her life in my care where this money will help us. If this new reform was to make it more</p> <p>*difficult for HoH children to receive then families like us would really struggle and our children would not be able to have the same life as hearing children. I do hope that the government will think and be fair in changing the DLA for children.</p>  |
| EM212             | 14-Jan-11     | <p>I am assuming this will be ignored like hundreds of thousands more like it. I fear any proposal that gives independent control over anyone who is getting DLA. Using an independent medical unit(questionable) whos' only purpose is to gain for one side only, i.e. government (stats and money) There is not one system better than that of a GP(or Consultant ) to assess any human being in their care. ( Atos and similar are utterly disgraceful)</p> <p>*</p> <p>The nonsense given out by Clegg etc,, , that we who are in receipt of DLA and disabled want this change is so disgustingly false. The only real change is the stupidly incoherent forms and the almost trip me up guv, type questions .If any MP in parliament is able to understand these benefit forms I would extremely surprised. They are geared almost to the point of incredulity, as if it is a legal proposal in damning an individual who does not have the ability to 1/ read it, 2/ understand it, 3/ or recall the almost impossible events of a single day in the life of.Many give up trying and do without any claims.</p> <p>*</p> <p>It is a shameful experience to see oneself in all its glory of a living hellish existence, down on paper , only to have another total stranger disregard them and attempt to take a benefit away ,to save what? Only for the hellish wait on appeal to recover their rightful income,and cause God knows what ills,pains or tragedies can come of that experience .</p> <p>* I would say the same to any political party in Goverment, and Labour is</p>  |

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|                   |               | conspicuous by their lack of words on this matter, which I on benefit assume is a complete disregard from all in parliament. If nothing else, then the term inhumanity, and an obliteration of <u>humane rights to life</u> by any UK gov, is by these proposals, shows it to be patently and utterly cowardly attack on those who cannot fight back ,and for many that means an early death by pain, confusion and poverty and ultimate the end of any British sense of Justice . SHAME ON YOU ALL!!!  |
| EM213             | 14-Jan-11     | Hi my name is [REDACTED] I suffer from depression, CFS, FIBROMYALGIA IBS,.is this away for the government to get us of benefit so we are out of sight.hope not. if the atos is going to do the medical we have no chance.   |
| EM214             | 14-Jan-11     | <p>Dear DWP and those trying to save money on DLA</p> <p>*I just want to have a say, as a sick and disabled person, (I suffer with ME and a related condition that courses regular but unpredictable blackouts), I rely on DLA it pays for the things that I need, things like somebody to cook for me because it is too dangerous for me stand over a hot cooker or use sharp knives, taxis because I can't drive and using public transport is just not safe when I am on my own, plus others things that other people manage without thinking about and with no problems, if my DLA is removed not only will I not be able to get the help I need but I believe my health and possible my life will be put in danger. However I am one of those thousands if not millions of sick and disabled people who are not easily categorised, from what I have read the way that you propose to change how people are assessed as being in need of DLA or its replacement will actually mean people like myself will fall though the rules and be judged as not needing the help I get at the moment. please please think again. the way you are going about this is all wrong, I'm not proud, of being sick and disabled, I worked hard before I was unable to do so, and if I ever recover I will be the first to gratefully NOT claim benefit. but sadly for me that may never happen. I need my DLA (and Incapacity Benefit which I am soon to be forced onto ESA which I am really worried over, another VERY UNFAIR process) Leave DLA as it is, Save money else where, this is not about making the benefit fairer it is about saving money and DLA is seen as an easy target. there are well off people who you could cut from instead eg. NO child benefit to households with total income of more than £35.000, put bus passes back to half price or give only to those with income of less than £35.000, same with winter fuel payments, limit the wages of NHS bosses, I could go on, these of course wouldn't be as popular as hitting the disabled as we all know they are all cheats so you want us to think, I don't buy the propergander that these cuts are to make the benefits fairer that that no one truly needing them will be told they do not qualify, look at what is happening with ESA lots and lots of sick and disabled people who very much need help are NOT being given it, I fear that and the worry is already making me sicker Yours in hope you will have some compassion</p> |
| EM215             | 14-Jan-11     | <p>I and many hundreds of thousands who have joined forces consider it totally inappropriate that the under minister for disability should be an abled bodied person. The current member has no 1<sup>st</sup> hand experience of what it is like to have disabilities? Who the hell is she to decide you can and cannot work? *</p> <p>I personally suffer from Sever Ankylosing Spondilitis. Chronic pain Syndrome and Chronic Cluster Headaches. Many occasions I have failed to attend medical appointments due to a cluster attack that is described as the most severe pain the human body could endure. Yet I get punished by able bodied plonkers who have become megalomaniacs working for ATOS who rewards them with a bonus for everyone they can discredit. It won't last long as last night you got slaughtered in a by-election. So it's off to the back benches again for you lot.</p>   |



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| EM216             | 14-Jan-11     | <p>The above mentioned Reform is both ill thought out and unnecessary . . .It appears that this is just yet another attempt at re-assessment of existing and bona-fide claimants , putting them through a further round of extreme distress and hardship caused by : having to fill out Book-Length forms that are designed to be obscure and misleading in content ; interviews with Government Health Department appointed Doctors whose prime objective is to deny claimants their rights ; to have to travel too and present themselves to Appeals Tribunals Panels on however many occasions it takes to actually win their case(yet again!) when they have been denied their rights out-of-hand , to Benefits fitting their Disabilities ;them being constantly barraged/barracked by Government Representatives trying to find them 'employment' in non-existent positions in the ever-failing 'jobs-market' , when it is economically more feasible to allow the status-quo not to put a further strain on both the Benefits Claimant , and the Benefits System what with the extra transport ,workplace ,legal ,medical needs not counting the fact that no employer will keep a person employed who has to continually take indefinite periods of time off for medical/health/Doctor and Hospital visits for treatment or therapy etc. . . . The Disabled and their families , friends ,and representatives , have already fought and won these fights to obtain the current fairer system , and can only see increased hardship , stress , distress and disbelief in your ability to govern fairly being caused by your proposed reform . . .</p> <p>*N.B. We also find the speed with which you are pushing through this consultation to be alarming in the extreme . . .</p>  |
| EM217             | 14-Jan-11     | <p>1. The disabled have many barriers, including Lack of funds and understanding from able people. Why are you taking us back to the Dark Ages this is 2011.</p> <p>*2. The DLA is not broken so there is no need to change it. But listen to qualified professionals and Consultants.</p> <p>*3. Cost are rising every day increases in power, communication, transport and daily requirements like food even the need to belong to society is costing more. Care; Mobility; Communication; Insurances. We are all humans and entitle to a full life.</p> <p>*4. The World of the Disabled Person is far too complex to have just two criteria. How long does it take for Doctors to qualify in and specialize in these areas how many departments are there in Hospitals. What is being considered here is to totally ignore what the specialists who are qualified in these different fields say about the disabled person which is totally vain of Government to assume they know better.</p> <p>*5. The Disabled are Disabled</p> <p>* 6. Reduce their outgoings; Respect them; Care for them; Love the them</p> <p>*7. By seeking advice from the Qualified Specialists looking after the individual</p> <p>*8. All adaptations should be excluded. As to what adaptations the Qualified Specialist in the particular field would be able to assess this is not the unqualified. It is part of the Disabled person's burden; it also makes a visual statement.</p> <p>*9. Obtain a written report from the Qualified Consultant who specializes in the area of the Disability to provide a written notice of the disability and accept his conclusions.</p> <p>*10. The individuals Qualified Consultants report is all that is needed.</p> <p>*11. Perhaps you could appoint a Qualified Social Worker to sit in on a meeting with the Qualified Consultant of the individual and the individual, so as to understand a bit more about their disability. But if you have the individuals Qualified Consultants report surely that is all that is needed.</p> <p>*12. This would depend on the Qualified Consultants reviews</p> <p>*13. Listen to the individuals Consultant</p> <p>*14. The process should be simple enough ask the individuals consultant the question.</p> <p>*15. The allowance should be made available to all disabled people. The support network should be left to qualified practitioners.</p> |

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|                   |               | <p>*16. No. the adaptations should come from the NHS in relationship with the individuals Qualified Consultants recommendations. The disabled should not have to incur further costs</p> <p>*17. Listen to the Qualified Consultants</p> <p>*18. Please stop this desire you seem to have to torture and break the disabled.</p> <p>*9. The DLA works perhaps the only improvement would be to listen to Listen to the Qualified Consultants</p> <p>*20. Listen to the Qualified Consultants.</p> <p>*21. You are going to make more people discriminate against the disabled. Even the disabled will start to discriminate against each other. You will take all independence away from the disabled. You are about to turn the clock back to the days when the disabled were seen as freaks.</p> <p>*22. Please reach into your hearts and stop hurting the poor. You are about to turn the clock back to the days when the disabled were seen as freaks Reevaluate yourselves why are you targeting the disabled are they not worthy. Remember these people, so delicate whatever their disability is. Also it is by the grace of God you don't have these problems.</p>         |
| EM218             | 14-Jan-11     | It has been said that a Country is judged by how it treats its Disabled and Elderly, so how does this make Britain look. ? Don't make the majority suffer for the same of the 05% that are playing the system.  |
| EM219             | 14-Jan-11     | I am a disabled person with several conditions which prevent me from working or having a 'normal' life. What concerns me is that prior to this 'Consultation' taking place, prior to anyone be re-examined or assessed as to their individual circumstances, This Coalition Government are talking about 20% of people losing their benefit. This is preposterous. Are they guessing, or is this the target figure being set by them and the Privately owned, Financially driven Company who will be doing the new assessments. It is very apparent that this whole exercise is not for Additional or better conditions for Disabled people, but is entirely a case of cutting numbers and saving money.  |
| EM220             | 14-Jan-11     | the DLA helps me with my car and my care , which i need to get around , and yet i am in fear that i will not get the new PIP as the criteria has changed to save money , the fact that it is software that has the outcome of you application and not a proper medical is somewhat disappointing as software can be manipulated to either to pass or not to pass the test , which is input by a human who can and will make mistakes , and then all the distress in appealing . and the difficulties this will bring .  |
| EM221             | 14-Jan-11     | <p>I have read the consultation document and have had a number of telephone conversations with organisations connected with mental health disabilities. The consultation document has been deemed by these organisations as "not the real world."</p> <p>* Mental disability, including acquired brain injury, doesn't necessarily go away with "treatment." There is an underlying assumption in the document that if you give a mentally disabled person enough support that they will then be able to regain employment. What exactly is this "support" that has been referred to and how much is the cost of administering it? Also if any more support could have been given to people with disabilities then I am sure it would have been done already. You cannot reason with a person suffering from ABI as the problem lies in the way the brain is damaged.*</p> <p>I have read the descriptors which focus on physical disabilities and consider that they are grossly inappropriate for assessment of mental illness. Furthermore the company ASOS selected to assess persons with mental illness are not qualified to do so. The patient's psychiatrist is. If the</p> |

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|                   |               | <p>psychiatrist has already assessed the patient as not fit for work and considers that they need assistance in their daily lives and from mobility criterion, then a private company without equivalent qualifications are simply not competent to overrule that assessment. The logic follows that if ASOS overrule the psychiatrist's diagnosis then there is not point in having psychiatrists! People with ABI are stuck with it for life and the stress caused by putting these patients through this process is enough to make a depressed person severely anxious with dangerous consequences.</p> <p>* I would also like to point out that the assessors should be required to give at least a month's notice to the patient regarding the assessment so that an appropriate adult may be present at the interview. It should be possible for all interviews to be recorded on basic home equipment. This is the very minimum protection for what is currently a system which could be abusive in its manner of handling people with disabilities. There is actually nothing wrong with the system as it is. Just because a few people have cheated doesn't make the whole DLA system bad.</p> <p>* As a whole the welfare reforms have been aimed at the poorest and most vulnerable members of society and proportionately they are being asked to pay the biggest share of any attempt to cut the balance of payments. This is one of the most unfair and dishonourable things a civilized society can do.</p>   |
| EM222             | 14-Jan-11     | <p>I write as an individual. I am currently in receipt of DLA on high mobility and low care. I feel that I have been very fairly dealt with by this system, initially granted the benefit at this rate for 12 months and then reviewed and awarded it for 3 years unless my health improved. I am very concerned about your proposed changes as I cannot see the changes being positive for people in my position.</p> <p>*I am a registered nurse with a degree which I self-funded. I set up the Chlamydia screening programme for [REDACTED] and ran it for a couple of years, we were the first [REDACTED] area involved so it involved a lot of 'firsts' and problem solving to make it work over a large geographical area and was recognised, at that time as one of the best in the country. I then returned to district nursing but in 2007, after a long time suffering from a variety of infections (still working) my system finally gave up in a fairly dramatic way. I have been diagnosed with ME and MRI scans have shown abnormalities within my brain. Recent developments mean I am now undergoing investigations to ensure there is nothing else going on. I have lost my career (retired on a tier 1 from the NHS in May 2010) and unless I return to work by October this year I will lose my nursing registration.</p> <p>*Unfortunately, the timing of my sickness meant I was one of the early claimants for ESA. I was initially given only 6 points at my first assessment, my appeal was turned down, as the decision maker said she had 'no reason to disbelieve the healthcare professional's statements'. A very traumatic tribunal followed at which I was awarded 21 points. This was November 2009, by Christmas I had received the forms to apply for ESA all over again. My assessment in April 2010 gave 21 points (on different criteria) the documentation also stated I was entitled to 6 more points but they were somehow missed in the calculation, I did not query this as I was just so relieved I didn't have to go to appeal again. In December I had to go for yet another assessment where I was given no points at all. My condition has not changed, nor have the answers/information I am supplying. *</p> <p>I can assure you, if I could go to work I would do. As a nurse I earn a good wage in relation to many in [REDACTED] I am also very career orientated and it has been a very difficult time for me trying to come to terms with the loss of my career, way of life and general independence. Having a fluctuating condition means I am reliant upon people who often seem to have little understanding of my condition making so-called 'assessments' on what I can do. I find that the questions asked are little different that what I asked patients in assessing the help required with daily living, it doesn't deal with any of the problems I have trying to return to work. My employer gave me the opportunity to return to work just 6 hours a week over 2 or 3 shifts working at a desk but I could not even sustain this.</p> |

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|                   |               | <p>*Whilst I realise I am talking about a different system, what I am trying to ask is that one new system is made to work correctly before the next one is changed. Those who are genuinely ill find it very difficult dealing with the stress of constant requests for paperwork to be completed, assessments to be attended and then appeals to be gone through. It does not help when you are genuinely trying to find some way of returning to work as it feels like you are being accused of being too idle to work. I did not put myself through the difficulties of nurse training as a single parent and then the qualifications and work experience I have gained since in order to sit at home on ESA/DLA as I was the main wage-earner.</p> <p>*The thought of having to go through two ESA and PIP assessments fills me with horror (I genuinely mean that). Alternatively, will it mean that the people currently assessing ESA claimants after a whole two weeks training, will be making decisions about both benefits?* I am, I think probably not the average claimant. I am used to writing reports and presenting/arguing my case in front of department of health representatives at conferences/meetings etc. However, I find the ESA system so depressing and oppressive that it leaves me exhausted (not to mention often bed bound) each time I have the misfortune to deal with it. I take anti-depressants to help deal with my current situation despite my previous confidence/experience and with the support of friends/family who know I would not be living most of my waking hours alone within the confines of my own home by choice. I can imagine many in my situation who might not have the strength to keep on arguing and I am very concerned about the effects on these people of yet more hoops to jump through.</p> <p>* The current 'improved replacement' for incapacity benefit simply does not work, the government review last year stated that it dealt with fluctuating conditions very badly but this made no difference to my last assessment. PLEASE sort out the current systems before making life for the disabled even more difficult with new ones. I know the official line is that it will target the deserving more appropriately but this was supposed to be the case with ESA. I am very concerned that many genuine cases will have even more difficulties to deal with and will simply fall through the net.</p> |
| EM223             | 15-Jan-11     | <p>I am in receipt of the higher rate mobility component of DLA but only after appealing the original decision which rejected my application. I know the current system is flawed as I see so many people with the Blue Badge who have no apparent mobility problems. However, I also am strongly against the DWP employing outside agencies to carry out medical assessments where there are financial incentives to meet targets rather than create a truly unbiased process.</p> <p>*All these proposals do is give the Government a way of reviewing each claimant to see how their benefits can be reduced rather than provide the appropriate assistance. For example, if I were to spend my own money, or received a grant to make adaptations to help ease my difficulties it appears to me that this would be used to justify a reduction in benefit simply because a long-term problem has been minimised. It is cynical to suggest that these reforms are being introduced to help the disabled when the main reason is to reduce the amount spent on benefits.</p> <p>*Whilst I fully understand any government wanting to reduce the amount spent on benefits, I am against carrying out such an exercise with what appears to be the sole intention of reducing costs which will ultimately mean that more and more genuine claimants will lose out. Government should strive to have balanced procedures which are stringent enough to weed out false claims whilst protecting those in genuine need.</p> <p>*I am unusual in that I was successful in obtaining a Blue Badge before receiving higher rate mobility DLA by being examined by a Occupational Therapist who confirmed my disability. She said she was completely unbiased and so was able to make an accurate assessment of each individual and was confident that no one she approved was fooling the system. Other than a possible shortage of Occupational Therapists would it not be cheaper to use these professionals rather than a medic working for a</p>   |

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|                   |               | private contractor who's priority is to achieve unrealistic targets rather than meet the needs of the claimants?   |
| EM224             | 15-Jan-11     | <p>I would like to add my comments to the growing number of concerned individuals regarding the proposed changes to the mobility component of DLA. *</p> <p>My daughter is fifteen, has complex needs, and attends a special school. Currently she has respite there two nights a week, but as she moves into the 16+ provision, the hope is that she will be a weekly boarder.*</p> <p>We have just taken delivery of our most recent Motability vehicle, which is wheelchair accessible as my daughter can now only travel in her wheelchair, and public transport is and will always be out of the question.</p> <p>*Because my daughter has very complex needs we have numerous hospital appointments etc... and she is often unwell, which means that I am unable to work as I receive no other respite. This means that our Motability vehicle is the only vehicle in our family, and I couldn't begin to contemplate either buying or running an additional car.</p> <p>*Were my daughter to be lucky enough to become a weekly boarder at her school, we would still need the current vehicle. You seem to be under the misapprehension that residential settings have their own transport facilities, but this is usually for group outings or school trips. Without our vehicle I would not be able to get my daughter to any appointments; go anywhere when she was at home; collect her from school when unwell; attend parents evenings or assemblies. School holidays, periods of illness, family occasions would all become untenable. The list is endless.</p> <p>*I appreciate that there may be circumstances when a child or young person has a 52 week placement, but this is a very small percentage of the total, with most young people still in education considering the family home to be home. *</p> <p>I can assure you that a far from economical "van" would not be my first choice of vehicle anymore than not being able to afford my own car, not being able to work, not being able to access respite services, etc - but there is the reality.</p> <p>*</p> <p>From a purely economical point of view, were the mobility component to be withdrawn from young people in residential schools, meaning that they would then have to remain at school for 52 weeks a year, the care costs would far outweigh the mobility payments.</p> <p>*</p> <p>Please think very carefully about the consequences of your decisions. Not all disabled people can be considered as a single group, and for children and young people and their families, the consequences of these actions could be devastating.</p> <p>*</p> <p>Please note that I am writing this email at 1.02am, unable to go to bed because my daughter is unsettled and will need turning in about an hour. Tomorrow we will drive a total of 97 miles to our local children's hospice youth group. On Monday we will be driving from the [REDACTED] into central London for a 9.00am appointment, and then back to [REDACTED] for school, when I will then drive another 45miles home. We also have a therapy meeting and a wheelchair appointment this week, blood tests to be done on Friday and then it starts all over again.</p> |

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| EM225             | 15-Jan-11     | <p>I am writing to you as an individual who has a severely disabled relative in a care home and in response to the governments proposal to the reform of Disability Living Allowance. I'm shocked and appalled at the proposal to remove the mobility allowance component completely from my brother. I understand there may well be a need to review these payments generally, particularly in the current environment where government finances are under considerable pressure but it strikes me as incredibly unfair to in effect impose a greater than 50% reduction in my brothers income – a price far higher then the vast majority of the population has or will be facing over the next few years.</p> <p>*</p> <p>The comparism made between people staying in hospital and those in residential care simply doesn't make sense (like many other elements of this proposal). Hospital is for the most part a temporary state for an individual whereas a care home is permanent and people in hospital for the most part aren't able to (or want to) travel anywhere. They simply want to get better and go home. I'm told that in some cases there are payments made by local authorities to care homes to cover transport needs but in these cases where this is true this money is only intended to cover hospital trips and some communal transport. None of this caters for an individuals individuality needs within a care home situation. Why else would my brother have to pay 61p per mile to use his care home transport. The existing system may well be flawed but it does provide a vital function for people like my brother – support for independence in many areas like accessible taxis and motability car/powerd wheelchair payments.</p> <p>*</p> <p>It is also most confusing to me to read that if an individual pays for there own residential care then they will continue to receive the existing mobility payment. This just does not make sense. In fact none of this makes sense. How can the government justify punishing some of the most needy people in our society in this way. My brother is an intelligent active man who will become a virtual prisoner in his room as a result of this change. This is a cruel and ill thought through proposal which I urge all concerned to rethink. The needs of severely disabled people in residential care are not addressed in the slightest by these changes, in fact they are simply being forgotten about. It's just not right.</p> |
| EM226             | 15-Jan-11     | <p>1. As a wheelchair user I face many barriers, such as lack of access to most shops, trains, tube and also buses as there is only one space for a wheelchair user and parents with buggies harass me if I take the space they need too.*</p> <p>We also face lots of hostility and hate crime, I have been attacked on high streets locally several times, told I should have been killed at birth, a burden on the state etc etc. So I never go out alone as it's not safe as a disabled person. Social activities are also difficult, many take place in old inaccessible buildings, cost too much for someone on a low income especially when I also have to pay for my PA/Carer to attend with me. Health and safety polices have become extremely difficult for many disabled people now. We are a deemed a high risk in buildings; have to be escorted even to the toilet I have found this embarrassing and intrusive.</p> <p>*</p> <p>So there are many physical access issues, the built environment is still hostile, lack of repairs to roads and pavements, lack of ramps to cross roads safely, stairs and doors too narrow. Then there are people's attitudes which are very negative towards disabled people, we are deemed a nuisance, an irritant, costly to employ or include in anything. We also face our own illnesses and impairments. Chronic pain is very disabling regardless of medication which causes tiredness and confusion. I have a Motability car, one I did not choose, but was only one suitable for me and my NHS wheelchair and the pain I have. It costs a lot to run as it's so large.</p> <p>*</p>   |

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|                   |               | <p>I use Taxicard when needing to go up to centre of London for voluntary work as nowhere to park and too long a journey in my own car. This costs as I have to use accessible black taxi. Now taxi cards are to go up in price I will not be able to afford it as just to use it only meets the cost of actually getting my wheelchair in the taxi and strapped in. I get charged for the time this takes which no one else is charged for. I do voluntary work when I can but it costs me to do so in pain, tiredness and travel stress. I want to do it but I get no help from Access to Work which I would if employed therefore no adaptations can be made for me to access venues or get equipment I need in so it restricts me but I try hard to contribute where I can.<br/>*</p> <p>2. The two components, care and mobility. The ability to use Mobility allowance for Motability car, wheelchair, and mobility scooter or towards mobility costs. I think those who have already been assessed as having a lifetime or indefinite award should not have to go through new assessments especially when they would have had to evidence so much to get such an award as I did. There is an assumption those of us with lifetime awards gets this just by a paper application, this is not the case. Many health professionals, social care professionals had to evidence all I claimed.<br/>*</p> <p>3. I have a spinal injury, am a wheelchair user, assumptions are made that as a wheelchair helps my mobility I need less help or DLA when this is not the case.*<br/>I have nerve damage to bladder, bowels and legs and arms, constant intractable pain, asthma, glaucoma, high blood pressure and have to take many medications.<br/>*</p> <p>Utility Bills - I have many electrical accessibility gadgets to help me at home, such as through floor lift, recliner chair, door openers, intercom, wheelchair charger, electric Closimat toilet (made to wash and dry disabled person), adapted power shower put in as adaption by local authority, all cost more to run. Then I need more warmth as cold makes my condition and pain worse so electric and gas bill very high. Due to incontinence I have to shower more then others too this leads to more electric cost for showers and extra loads of soiled laundry.*</p> <p>Personal assistants/carers - I have personal assistants/carers via Direct Payments from Social Services and Independent Living Fund but it cost's to have them in my home all day, they need to use toilet tissue, hand soap, hot water for drinks, extra electric fans in hot weather, medical gloves etc<br/>*</p> <p>I get no extra money to meet this extra cost via Direct Payments as this can only be used for my care needs. If I do manage to afford to go away on holiday I have to pay for a PA/carers to come with me which means an extra bedroom, this means I have only had three holidays of one week each in UK in 20 years. I have not been able to afford to attend my sons wedding due to this extra cost. I also have to pay for my PA's attending any social events with me like entrance fees, not all venues/events allow a carer to have free entry.*</p> <p>Motability wheelchair accessible vehicle - I have a large Motability wheelchair accessible vehicle which uses a lot of diesel, I did not choose this large car, Motability said it was the only one suitable for me but it does cost much more to fuel then a smaller and more economical vehicle. *<br/>I also had to pay several hundred pounds in down payment towards this vehicle as do most users of Motability. We do not get this refunded and we are only allowed to keep the car for 3 or 5 years then we have to pay out again to lease another car.*</p> <p>NHS Electric Wheelchair - I have to insure my NHS wheelchair; it is a requirement of having the chair. I have to buy special clothes suitable for sitting in wheelchair and not restrictive to my spine.<br/>*</p> <p>Special rain covers and leg covers for my wheelchair which get damaged by</p> |

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|                   |               | <p>the wheels on the chair and have to be replaced regularly and are very expensive.<br/>*</p> <p>Accessible home - I live in a large council house which has been adapted to my needs, its far too large I would like smaller more economical home but have no choice so all my household bills are more costly as I need accessible home but very few in my local authority.<br/>*</p> <p>Heating a large house to my needs is extremely costly.<br/>*</p> <p>Illness/Pain Equipment/medication - I have to buy equipment myself such as TEN's machine and replacement pads ( this is used for pain), Nebuliser for asthma medication, prescription glasses as I only get one lens covered by NHS yet I need glasses in car, living room and bedroom, I cannot carry one pair around with me.*<br/>I have to buy heat pads, hot water bottles, specially adapted mattresses for my electric bed, memory foam mattress topper and pillow.<br/>*</p> <p>NHS and LA do not provide small pieces of equipment like special cutlery, food trays, adapted kettle holder, picking up stick, adapted trays, or add on equipment for my wheelchair like cup holder and lights.<br/>*Extra Shopping - Extra personal washing toiletries to due to extra bathing requirement due to incontinence Extra towels and bedding due to extra washing wear and tear and bed changes.<br/>**</p> <p>Extra cost of having some ready meals for when PA's not available as I cannot cook food<br/>**</p> <p>Incontinence pads suitable to my needs which are not supplied by NHS as I am allergic to their ones.<br/>**</p> <p>Computer - I can only use a laptop computer as cannot sit at table as I have to recline so have it on my lap. I cannot read documents on screen, due to visual impairment, so have to print all papers including consultation documents like this one to read. Extra cost of printer ink and paper.<br/>*</p> <p>I use computer to socialise online as cannot get out and about much, also for voluntary work, its essential to my life but no one will pay for adaptations I need so I have to pay for Speech software and related software.*<br/>Charges for Care - Half of my DLA high rate care component is taken as charges for care from ILF or local authority. This should not be the case DLA is meant to cover extra cost of being a person who needs care not to pay towards the care itself. It is not appropriate to charge disabled and elderly people for care as we all pay taxes anyway, we should not have to pay twice for such a service as no one else pays for public services twice, do they?<br/>*</p> <p>4. It may make it easier but it depends how many questions that are asked in each section and how much detail is required. I am concerned that the range of disabling factors will not be captured in just two levels.<br/>*</p> <p>• What, if any, disadvantages or problems could having two rates per component cause?*</p> <p>Those with lower care and mobility needs may not qualify as bar may be too high for them.<br/>*</p> <p>Remember it's not dependent on what equipment or adaptations we have as these have extra cost included too. Each person's impairment and its impact may be different, some may get good health care, support and equipment others may not it is a postcode lottery out here. It should not be assumed that what is deemed as a lesser impairment means less extra costs.</p> |



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|                   |               | <p>*<br/>5. No there should be some automatic entitlement as having certain medical conditions does mean certain level of support and extra cost will be incurred. I think this should actually be widened as at the moment some severely disabled people are put through repeated assessments which are not necessary and not cost efficient. For instance Muscular Dystrophy does not go away or get better it gets worse over time so needs increase. A spine injury does not go away, nerve damage does not repair itself after a certain period of time.<br/>*</p> <p>6. I think you should be prioritising any disabled person who has extra cost related to being a disabled person, to do otherwise would flout Equality Act and Human Rights.<br/>*</p> <p>The human rights act details quite clearly what is essential for our lives.<br/>*</p> <p>But here are some factors to consider;<br/>*</p> <ul style="list-style-type: none"> <li>- There are huge cuts in local care services to disabled people regardless of your intent this is fact and happening now.<br/>*</li> <li>- This means DLA or Pip will be even more essential to all who need care and help with mobility.<br/>*</li> <li>- I cannot go out of my home on my own, if my care is cut which I have been told it may be I will be trapped in my home.<br/>*</li> <li>- I have ILF which is to be scraped, yet no extra funds are to be available to local authority to take over this extra cost of more care needs I have been assessed as needing.<br/>*</li> <li>- Also I have been attacked several times as a disabled person, for my safety I need someone with me let alone for mobility issues.<br/>*</li> </ul> <p>I would like to see more assistance and recognition of disabled people doing voluntary work which is suitable for them, this will not happen if DLA is taken away or reduced.<br/>*</p> <p>Also I do not think applying 'models' should constrain an assessment process, it is human beings you are dealing with not machines, also a society that still perceives disabled people as something less than valid, best to be aborted, assisted to die or segregated or killed off, this is my, and our, reality.*<br/>Whilst the Social Model of Disability helps society think about how it 'disables' us it does not lend itself well to assessments based on how our impairments cause extra costs and need.<br/>*</p> <p>Family life is important as is the freedom of choice about where/who provides our care, social activities, voluntary work, provisos for meeting religious/cultural requirements is also essential.<br/>*</p> <p>Mental and physical health and wellbeing is essential.<br/>*</p> <p>Being able to plan a journey does not equal the ability to do the journey on your own or meet its costs. The fact I can articulate myself does not mean I need less help, it just means I have intelligence in how I write but you do not see me lying in bed doing this with specialist medication and pain support.<br/>*</p> <p>I can plan a shopping trip but cannot do it unless I have Carer with me and money to meet costs of accessible travel, I can plan a meal but cannot prepare, cook it, serve it up or eat it without assistance.</p> |

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|                   |               | <p>*<br/>I know when I need a wash but cannot do this with out support, accessible equipment/shower, carer to wash me, and adequate clothing, towels ect. I can plan a journey to socialise but cannot do it on my own without regard to my safety, accessibility, travel arrangements and extra costs plus cost of taking carer/PA with me.</p> <p>*<br/>Your thinking around this is not suitable as it does not recognise how many complex factors affect disabled peoples lives. We do not fit in boxes or simple questions like 'planning and making a journey', if you went by that criteria I would not be entitled to DLA at all as a full time wheelchair user, yet I cannot even access my wheelchair without a whole load of support, equipment and extra costs.</p> <p>*<br/>Let alone manage the medical conditions I face with acute pain a factor in every aspect of my life.</p> <p>*<br/>7. Certain conditions are variable from day to day yet the impact on the home, travel, work, social life etc is the same. If you know sometimes you will fall over then you need equipment on hand whenever you need it plus support, adaptations, all sorts of things on stand by. The uncertainty of a variable condition is extremely stressful and caution has to be taken at all times so a disabled person is safe and prepared. So I can see one off cost for certain pieces of equipment may help. The type of variability needs also to be assessed, is it day by day or months at a time, how sudden do things change, how much warning do you get?</p> <p>*<br/>8. I think there is flawed thinking here, just having an aide or adaption does not mean all problems are resolved for a disabled person as I have detailed above. I have electric wheelchair but it actually causes me more problems not less. Of course it does assist my mobility in my home and getting out but it does not overcome broken pavements, broken roads, steps to get in shops or other peoples homes, narrow doors and peoples negative attitudes towards wheelchair users due to derogatory media and government comments as well as deeply held stereotypical beliefs re disability.</p> <p>*<br/>Prejudice and discrimination is a fact in every aspect of our lives. The fact we may need a certain adaption or aide should help indicate level of impairment a person has, not to lesson DLA as for each aide and adaption come extra costs as detailed above in Q3</p> <p>*<br/>Also you are making assumptions about the availability of aides. NHS wheelchairs are extremely difficult to qualify for and you can only get an electric wheelchair if you need it indoors as well as outdoors. So many have to buy one themselves or use Motability scheme to help which they can only do if they qualify for middle or high rate DLA mobility, which again is an extra cost.</p> <p>*<br/>The cost of disability related equipment and accessories are extremely high, equipment breaks, needs to be repaired or replaced. Accessories wear out, get broken, need replacement again and again. The fact I have a wheelchair does not mean my pain is less or condition will not deteriorate. It's a tool like a car, much appreciated, but costly to run and difficult to use in the town environment.</p> <p>*<br/>The extra costs of being a wheelchair user is not lessened by getting the wheelchair it goes up.</p> <p>*<br/>I have adaptations to my shower its now a Wet Room, made safe for me to use but I cannot use it on my own, I need the help of a PA/carers to ensure safety and wash properly due to my limitations.</p> |

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|                   |               | <p>*<br/>I have a through floor lift to get up to first floor of my home, this does not mean I need less help to go to the toilet or bed, it just means my wheelchair can get upstairs nothing more. Using it costs more in electricity.</p> <p>*<br/>I have partial adaption to my kitchen so a work top is at wheelchair level, this does not mean I can prepare, cook and serve a meal it just means I can participate with help of my PA/Carer in saying what food I want, how to cook it and watch the process.</p> <p>*<br/>My garden has been made accessible for my wheelchair, this does not mean I can do gardening, it means I can enjoy this space and be involved in choosing how my garden is cared for.</p> <p>*<br/>I do not see how having a certain adaptation automatically means some need less support, this is just not the reality, often it makes it easier for the PA/carers to help us, means we can access parts of our home we could not before or be a bit more comfortable and safe. Not one of my adaptations equals less extra cost of being a disabled person they equal more costs like in electric bills and accessories.</p> <p>*<br/>I have an adapted wheelchair accessible car, which costs a lot to fuel so I use it only for essential journeys. It does mean I can go out in my wheelchair further then locally but I cannot do this on my own, I need help to get wheelchair in car and safely strapped in, help when I get out and help where I am to be. The back door and ramp are electric but someone has to ensure no one is walking or standing behind the car who would be hurt when door/ramp opens.</p> <p>*<br/>Controlling a wheelchair takes focused attention to ensure mine and public safety, I cannot carry shopping or bags, I have been attacked several times, hate crimes even when I have PA/Carer with me so will never risk being out totally alone now its not safe for us.</p> <p>*<br/>When I have used a black accessible taxi I have to have help to get in and strapped. I have had three accidents with taxi ramps where they have been faulty or driver does not guide me correctly, the drivers do not know how to safely restrain me. I rely on my PA's/Carers to keep me safer, they know what help I need and what is safe or not for me.</p> <p>*<br/>When I am out at a venue or meeting I cannot get around on my own, I need doors opened, obstacles moved or find way around them, find safe ways to cross roads, avoid crowds, access toilet.</p> <p>*<br/>I have had several accidents in accessible toilets due to equipment being faulty and not maintained.</p> <p>*<br/>Even when in supermarket I get knocked in face by peoples bags, trolleys knock my wheelchair causing pain, people get irritated, I cannot put food on till area or pack it or carry it. All these I need help with from door to door.</p> <p>*<br/>My fear is not about not using my aides, I could not live without them, its about assumptions that are made that a particular aide is interpreted as me therefore not needing any help or having extra costs.</p> <p>*<br/>Fantasying about what help a disabled person would need if it was imagined they had a wheelchair for instance is idiotic. Please focus on a person's reality, equipment does not equal less extra cost for the disabled person it equal more cost if you are to use this criteria at all.*<br/>9. I do not believe this consultation is genuinely about increasing the uptake of benefits or allowances disabled people are genuinely entitled to. If it was it</p> |

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|                   |               | <p>would not have an automatic goal of reducing use by 20% regardless of need. Any changes and publicity would have to be made fully accessible for all disabled people and support provided to fill in forms and access appeals process.</p> <p>*</p> <p>10.It's really important not to add repeated assessments by additional processes which cause stress and anxiety to disabled people. Such assessments can become abusive in and of themselves if used in such a way. Care Managers, Specialist consultants who have treated the client, Clients GP, Specialist Practice Nurse who has treated the client, Occupational Therapist who have assessed the client, Physiotherapist who have assessed the client, Therapeutic Counsellors or Psychiatrist who have treated the client*</p> <p>ONLY these have the in depth knowledge of how the persons illness or impairments impacts on them in daily life, its impossible to get a correct assessment by a strange assessor who has no specialist knowledge of the ongoing impact of the persons medical conditions which are often multiple.</p> <p>*</p> <p>For instance I have a GP, Neurosurgeon, Pain Clinic Consultant physiotherapist, occupational therapist, Asthma nurse practitioner, Social care manager, Incontinence Nurse Practitioner, Specialist bowel physiotherapist. All these know my illnesses and how they impact me medically. But they are focused on different aspects of my body/impairment, they do not see the whole picture</p> <p>*</p> <p>BUT they do not know how I manage my daily life for that you need to have the client describe how they do or don't manage. Many disabled people find it hard to get access to specialist consultants due to NHS cutbacks which can also mean a condition may be well managed or treated for one but not another. The current brief ATOS medicals are totally inadequate to assess complex impairments and conditions and the ongoing impact on what a person can or cannot do.</p> <p>*</p> <p>You cannot see my pain, you can know the prescribed medications I take for it, the strategies I use to try and cope, but only I can tell you what its like day in day out to have such pain, the side effects of strong meds, the tiredness and depression it causes. I have been diagnosed with Centralised Sensitivity, a pain condition, which means any movement or slight bump or bruise can cause acute pain response. Only my Neurosurgeon, Pain clinic consultant and physiotherapist know what this condition means. Only I know what I can and cannot do. There is no way a midwife, nurse, or locum doctor would know about the impact of such a condition.</p> <p>*</p> <p>11. I think when a person has multiple health care professionals already dealing with them it's a waste of time and money, stressful and at times abusive to require yet more face to face sessions with strange health care professionals. I certainly would find it threatening and unhelpful considering how much evidence my own health care professionals could give.</p> <p>*</p> <p>I think you should take this into consideration, that if a disabled person has multiple health care professional engagements already another one off visit is not appropriate or likely to capture the whole picture. Use current providers for clients to do assessments. It can be very difficult as a severely disabled person to travel and get to appointments, if dependent on social care provision, health issues and accessibility of travel arrangements.</p> <p>*</p> <p>Therefore home visits would have to be done but this invades a person's privacy and they may have relatives or carers who they do not want to know all their health issues. I do not want my son to know all my incontinence issues for instance. Yet he would be present in any home visit from a stranger for my safety. If you used/commissioned/ paid one of the current</p> |

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|                   |               | <p>clients health care providers to do the assessment it would relieve stress and ensure appropriate assessments take place.</p> <p>*</p> <p>12. It's a waste of money and resources to repeatedly review disabled people with conditions that will not get better or go away. So for instance a spine injury and nerve damage which I have will not suddenly get better, arthritis sets in as years go by and condition worsens. If the person is to have surgery which may improve the condition a report from the consultant concerned may be enough.</p> <p>*</p> <p>13. It's hard enough being a severely disabled person without thinking what possible changes I have to report especially when most see this as automatically meaning payments will be cut or taken away. The list of changes has got too long, an annual questionnaire asking about any specific changes would be good I think rather than expecting everyone to remember what is classed as a change. So you could ask what medication a person is on, any surgery, changes to family relationship like marriage, social care provision, etc etc. Obviously this needs to be unthreatening, not too complicated, but routine. If not filled in then let people know what penalties this would mean in a non threatening way. Like first send written reminder, then phone or send email, then ensure person has actually received the form and get any help they need to fill it in. After all if I am in hospital or too ill to do forms it will be postponed due to no fault of mine.</p> <p>*</p> <p>I would like to see the threatening stance we get from DWP change to one of constructive advice, support and assistance to help compliance. After all we are all tax payers, my four kids are tax payers too, so as someone who pays for this service we should be treated more appropriately. Many people would have no jobs if it were not for the needs of disabled and sick people. Its hard enough coping with severe illness and disability please do not make the processes cause more distress, anxiety and upset.</p> <p>*</p> <p>14. Funding must be provided to independent organisations to provide support like Citizens Advice bureau, disability organisations, advocacy services. This would be required for;</p> <p>*</p> <p>Form filling Understanding what is being asked. Complaint and appeal processes</p> <p>*</p> <p>Independent Advocacy for those who cannot process such applications themselves.</p> <p>*</p> <p>15. An independent service provided by a disabled peoples organisations would be most appropriate, empowering, give employment opportunities for disabled people and assist networking and confidence.</p> <p>*</p> <p>16. Individual Budgets which are meant to be rolled out are meant to help disabled people fund equipment as well as care but in reality there is less and less finance for this due to spending cuts so not realistic at all. Access to funds for one off payments for equipment which would enable a disabled person would be very good but the ongoing cost of having such a piece of equipment needs to be understood and cost met by new PIP This could be for insurance, maintenance, repair, and running costs. I have most of my equipment supplied by NHS but the assessment processes often exclude many disabled people and as with all such services budgets have been cut so getting this equipment is increasingly difficult. There are some charities that fund some types of equipment but again you have to know who they are and how to apply.</p> <p>*</p> <p>17. You have to work with the family as they are the carers of the children as well as evidence from associated health professionals</p> |

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|                   |               | <p>*<br/>18. The mobility component of DLA plus a grant has enabled me to have a wheelchair accessible vehicle which has changed my whole life, it means I can socialise, do volunteering, keep to my faith commitments and have a family life and some independence. I do think more information should be provided during application processes, as I did not know my full entitlements till several years after my spine injury.<br/>*</p> <p>I DO NOT think DLA or PIP should be taken away as charges for care. Recognising that someone who needs social care automatically has extra costs is what this allowance is about regardless of income. Giving with one hand and taking away with another is bewildering and distressing.<br/>*</p> <p>Due to charges for care half my DLA care component is taken away, so I am left with very little to meet a small portion of my extra costs. It should be obvious that if someone has mobility difficulties they will need to access the Blue Badge scheme. If they are not earning much or not able to sustain paid employment and therefore on very low income again the extra costs of being a disabled person needs to be recognised and assistance given. I DO NOT think DLA or PIP should be a qualifying factor for social care as it has been for Independent Living Funds. This should be assessed and met as required.<br/>*</p> <p>19. The immediate impact would be; - Loss of access to Motability Scheme, which would mean loss of wheelchairs, mobility scooters and accessible cars this will result in loss of ability to travel to work, maintain employment, volunteering activities, religious activities and family life.<br/>*</p> <p>Also huge impact on disabled person's ability to get out of their home.<br/>*</p> <p>-Repeated and unnecessary assessments are costly to administer can cause delays and extra barriers for disabled people to overcome<br/>*</p> <p>- Need for advocacy and support would be increased*<br/>- The change over could lead to disabled people being left in severe poverty and distress, some would not be able to manage or cope, some will commit suicide as the barriers they face become too much to cope with when so poorly. Some have done this already.<br/>*</p> <p>It has to be recognised that disabled peoples lives can be extremely complex, like a tower of cards, remove one form of support and the rest falls down.<br/>*</p> <p>For instance I am on Independent Living Fund which is to be scrapped after 5 years, its assumed that local authority will meet the extra care cost that the ILF have met for severely disabled peoples assessed care needs. Yet the reality is there is no extra funds given to LA's so the impact is care will be cut to severely disabled people possibly by half. This will mean the person has to find help from family or volunteers or go into residential care a much more expensive option.<br/>*</p> <p>Stress of family carers will increase, they may have to stop working so they can care for the disabled person, the independence of the disabled person is then affected. Any activities which were enabled by extra care package stop, no voluntary work, no faith activities, no social life, increased risk of accidents and deteriorating health due to lack of sufficient care. NHS will be left with more beds blocked due to no care for newly disabled people, or affect of reduced care.<br/>*</p> <p>-Residential care homes will become overloaded as less and less care and support is given to disabled people due to all your spending cuts.</p> |

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|                   |               | <p>*<br/>20. I do not agree with DLA or PIP being used or linked to social care entitlement. An assessment for PIP could not possibly assess the complicated health and personal care needs of an individual, it would be intrusive and invade privacy. This also applies to sharing information; I do not want my personal health and care needs shared across so many departments and people. We are all entitled to some privacy and respect. Electronic data has often gone missing, stolen, been mislaid or accessed by those not allowed to access it. Protecting such information is of the utmost priority and therefore should not be automatically accessible to local authorities or health providers.*<br/>I think legal cases will ensue if this happens.<br/>*</p> <p>21. Disabled people are part of all communities and ethnic group, all religions, have families, work and a life. DLA was the one allowance that recognised this regardless of our differences our joint experience of being disabled means we are always at a disadvantage in society unless those in government recognise we should have as equal human rights as others. Violations of human rights can be insidious such as this one deciding a 20% cut regardless of need contravenes disabled peoples human rights.<br/>*</p> <p>22. DLA Mobility for people in residential care should not be stopped. This has been a heartless and discriminatory decision based on assumptions about the local authority's provision of equipment, and mobility assistance in care homes that is totally false.<br/>*</p> <p>The reality is very little is provided by inexperienced staff. Budgets are less and less and the individual needs become less then important. Electric wheelchair and mobility scooters are NOT supplied to residents, nor are accessible vehicles so the person can drive, or family member can drive to do social visit and activities.<br/>*</p> <p>I am very concerned about the assumptions and implications of some implied decisions that have been made without considering the impact. Repeatedly in this document you refer to only meeting the needs of severely disabled people, and then only partially.<br/>*</p> <p>Yet the impact of an impairment or illness cannot be categorised this way if you really do wish to use the Social Model of disability. A person who can walk with assistance of crutches faces the same barriers that a wheelchair user does, their impairment may be what on the outside appear less but the pain, difficulty trying to travel, shop, care for themselves may be just as severe. *<br/>They will certainly face discrimination, prejudice and hostility. The assumptions that equipment, adaptations and changes in society over last 17 year has improved disabled peoples lives so much they have less extra costs or 'barriers' to face is ridiculous.<br/>*</p> <p>The cost of living has gone up for everyone, the cost of maintaining and running disability equipment is extremely high, utility costs are huge escalating every day. Renting or buying an accessible home is costly, choices are very limited. Social care has become harder and harder to access and get due to local authorities cutting the eligibility for care leaving those with low and moderate care needs to struggle by themselves till they get sicker or have an accident due to lack of care.<br/>*</p> <p>Attitudes which were beginning to become more positive towards disabled people has swung now to perceiving us as fraudsters, a cost too far as this document says 'unsustainable' certainly encouraging others to think our lives are less valuable to society, too costly to maintain.<br/>*</p> |

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|                   |               | <p>Whilst legislation is slowly improving re equality it is not backed up by the full redress in law for disabled people that it should be. Access to legal aid is to be so limited no disabled person in poverty will be able to challenge discrimination when they experience it. I believe this consultation is inherently flawed based upon assumptions and beliefs which have no basis in fact or the reality of sick and disabled peoples lives.</p> <p>*</p> <p>I struggle every day to keep out of debt, budget well, contribute to society, assist other disabled people</p>   |
| EM227             | 15-Jan-11     | <p>I am the mother of a young man who has autism, severe learning difficulties and severe behavioural problems and has been claiming DLA for some years.</p> <p>*</p> <p>Quite simply I ask that the needs of people with mental disabilities are recognised as much as those with physical disabilities. Currently the DLA form is biased towards physical disability and it is very hard to find the right place on the form to explain about my son's disabilities.</p> <p>*</p> <p>Please understand that autism, severe learning difficulties and severe behavioural problems ARE a severe disability and make it incredibly hard for my son to access a 'normal' life.</p> <p>*</p> <p>Please also employ relevant professionals to deal with claims - in our case, my son's case was reviewed by a GP and nurse, both who clearly had no understanding of autism, severe learning difficulties or severe behavioural problems - and I ask, would you ask a psychologist to examine a broken leg? Of course you wouldn't so why would you ask a GP or nurse to assess someone with autism or mental incapacity? It is not their area of expertise, so PLEASE employ people who understand these difficulties and can accurately assess their case.</p>  |
| EM228             | 15-Jan-11     | <p>My partner was diagnosed with M.E. 15 years ago and has been unable to work since. Previously she worked as a full-time nurse for 24 years. The present government's rather sinister idea that people like my partner should be 'helped back into work' is wrong and, in essence, cruel. What they should be doing is helping people to get back to a level of health where they are once again able to work. If people are unwell, the priority should be making them healthy again, not forcing them to work. In the meantime there are plenty of people well enough to do the work that needs to be done. Concentrate on creating jobs for those that enjoy good health. A compassionate society should aim to give meaningful work to those that are able, and to care for those that are less able. That care should involve trying to restore their health; instead of this the reform proposals run the risk of worsening the health of the unwell by emphasising the supposed benefits of returning to work, when the effects of this return will often be negative and counter-productive. Employers don't want to take on people who, at worst, are simply not well enough to work, or, at best, have been arbitrarily classified by non-experts as having some marginal ability to do a bit of work. Like the rest of us employers will surely recognise that health must be the priority. Work comes second. The proposed reforms will lead to the harrassment and persecution of some of the most vulnerable people in society. Let's put kindness before cruelty. The entire package of benefit reforms, including the DLA reforms, should be scrapped. (I have written this on behalf of my partner as she cannot sustain the concentration levels to sit at a computer screen and type a message of this length, without becoming unwell.)</p> |



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| EM229             | 15-Jan-11     | <p>Q4 - Will having 2 rates per component...? Having 2 rates for each component should make it easier to differentiate between individual needs and simply the process for claims. It should also minimise the need to appeal. The daily living component must consider the night time needs. Even though individuals are normally asleep there would obviously be times during the night when they wake up and their needs are at least as much as required during the day. Where individuals have severe learning difficulties waking up at night can often be traumatic, leading to unpredictable behaviour.</p> <p>*</p> <p>Q5 - Should some health conditions ..? In principle yes, certain impairments should mean automatic qualification. In our case we have a 21 year old daughter with severe learning difficulties, although in normal physical shape. If it were possible to describe the mental ability in terms of age we would say an enquiring toddler. The problems we have encountered over the years are that her needs have normally been underestimated as the impact of mental impairment on normal daily living is hard to pin down.</p> <p>*</p> <p>The system needs to recognise that some individuals in this category need constant supervision.</p> <p>*</p> <p>The reasons for this are many, although in our case behaviour exhibits itself on an ad hoc basis as:</p> <p>*</p> <p>very unpredictable , aggressive , instant mood swings, complete mobility freeze - a sort of mental shutdown, a complete disregard for personnel safety</p> <p>*</p> <p>The current system requires you to estimate the numbers of times in a day certain behaviours occur.</p> <p>*</p> <p>The problem we have found with this approach is that the number of times something happens is not in direct proportion to the scale of need or care unless the risk of injury or harm is discounted. The way we have minimised the amount of this type of behaviour is to restrict access to certain activities and environments. This can be double edged sword since whilst behaviour generally is improved, daily living becomes limited and restrictive, and the individual is slowly cut off from the community. In summary, our experience of individuals with severe learning difficulties is that they require constant care and attention and we hope the new process will reflect this.</p> <p>*</p> <p>Q6 - How do we prioritise...? We would consider the ability to access the local community, get out and about as key.</p> <p>*</p> <p>Q9 - How could we improve...? In principle we agree the forms should be refocused on what an individual can do rather than the negative aspects, although it is only by stating the negative aspects (refer to answers to Question 5) that needs can be fully assessed.</p> <p>*</p> <p>Q11 - An important part of the new process.... In principle we agree this is essential. The difficulty occurs when the needs are not easily identified. However providing the assessment enables carers/parents to state those needs on behalf of the individual then it should work. In our case a 3<sup>rd</sup> party would need to observe/live with our daughter for a few days to understand the nature of the problems.</p> <p>*</p> <p>Q18 - How important or useful has DLA been? We consider access to the motability scheme is essential for our daughter to avoid being imprisoned in her residential care home as the carers, quite rightly, are unable or unwilling to use their own vehicles to get her out and about. We note the intention to cease the motability scheme for those in residential care. In our case this may mean we seriously reconsider whether leaving our daughter in care is</p> |

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|                   |               | <p>the right option. We only hope that if we do ultimately consider having her living back at home by my wife giving up her part time job, that suitable support networks will be put in place eg day care, access to respite etc.</p>  |
| EM230             | 16-Jan-11     | <p>I am responding to this consultation as an individual who is in receipt of Disability Living Allowance.</p> <p>*</p> <p>Q1 - In my opinion there are a variety of barriers facing disabled people and many of these will depend on the precise nature of their disability. However, some of the common themes include physical considerations (inaccessibility for certain disabled people of the physical environment, public transport etc) but also issues of perception, both self-perception and the perception of others. It is often the case that even a relatively small adaptation can make all the difference to a disabled person, for example in the workplace and this can dramatically increase the ability to live a full and independent life.</p> <p>*</p> <p>So, from my personal perspective, the simple purchase of a computer with screen reading equipment allows me to work as a manager within a busy NHS environment. Outside of work, the fact that I receive DLA enables me to pay for taxis to visit friends and participate in social activities as public transport can be challenging in terms of access. Therefore, I fully agree with the sentiments in the Consultation Paper around maintaining the "extra cost" nature of DLA enabling people to use the benefit in the way that best fits their needs.</p> <p>*</p> <p>Q2 - I agree with the points set out in the Consultation Paper that are to remain the same and believe that this captures all points that should remain unchanged.</p> <p>*</p> <p>Q3 - The extra costs faced by disabled people would seem to me to be those associated with transport, where public transport may not be fully accessible to disabled people (as a blind person I certainly find this to be the case). In addition, whilst help is available for the purchase of specific aids and adaptations to assist disabled people, the costs of such remain high and DLA is an important way of offsetting some of these. For the most disabled there will also be the need to consider the costs of personal care, and it is at those with the most complex needs that greatest resource should be targeted.</p> <p>*</p> <p>Q 4 - I think having two rates for each of the two components will make the benefit easier to understand and administer. The potential disadvantages of this approach are that it creates more of a "all or nothing" system, with the potential for less discretion at the margins.</p> <p>*</p> <p>Q 5 - I am generally in favour of the concept of looking at an individual's specific case rather than automatic entitlement due to specific medical conditions or disabilities. However, for certain individuals with certain conditions that neither improve nor deteriorate there seems more justification for automatic entitlement to certain rates of benefit, as their situation is unlikely to change dramatically. From a personal perspective, I am registered blind and that condition will not improve, nor will it deteriorate. So if I were entitled to a particular rate one year it seems reasonable to assume that the entitlement would continue unchanged as my disability also continues unchanged.</p> |

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|                   |               | <p>*<br/>Q 6 - I think that the activities suggested in the Consultation Paper that may form part of the assessment process strike the correct balance. I would agree that the current system has become overly bureaucratic and does not reflect the realities of life for many disabled people, focusing as it does on what a person cannot do rather than what they can. I think the more objective, person-specific assessment methods discussed in the Consultation would be more appropriate, although clearly further work is required on developing these.<br/>*</p> <p>Q 7 - The question of fluctuating conditions is a difficult one. Perhaps for certain of these conditions a more regular assessment process will be necessary to ensure that the payment accurately reflects an individual's circumstances. This seems to be an area where it is particularly important that an objective and individual approach is taken to a person's needs.<br/>*</p> <p>Q 8 - I am fully in agreement that aids and adaptations utilised by disabled people should be taken into account when determining their entitlement to DLA. However, this must not discourage the successful use of such adaptations, and should certainly encourage the use of adaptations that the person may not have but that may be beneficial to them.<br/>*</p> <p>Q 9 - I think that the form could be adapted so that it poses questions about what a person can do rather than what they cannot. I also find that, as a blind person, I often have to rely on someone else to assist me in filling in the form as it is not possible to complete it online etc. I think that this would be a welcome development. Perhaps a more interactive process would also be beneficial with a discussion as opposed to a lengthy form to determine eligibility.<br/>*</p> <p>Q 10 - I agree that evidence from a variety of professionals is required. However, I also believe that for many disabled people they themselves are in the best position to discuss their abilities and needs. I therefore think that an appropriate balance will need to be struck.<br/>*</p> <p>Q 11 - See comments above – I think that in most circumstances it will be appropriate for a face-to-face interview to take place. I agree though that in certain circumstances, for example very complex disability, this may not be appropriate but I think that this will be the minority of cases.<br/>*</p> <p>Q 12 - Reviews should be dependent on the specific needs of the individual and the likelihood of their condition or impairment changing substantially over a given period of time. As stated above, for certain individuals with certain long-term conditions, for example sensory impairments, where these do not change substantially the period of time between reviews should be longer than for those that undergo significant changes. I also think that consideration should be given to a person's individual circumstances, for example whether they are in work etc. Perhaps reviews may need to take place more often for those deemed able to work but who remain out of work.<br/>*</p> <p>Q 13 - I think that it will be necessary to give recipients a better understanding of what constitutes a change in circumstances. With better explanation I think it entirely appropriate that people should be required to take responsibility for reporting changes in their circumstances and the accompanying penalties for failure to do so.<br/>*</p> <p>Q 14 - I think that the Consultation Paper accurately identifies some of the help and signposting that may be necessary and I think that it would</p> |

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|                   |               | <p>be beneficial if advice and information on the help available were to be provided along with the claim process.</p> <p>*</p> <p>Q 15 - I think that such a requirement could encourage claimants to take action. Clearly this would need to be carefully worked through with the advice of those that help disabled people, for example charities etc.</p> <p>*</p> <p>Q 16 - As aids and adaptations are such an important part of increasing independence, I think that there should be the option of funding one-off aids that would assist an individual and potentially reduce their need for ongoing long-term support.</p> <p>*</p> <p>Q 17 - I do not feel that I am qualified to offer an answer to this question.</p> <p>*</p> <p>Q 18 - I think that DLA is an important way of gaining access to other services and entitlements, and I believe that this aspect should remain available under the new entitlement. I think that better information and publicity around the other services etc that can be accessed by means of DLA would be useful – perhaps this could be provided at the time of first applying for the benefit and updated on a regular basis to take account of any changes.</p> <p>*</p> <p>Q 19 - I think that were it not possible to gain access to other services by means of DLA or PIP there would be a general lack of awareness of the existence of such services, many of which could be of significant benefit to disabled people. This would clearly also have implications on the providers of services for disabled people, many of whom are charities, as they would need to invest greater resource into marketing and awareness raising to disabled people. This would have the effect of reducing the amount of resource available to frontline services which I believe would be a backwards step.</p> <p>*</p> <p>Q 20 - Whilst I do not have detailed knowledge of the various entitlements available to disabled people in different circumstances, I think that the concept of information sharing across government departments is a positive one if it leads to less duplication and assessment. Whilst this would clearly have to be carefully managed to ensure confidentiality etc I believe that the basic concept is a good one. The type of information that might be shared would include letters from professional practitioners on the individual's circumstances, results of assessments and reports etc. This would have the benefit of ensuring that the same information was not requested from the same person by different departments.</p> <p>*</p> <p>Q 21 - I do not feel that I have a detailed enough knowledge of the various equality strands to usefully comment on this question.</p> |
| EM231             | 16-Jan-11     | <p>I have just been reading all the dreams you have regarding on how disabled people, both physically and mentally can get better, by reducing and reforming the little benefit they get at the moment. All you Governments keep going on about is, how you admire the carers on the amount of work they do to the society, yet you put on so much pressure when you start reforming and changing their benefit system, not particularly for their benefit but yours.</p> <p>*</p> <p>More than anything you should be increasing the amount of money disabled people and carers get and leave their benefits reform in the hands of the charities who understand what these people need NOT YOU.</p> <p>*</p> <p>My daughter has autism, not the kind you see on TV sometimes where they show you the intelligent parts, I am talking about the bits you don't see, the violence, tantrums', routines, up all night, walking the streets, running off and being trapped in your home without a social life and unable to access certain</p>  |

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|                   |               | <p>shops before they close. Your reforms are not going to put this right, they are just more add on worry for the carers and their disabled relatives.</p> <p>*</p> <p>The only thing that you should be looking at is the more pressure that's been put on the carers and their disabled relatives by introducing the suing society against people like my daughter and me her carer, we have to find insurances and pay for any damages their disability causes the general public.</p> <p>*</p> <p>LEAVE THE DLA ALONE IT SERVES THE PURPOSES IT WAS MEANT FOR ORIGINALLY IT DOESN'T NEED LESS MONEY IT NEEDS MORE.</p>  |
| EM232             | 16-Jan-11     | <p>HUG (ACTION FOR MENTAL HEALTH) HUG is a group of people with experience of Mental illness in the Scottish Highlands. It has about 400 current members most of whom are in receipt of benefits, many of these on being DLA. The following is a response from the HUG Friday Forum about the above consultation, it involved 7 members mainly from the inner Moray Firth Area. The HUG Friday Forum is a meeting where more active members can look in detail at documents such as this. This response could also be accompanied by our reports on benefits and employment which can be found on our website hug.uk.net and which generally include the views of 80 – 90 people. We have a report on poverty in production which involved the views of 88 people 93% of whom are in receipt of benefit. That report could be supplied in draft form if requested.</p> <p>*</p> <p>*</p> <p>Question 1 Access to buildings is hard for people with other disabilities but can apply to people with mental health problems who sometimes find noisy and busy public spaces hard to cope with</p> <p>*</p> <p>People with mental health problems often feel excluded by wider society.</p> <p>*</p> <p>People with mental health problems often become isolated and can be unable to associate with other people as a result of illness and stigma from other people as well as self stigma.</p> <p>*</p> <p>Being ill is in itself a major barrier to independence and participation.</p> <p>*</p> <p>Being exploited as a result of being vulnerable because of mental illness can be a major barrier.</p> <p>*</p> <p>Stigma about mental illness is an important barrier</p> <p>*</p> <p>Discrimination as a result of mental illness especially in work is a major barrier.</p> <p>*</p> <p>Low self esteem and confidence can be a result of illness, exclusion and the self image mental illness provokes in us. This can lead to lack of ability to participate in society or have friends or acquaintances.</p> <p>*</p> <p>Feel low is something many of us feel, especially those of us with depression– this can cause us to lack motivation which can lead to an increasing spiral of mental illness and physical illness and which can make it hard to engage with ideas of recovery.</p> <p>*</p> <p>Mental Illness varies and can cause – inability to: travel, work, concentrate or do daily activities such as cleaning cooking, organising everyday life.</p> <p>*</p> <p>Mental Illness is changeable and can make it impossible for some of us to work at some points in our lives. This can be prolonged, frequent or occasional. A lack of a healthy work place can prevent us from working too as can discrimination or a belief in discrimination.</p> |

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|                   |               | <p>*</p> <p>Not being allowed to drive as a result of mental illness</p> <p>*</p> <p>Not having enough money to do things or participate and not being able to gain an income as a result of the mental illness that would allow us to get more money and therefore participate.</p> <p>*</p> <p>Paperwork for the benefits we claim or when changing benefits can be impossible to deal with. We sometimes cannot fill in forms correctly or do not claim at all. We find the d.l.a. form particularly hard to deal with. This barrier has a big impact on the way we lead the rest of our lives</p> <p>*</p> <p>Sometimes we find the society that states that we should be included unpleasant and unwelcoming. On occasion we are happier being with each other than with, what can be a judgemental and patronising society that can demonstrate a poor value base.</p> <p>*</p> <p>There is often nowhere to go and participate in</p> <p>*</p> <p>We sometimes don't tell people the degree of disability we suffer as a result of mental illness as we can't face it or acknowledge it or reveal it to other people. Also our disability is often variable and therefore can be hard to define. This can mean that we face lack of understanding from other people, inappropriate services and the wrong benefits.</p> <p>*</p> <p>Some of us don't acknowledge illness, either because it doesn't fit with our belief system or philosophical approach to illness or because our illness is so severe that we are not aware we are ill. As a result we face increased barriers</p> <p>*</p> <p>Some people do not believe that we are ill, believe that it is our own fault or that we could overcome it with a bit of effort. This is extremely unhelpful. *</p> <p>Question 2 Having a long gap between DLA assessments is good; ideally they should be longer. Having DLA on what appears to be a permanent basis, is also good</p> <p>*</p> <p>Question 3 Extra costs - Many of us are likely to be unemployed for a considerable time. We have a need for long term items – replacement of furniture, clothes, white goods - these occur more the longer we are on benefit. Long term benefits such as this need to take account of the fact that employment and therefore a higher income to afford these things will never be a possibility for some of us.</p> <p>*</p> <p>Using taxi's when we can't face walking or public transport because of our illness</p> <p>*</p> <p>Basic benefits are not designed to support people over the long term. For those of us with a mental illness: we may never work through no fault of our own and need a level of income that supports us in a way that doesn't put us in a place of basic existence.</p> <p>*</p> <p>Phone bills and the internet to reduce isolation and allow communication are very important*</p> <p>Increased food bills when we cannot face cooking and need ready meals and carry outs</p> <p>*</p> <p>Increased electricity bills because we can't face getting out of the house and therefore rely on heating and electricity in the day time. Our condition may mean we forget to switch things off.</p> <p>*</p> <p>The cost of paying for a carer to provide support if we are not assessed as</p> |

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|                   |               | <p>needing one</p> <p>*</p> <p>The cost of paying for support workers from the mental health team as this is now means tested.</p> <p>*</p> <p>The cost of new clothes as a result of varying weight due to illness or medication.</p> <p>*</p> <p>Q 4 How does having two rates ensure appropriate levels of support? This is not a suggestion that is responsive to individual need</p> <p>*</p> <p>Q 5 It should be based on individual needs but equally some of the costs apply across groups – mental illness can lead to increased costs and long term unemployment irrespective of the impact of the illness itself. The costs we face and the barriers we need to overcome are often a result of the way we are treated by society and the way we perceive society.</p> <p>*</p> <p>Question 6 We disagree with losing DLA when in hospital. Many of the costs that we commit to with the DLA we get, remain the same when we are in psychiatric hospital. Some of our care needs remain uncatered for as do our mobility needs.</p> <p>*</p> <p>We need to acknowledge that many of us with mental illness strive towards recovery as a possibility. Yet the possibility of managing better and showing some signs of recovery may mean we no longer qualify for benefit despite that income being key to that very wellbeing and recovery. The risk of losing DLA is a discouragement to recovery.</p> <p>*</p> <p>Q 7 It needs to be more flexible. It can be hard to fill in forms or be assessed accurately when we are for a time free of symptoms. We may not be in a position to communicate how bad we can get when we are ill.</p> <p>*</p> <p>Q 8 We can have a need for emotional and psychological support which can cost money but which is not considered an aid or adaptation but which is in reality just as essential to us as a wheelchair may be to someone with a physical disability.</p> <p>*</p> <p>*</p> <p>Question 9 On line help with suggestions about how to fill it in.</p> <p>*</p> <p>We need the support of social workers, cpn's and cab to fill in forms</p> <p>*</p> <p>The language of the form feels judgemental and makes us feel inferior</p> <p>*</p> <p>We agree that the forms are intimidating and unpleasant to the degree that they can actually trigger illness or prevent us from making applications.</p> <p>*</p> <p>We need benefits agencies to actively offer help and advice about benefits. Their refusal to help us find out what we are entitled to or to get it is deeply dissatisfying.</p> <p>*</p> <p>Q 10 Mental illness – Our g.p's, psychiatrist or c.p.n. are all in a position to provide informed evidence about our health. This sort of evidence needs to be from a person who knows us personally.</p> <p>*</p> <p>Q 11 As long as the health care professional knows us this is an advantage. (Although if they disagree with our views it may damage our relationship with them)</p> <p>*</p> <p>If the health care professional has no personal knowledge of us this will be very unhelpful especially when looking at the personal and sometimes very</p> |

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|                   |               | <p>private matter of mental illness.<br/>*</p> <p>We can find the whole process too traumatic to face and there should be room to excuse us from interviews and move us straight on to benefit because of this.<br/>*</p> <p>Sometimes we are not able to articulate our feelings and this may be a problem<br/>*</p> <p>Sometimes we are seen as more capable than we are because we are articulate<br/>*</p> <p>Sometimes we think health care professionals have a limited understanding of mental illness, especially some of those commissioned to assess us by the benefits agency.<br/>*</p> <p>Q 12 We can find reviews deeply traumatic; they create great insecurity and can cause illness. We do not agree with periodic reviews for everyone. Some of us should be excused reviews on the grounds that our condition is not likely to change and that they will damage us and increase our disability.<br/>*</p> <p>Question 13 Help us to trust in the possibility of fairness and justice in DLA assessments and systems rather the present situation where we assume benefits staff are only interested in removing us from benefit. Realise some peoples' conditions and lifestyles make it almost impossible to report changes in their situation or illness.<br/>*</p> <p>Q 14 15 16 Compliance with treatment as this implies, sounds like unwarranted social control<br/>*</p> <p>Some people with mental illness lack insight and agreement about their condition and would not be willing to access support and advice. This is a part of their condition.<br/>*</p> <p>Other people are philosophically and emotionally opposed to some forms of psychiatric care. They can see psychiatry as coercive or medication as having unwarranted side effects or talking treatments as too traumatic. They should also be entitled to resist the offers made available to them.<br/>*</p> <p>Making people with a mental illness agree to treatment a condition of getting the benefit that allows them to cope with life is a backhanded way of detaining anyone on DLA whether they have impaired judgement or not or pose a risk to other people.<br/>*</p> <p>Taking away control does not encourage recovery<br/>*</p> <p>17 we had no opinion<br/>*</p> <p>18 There needs to be clearer information about what entitlements DLA gives us access to.<br/>*</p> <p>19 Other ways would have to be found to help us and others qualify for these benefits and services as they are often essential and important to our health<br/>*</p> <p>20 We had no opinion<br/>*</p> <p>21 It could devastate many equality groups; disability groups could be thrown wholesale off of DLA and on to mainstream benefits<br/>*</p> <p>22 We had grown too tired of the questions by this time to have the energy</p> |



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|                   |               | <p>to add anything else but overall we worry that this is going to be a way of reducing the number of people on benefit who should in our view still be getting it. We find this offensive.</p>  |
| EM233             | 17-Jan-11     | <p>What are the problems or barriers..? The primary barrier is society's view of disabled people, lesser beings, inadequate. As you say in the document disabled people may fear getting a job, going to work meaning that they will lose their DLA. Yes DLA is not theoretically/legally linked to capacity to work. But the overwhelming feeling that one gets as a DLA claimant is that the primary goal of those assessing you is to prove that you don't qualify. Eg I just led 3 days of workshops at an [REDACTED]. I was accompanied by care support. But being a recipient of the highest levels of DLA would I be reassessed and downgraded?</p> <p>*</p> <p>*</p> <p>Is there anything else about DLA ...? It is not really possible to answer this question until we have a draft of PPI. May I suggest that you ask us to review PPI in it's draft form, as you did the Disability Discrimination Bill?</p> <p>*</p> <p>*</p> <p>What are the main extra costs that disabled people face?</p> <p>*</p> <p>Employing people to do things that others take for granted eg, cleaning, shopping, transport...</p> <p>*</p> <p>Care support relevant to the particular impairment.</p> <p>*</p> <p>Equipment eg wheelchairs</p> <p>*</p> <p>Rebuilding/restructuring one's house and/or moving house</p> <p>*</p> <p>*</p> <p>The new benefit will have two rates for each component:</p> <p>*</p> <p>Will having two rates .....?</p> <p>*</p> <p>What, if any, disadvantages or ...?</p> <p>*</p> <p>Mobility only has two rates so there will be no change.</p> <p>*</p> <p>How are the rates for Care assessed?. When I first came out of hospital in June 1996, I received twice daily care support and meals on wheels, despite having been awarded only Care DLA.</p> <p>*</p> <p>Two years later, following the Tribunal review in December 1998, I receive the highest level Care component, yet the actual care which I receive had reduced.</p> <p>*</p> <p>I believe the philosophy of PPI is good in that it is up to the recipient to decide how to spend the benefit so as to exercise choice and control and lead independent lives.... Play a full part in society. Thank you. The fear with DLA is that if one is seen as leading too active a life one may be disqualified.</p> <p>*</p> <p>5 Should some health conditions ...? Doctors and healthcare professionals</p> |

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|                   |               | <p>should automatically refer patients and help them complete PPI application forms. Eg a friend had suffered chronic depression for 10 years before he applied for DLA. A healthcare professional supported his application: he was automatically awarded the highest Care rate. However, I believe the standard approach of the DLA administration is either to refuse the application or to offer the lowest rate. The applicant is therefore obliged to reapply. Many don't. When my application was refused following the independent review, a friend told me to contact the Disability Advice and Resource Team in Halifax. If I hadn't I would certainly not now be receiving the highest rates for Care and Mobility.</p> <p>*</p> <p>6 How do we prioritise support ...? Beyond food and drink, an active social life – contact with other human beings who don't simply regard you as a care recipient – is the most essential. If one's contact is restricted to those who care for us, we rapidly lose our sense of self worth. Carers don't talk to us. They are too busy caring for us. Although I've been very lucky, I have found several people who both offer the care support I need and communicate with me as a friend, someone who has got something to offer the world. The label dis-abled is very disenfranchising. We can't do anything, is what it says. Yes we can.</p> <p>*</p> <p>7 How can we best ensure...? If the people who are assessing us are trained in the full understanding that our conditions fluctuate. That this is quite normal. Eg I can often walk all the way into town. Of course nobody sees me on the days I can't even climb down the stairs to make a cup of tea.</p> <p>*</p> <p>8. Should the assessment ...?*</p> <p>What aids and adaptations should be included?*</p> <p>Should the assessment only take into account .....?*</p> <p>What about aids and adaptations that are NOT easily obtained? Eg I had to borrow £10,000 from the bank in order to have my stairs rebuilt with lower steps, .so that I can continue to walk up and downstairs and not have either to have a through floor lift installed by the Council, or move into a care home. The Council had already reviewed my staircase and said that a stair-lift would not fit. Also I live in a four floor house, and even if the local Council had agreed to install a stair-lift it would only be between my ground-floor and my first floor. They would only install a through floor lift between the ground and first floors. The basement where I am working now, and where my washing machine is does not qualify for a lift. Aids and adaptations should be assessed according to each person's needs and requirements. There should be no set categorisation: we should be respected as individuals with our own particular needs.</p> <p>*</p> <p>How could we improve the process...How could we make the claim form easier to fill in?*</p> <p>Currently the DLA claim form is designed to cover any and all types of impairment. It has a huge impersonal and very general feel to it.. Also there is nothing which acknowledges that your disability is a variable phenomenon. Thus it is very depressing to have to write only about your worst days. If you mention your good days, as I did trying to remain positive, they declare you fully able and you lose your DLA entirely. Is there a way of simplifying the form and/or asking your doctor to help you fill the form in?</p> <p>*</p> <p>How could we improve information ...?</p> <p>*</p> <p>Write it in simple, accessible language. You will note that many pieces of information about DLA are written both in detailed academic governmental language that is not accessible to ordinary people. I have a degree in English, two Master degrees and had studied for a PhD for two years; I don't find the language easy.</p> |

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|                   |               | <p>*</p> <p>10 What supporting evidence will help provide...? Close friends and family are best placed to provide a clear assessment of ability. Someone who knows the disabled person on an intimate basis can see the extent to which he/she suffers as a result of not being able to do things. Many disabled people (myself included* ) will put on a front to the outside world, unwilling to reveal the true extent of their impairment, in order to maintain a sense of self-respect, self-value..</p> <p>*</p> <p>The first time I filled in a Disability Living Allowance form with the assistance of a local volunteer I declared what I could do on a good day. My claim was refused. A year later the Tribunal awarded me the highest levels for both Care and Mobility.</p> <p>*</p> <p>11 An important part of the new process is ...? It is essential that the healthcare professional be an expert in the particular field of the impairment/condition. A review of my condition was conducted by a healthcare professional who I had never met before. I have no idea whether he had any knowledge of my impairment: head injury. I presume not as he declared me perfectly fit and healthy and able to work, despite the fact that I was quite unable to talk to him. When applying for a review, I was examined by a number of professionals in my impairment who each wrote letters outlining my condition.</p> <p>*</p> <p>How should the reviews be carried out?...? The individual's doctor should be consulted: the local general practitioner should be asked for referral to consultants who are overseeing the applicant's case. When my own case went to Tribunal, documents from professionals in the following fields, and who had personally provided treatment, were presented:</p> <p>*</p> <p>Consultant and Senior Clinical Lecturer in Neurology*<br/>Consultant ophthalmologist</p> <p>*</p> <p>Cranio-sacral osteopath Bowen Therapist*<br/>Psychotherapist</p> <p>*</p> <p>In addition, I submitted letters from long-term friends who could testify to the radical extent of the impairment which I suffered.</p> <p>*</p> <p>The system for Personal Independence Payments....? Doctors should encourage patients to report changes if they perceive that their situation has deteriorated. If a patient's condition appears to the doctor to have improved considerably, the doctor should interview the patient and monitor his/her condition over a period of at least 6 months before encouraging the patient to report improvement.</p> <p>*</p> <p>*</p> <p>What types of advice and information.? We need independent advice such as is provided by Disability Advice and Resource Team. This must be independent and should not be provided by the government.</p> <p>*</p> <p>*</p> <p>Could some form of requirement...? Independent advice should be available at doctors surgeries, as it in hospitals, eg prior to my discharge a member of staff completed a Disability Living Allowance application on my behalf. I certainly was in no condition to make the claim myself.</p> <p>*</p> <p>How do disabled people currently fund...? Would this be in addition to regular weekly payments? Or are you suggesting we should use our Personal Payments to pay for aids and adaptations, which is exactly how we</p> |

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|                   |               | <p>currently use Disability Living Allowance eg in order to have my staircase rebuilt with lower rises between each step, I took out a £10,000 bank loan. My Disability Living Allowance Care component covered the monthly repayments.</p> <p>*</p> <p>What are the key differences that we should take into account when assessing children?</p> <p>*</p> <p>*</p> <p>How important or useful has DLA been at getting disabled people access to other services or entitlements? Are there things we could do to improve these passporting arrangements? Difficult to answer. I currently receive Direct Payments to pay for care and support in my home. I am not aware as to whether the fact that I receive DLA gave me access to Direct Payments. I had been receiving DLA for more than 10 years before I was offered Direct Payments.</p> <p>*</p> <p>What would be the implications.... I believe PIP will still be divided between Care and Mobility. Therefore the higher level of Mobility allowance should still be a passport to car hire. To what other benefits is DLA a passport?</p> <p>*</p> <p>What different assessments for disability...? As stated under 12 above, the NHS has all the key information about the disabled person. However, benefits administrators having access to medical records would not be acceptable. A method of consultation should be established, however it is vital that the disabled individual be kept fully informed of any/all information requests. He/she should be required to validate and give signed permission before any copies of medical records are passes to PIP.</p> <p>*</p> <p>What impact could our proposals ...? Please clarify who identifies and how "disabled people with lesser needs". Are you referring to people who receive the lower levels of Care and/or + Mobility on DLA? My experience, and that of friends, is that current policy is apparently to refuse all first time applicants, unless they have medical backing as mine did, having been made on my behalf by [REDACTED] Hospital. And if first time applicants are accepted it is normally at a lower rate. Eg when the hospital applied on my behalf I received the middle level of Care allowance. Following my Tribunal appeal, several years later – when I was much better than on leaving hospital - the Tribunal awarded the highest level of Care.</p> <p>*</p> <p>Is there anything else you would like to tell us about the proposals?*</p> <p>Page 9</p> <p>*</p> <p>Yes the current system is too complex . It took me days, weeks to fill in the form, and I've got a degree in English and was a teacher for years. How on earth do people with a limited education manage.</p> <p>*</p> <p>Page 12*</p> <p>We are already involving disabled people in developing the new benefit</p> <p>*</p> <p>Who? Why did you not invite all of us who receive DLA and/or those of us who responded to the call for reviews of the Disability Discrimination Bill as it was going through Parliament in 2004? [REDACTED], the group which I lead held a public consultation at [REDACTED] Central Library and met with Chris McCafferty MP in the Houses of Parliament to discuss our review of the DDA. Why were we no consulted?*</p> <p>Page 16</p> <p>*</p> <p>We want the new assessment to be evidence based..... and how [an individual's] specific needs may change over time.</p> <p>*</p> |

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|                   |               | <p>we know that it essential to ensure the assessment adequately reflects the support needs of variable and fluctuating conditions.</p> <p>*</p> <p>How do you plan to collect evidence of my brain injury? Who assesses? *</p> <p>Currently a medical practitioner, apparently with no detailed knowledge of the particular impairment he is assessing, arrives at your house ½ hr early in order to catch you unprepared. His prime goal would appear to be to deny the validity of your claim. I was forced to submit numerous medical reports and then go to Tribunal following an independent review which denied my entitlement to DLA. What will qualify as evidence for PPI? Are medical reports evidence?</p> <p>*</p> <p>How do you plan to assess “variable and fluctuating” conditions?*</p> <p>Like probably the vast majority of disabled people, my condition changes on a daily basis and according to the situation.</p> <p>*</p> <p>Page 17</p> <p>*</p> <p>27 You say that currently you ignore the wheelchair. How is this possible? Does the use of a wheelchair not automatically entitle the user to high mobility allowance?</p> <p>*</p> <p>Page 18*</p> <p>I trust that the independent healthcare practitioner will be the claimant’s own doctor and/or therapist. Please see point 23 above.</p> <p>*</p> <p>Question 11 Again, if the face-to-face meeting with the healthcare professional is with one’s own doctor who is fully familiar with your case, then this is appropriate. Yes there are circumstances in which this would be inappropriate: if the healthcare professional was a complete stranger whose goal was to catch you out, prove you don’t need PP1.</p> <p>*</p> <p>Page 19</p> <p>*</p> <p>Penalties for not reporting changes in circumstances*</p> <p>Who assesses changes in circumstances and how? Part of living with a disability involves coming to terms with, and self-acceptance of, one’s impairment. Thus one may easily feel that one is not as disabled as one was 5 years previously. In fact that is a good thing; or do we need to feel severely disabled constantly in order to qualify for PPI?</p> <p>*</p> <p>Please note that in the response sent two minutes ago I failed to include the following para:*</p> <p>At the time of my accident I was in the third year of a PhD for which I was conducting extensive research in [REDACTED]; I was an international consultant for the [REDACTED]; I was National Secretary of the [REDACTED]. My impairment renders me virtually house-bound. To travel beyond the immediate of my home, I need to be driven door-to-door. I am allocated the highest Mobility Allowance which I receive in the form of a car. I am concerned that should I have to move into residential accommodation, under Personal Independence Payments I would lose my Mobility Allowance, ie I would lose my Personal Independence. In fact that condition alone means that although I had been envisaging moving into residential accommodation in the not to distant future: I am 60 years of age, I have changed my mind. I shall continue to live in my own home.</p> <p>*</p> <p>I have now added the above para to the answers to the final question Q22. Unfortunately a key aspect of my impairment, head injury, is memory failure. Thus when I edited the above para from a question to which it was not an appropriate answer I failed to reinsert it elsewhere.</p> |

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| EM234             | 27-Jan-11     | <p>What are the problems...? Firstly, the level of financial support received by disabled people, especially those who are unable to work because of their disability, can act as a huge barrier to leading a full and active life as they are unable to fund the same type of lifestyle as an average working person. For example, my partner has been disabled since the age of 13 and cannot work because of his disability. The annual total combined benefits he receives (many of which have reduced since we moved in together) is the equivalent of a below minimum wage job. Disabled people cannot live a full and active life if they cannot meet their basic financial obligations such as rent and bills with their benefit income.</p> <p>*</p> <p>Secondly, many disabled people can feel excluded from society because of their disability. Those who cannot work are particularly susceptible to this. The feeling of exclusion can lead to emotional problems such as depression which then have a detrimental effect on other areas of life such as participating in society.</p> <p>*</p> <p>Is there anything else ...? No. I agree with the proposals about what will stay the same once DLA changes to Personal Independence Payment (PIP).</p> <p>*</p> <p>What are the main extra.. ? The greatest source of extra costs for disabled people is probably the cost of care or health needs. For example, my partner has a degenerative bone condition in his hip which affects other joints in his body and therefore requires regular physiotherapy. However, the physiotherapy services available through the NHS are of poor quality in our local area and appointments cannot be provided on the frequency that is needed for my partner's disability. Therefore he has to pay for physiotherapy at a private provider himself, which at £40 a session, is very costly. Other costs would include adaptations to the home for specific care needs.</p> <p>*</p> <p>The new benefit will have ..? I agree that having different component rates will make the benefit easier to understand and administer. However, the only problem that could be encountered is where people suffer from degenerative conditions which worsen at a slow rate and therefore some people could end up in a 'grey area' where their needs exceed one component rate but don't quite meet the criteria for the higher component rate.</p> <p>*</p> <p>Should some health ...? Yes some conditions and impairments should automatically be entitled to the benefit. Some conditions are lifelong and have 'standard' care needs (i.e. needs that are always prevalent for that condition). What should be assessed in these cases is not the entitlement to the benefit but the severity of the care needs to determine which component rate should be awarded. A slimmed down application process could be developed for people in these circumstances.</p> <p>*</p> <p>How do we ..? As well as the existing care and mobility components, PIP should also include an assessment of an individual's emotional health and well being and their ability to participate in the social aspects of life. Emotional problems can be as big a barrier to leading a full and active life as a physical impairment so this needs to be captured in the assessment process.</p> <p>*</p> <p>How can we best ensure ....? Periodic reviews are the only way to take account of variable and fluctuating conditions.</p> <p>*</p> <p>Should the assessment ...? Yes; it should include aids and adaptations particularly around mobility and care needs. The assessment should include both the adaptations that a person already has as well as signposting them to additional adaptations which they may be eligible for and can be funded via PIP.</p> <p>*</p> |

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|                   |               | <p>How could we improve... ? For many people, putting in writing the problems they face on a daily basis because of their disability can be quite an upsetting experience and there isn't much that can be done to change that. However, a way of making the process more positive is to make it easier and more convenient to complete. For example, the large paper application form could be made available electronically so that people can fill it out on a PC and print it rather than completing it by hand. For existing claimants, their application forms could be pre-populated with their personal details and information they have already submitted on their condition. They would then simply have to amend any incorrect information and/or update their care needs if they have changed and return the form to be reassessed.</p> <p>*</p> <p><i>How can we improve ?</i> Obviously, information about the new benefit needs to be circulated to all existing claimants. For potential new claimants, I think it's a case of disseminating this information through the right channels so that the right people or groups of people are being targeted. For example, GPs and hospital clinics could signpost patients who they think may be eligible for the new benefit and provide them with information. Also, local authorities will have information on the benefits that people claim and they can identify those who may be eligible for PIP and provide them with information on the new benefit i.e. those claiming Incapacity Benefit.</p> <p>*</p> <p>What supporting evidence ...? An individual's own GP or specialist is best placed to provide a clear assessment of their condition and their ability and they should be asked to provide evidence to support their assessment (i.e. details of the condition and treatment history). Personal statements from carers or partners of disabled people should also be taken into account as evidence as they will have an in depth knowledge of the abilities of the individual, their current and future care needs, and any aids or adaptations used.</p> <p>*</p> <p>An important part ... The benefit of having a face to face discussion with a healthcare professional is that the disabled person can discuss their disability and the problems they face with someone who has a good understanding of the medical condition. Nothing will get 'lost in translation' as it could do when the disabled person is trying to convey this information via a written application form only. Preferably, the healthcare professional should have a good level of understanding of the disability being discussed. Perhaps healthcare professionals could specialise in certain types of disability (i.e. learning disabilities or lower limb disabilities) so that they can be 'matched' with specific claimants.</p> <p>*</p> <p>*</p> <p>Some difficulties may be encountered through using this approach. Firstly, the face to face discussion could potentially add another stage to the assessment process making it longer. The face to face discussion should add value to the assessment process by gathering information that cannot be captured through the paper application form or supporting evidence from medical professionals etc. Secondly, discussing your disability with a complete stranger can be an upsetting and emotional experience for many people. It would be preferable to have the face to face discussions in the home as it is a more safe and comfortable environment in which to have a relaxed discussion about a person's disability rather than an office or doctor's surgery.</p> <p>*</p> <p><i>Are there any circumstances in which .....?</i> A face to face discussion with a healthcare professional may not be appropriate for people with long-term conditions which won't change over time. The care needs may change but this information can be captured via the written application form. Again, the face to face discussion needs to add value to the assessment process and not become just a tick box exercise.</p> |

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|                   |               | <p>*<br/>How should the reviews...? For example:<br/>*</p> <p>I think there should be a standard time period within which a review needs to take place for existing claimants i.e. every 2 years for example, but the time period needs to be tailored to the type of disability in question. If circumstances change in the interim period between reviews, perhaps an earlier review could be triggered by a referral from a GP or hospital specialist when a person's disability or care needs change. Disabled people could also be given the opportunity to request a review because they know their circumstances have changed considerably.<br/>*</p> <p><i>Should there be ...?</i> Yes there should be different types of review because there are many types of disability, the rate at which people's conditions deteriorate (or not) will be different, and the rate at which people's care needs change will be different. A one size fits all assessment is probably not the most effective way of assessing someone's continued eligibility for the benefit.<br/>*</p> <p>For example, my partner has a degenerative bone condition in his hip which affects his mobility. He has had this condition since the age of 13 (he is now 29) and every year the condition worsens. However, over the last 5 years the rate of deterioration has increased and therefore his care needs have changed more in this period than the previous 11 years. Yet every time he is reassessed for DLA the same assessment is used and each time he has to provide the same standard information on what his disability is and provide medical evidence to support it despite the fact that his disability hasn't changed in the last 16 years, only his care needs have.<br/>*</p> <p>The system for Personal Independence Payment... ? Unfortunately, I think the only way around this problem is to introduce a financial penalty for failure to inform the Department of a change in circumstances. Although it may seem like scare mongering and there is something unethical about using financial penalties against disabled people who rely on benefits to improve their standard of living, it is the only way to ensure that <u>all</u> claimants are consistent when reporting a change in circumstances and prevent potential fraud. An example of a penalty could be a fine which will be deducted in regular instalments from a person's benefit entitlement over a period of time. Or similarly, if a person has been claiming too much PIP because they haven't informed the department that their circumstances have changed, they should be required to pay back what they owe as regular instalments to be deducted from their correct benefit entitlement.<br/>*</p> <p>What types of advice and ...? Yes, signposting applicants to other forms of support that they may be entitled to would be very helpful as often people are unaware of what support (both financial and non-financial) is out there. *<br/>Examples of advice and support that people may find useful include:<br/>information on entitlement to other benefits; advice on managing finances/debts when benefits are your main or only source of income; information on discounts available on goods and services for disabled people; information on available healthcare and alternative therapies which may be available but not signposted to via GPs/hospitals (i.e. free swimming, counselling etc); access to support groups or community groups in the local area etc.<br/>*</p> <p>Could some form of ...? I think it is important to encourage disabled people to take advantage of the different types of support out there but you can't force someone to accept help or support if they don't want to. I think the requirement should be that people make a concerted effort to access support and advice but that they don't have to continue with it if they feel it isn't beneficial for them. The only exception should be where the support will</p> |



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|                   |               | <p>have a beneficial impact on their disability i.e. the use of aids and adaptations in the home. In this instance it should be a requirement that support and advice is accessed <u>and</u> accepted.</p> <p>*</p> <p>If a requirement to access advice and support is introduced then the approach must take into account that some people's disabilities or quality of life will not improve regardless of the advice and support available to them. For example, requiring someone to seek advice and support on how to start work or become a volunteer wouldn't be appropriate for someone who has a physical disability which prevents them from working. It is also important to get feedback from claimants on what support and advice they have accessed (to prevent them being signposted to the same support twice) and on the quality of that advice and support. Being provided with poor quality advice and support will only discourage people from accessing other forms of support referred to them by the Department.</p> <p>*</p> <p>How do disabled people ...? In my partner's case, he gets any aids (e.g. walking stick and foam block for his shoes) free through the NHS but we fund adaptations to the home (e.g. grab rails for the toilet and shower) with our own money. He also has a car through the motability scheme.</p> <p>*</p> <p>I definitely agree that there should be an option to use PIP to fund aids and adaptations. Sometimes the aids and adaptations that are available at no cost i.e. through the NHS aren't always the best quality and some people may prefer to buy a better quality product with PIP.</p> <p>*</p> <p>What are the key differences ...? N/A – this is a question for healthcare professionals and families with disabled children.</p> <p>*</p> <p>How important or useful has ..? I think DLA has been very good at getting disabled people access to other services and entitlements and it is very important that this carries on when DLA changes to PIP. The only thing that I think could be improved is to ensure that the approach to getting people access to these services and entitlements is consistent across both new and existing claimants. Perhaps some of the different entitlements could be incorporated into PIP, for example the blue badge scheme could be incorporated under the mobility component.</p> <p>*</p> <p>What would be the implications ...? I think there would be a big impact if PIP could not passport people to other benefits and services. It would result in many people being unaware of the benefits and services they are able to access, there would be a greater number of applications for people to make to get these benefits and services (as well as duplication in the information that needs to be provided), and the cost of administering and assessing these benefits and services separately will increase dramatically.</p> <p>*</p> <p>What different assessments for ...? Steps are already being taken to address this issue i.e. Incapacity Benefit being included in the Universal Credit and, as mentioned in my response to Q.18, I think that some benefits and services such as the blue badge scheme and the motability scheme could be incorporated into PIP. In order to minimise bureaucracy and duplication I think information on a person's disability, level of care needs and the benefits and services they already have access to should be shared with relevant Departments on the basis that this information would be treated as highly confidential and kept secure.</p> <p>*</p> <p>What impact could .. ? N/A</p> <p>*</p> <p>Is there anything else ? In relation to point 21 in Chapter 2 where it proposes that payment of PIP will stop if an individual is in hospital or a care home. Could you clarify how this will affect people who claim the mobility</p> |

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|                   |               | <p>component (or equivalent under PIP) and use it to pay for a vehicle through the motability scheme? Will the stopping of payments whilst receiving care affect their entitlement to keep their vehicle for the duration of their stay in hospital or a care home?*</p>  |
| EM235             | 28-Jan-11     | <p>The proposed changes to the DLA benefit are really going to have a significant impact on many people and affect their quality of life in a detrimental way. This is not a review driven by the need for construction change but by the need to save money and this is so wrong. I would be the first to agree that the form itself seriously needs looking at as its 50+ pages and its negativity often makes claiming this allowance extremely difficult and many disabled people miss out because of this. However with only 0.5% of cases being deemed as not genuine there is no real need for the way this is being approached. The massive drive to lengthen the waiting period from 3-6 months is going to make disabled people's lives more difficult when they are already facing challenges and hardship. It is extremely expensive to be disabled. In order to carry out simple shopping tasks such as my weekly shop I need to do my food shop online and I have speech software on my computer as I am blind. It cost £800 to buy. I had to purchase it myself. I also have a talking phone again this costs money the software is £170 again social services don't pay it is the individual. The obstacles I would face trying to do the shop in store would be impossible. Getting to and from the shop in a taxi on my own with a large shop for myself and my children is a task in itself. Going around the shop even with a friend would be exceptionally difficult and very time consuming. The shop becomes an obstacle course of people, trolleys, things in the aisles and everything becomes extremely traumatic. It is so noisy you become disorientated and really you just get dragged around getting on everyone's nerves and there is no choice someone is doing the shop for you, you lose the right to choice and independence. This is why being able to do it for yourself is so important. Just try it for yourself, close your eyes when you are out shopping sometimes.</p> <p>*</p> <p>The right to a quality of life is essential and this allowance helps. It helps with transport costs. Getting out and about is a major issue. It is not enough to say a blue badge or a bus pass are enough. They are both very important but only parts of a system. I can't access a bus as I can't even get to my local bus stop without support as the road is too busy to cross unaided and needs a crossing. Even if I found my way to a bus stop how would I know which bus was coming there are no tactile or audio cues available and as we all know buses unfortunately do not arrive on time! You would have to rely on someone being at the stop who will tell you after announcing they are there. Very hit and miss. I couldn't even put my arm out as I can't see it coming. Getting on the bus is another obstacle as is finding a seat, I would have to shout out if anyone is sitting in it - very embarrassing. As you can see this is not a very easy mode of transport so I have to rely on taxis. These cost money. This is why DLA is essential. The government should be spending time putting their efforts into making community transport available if they want to look at mobility for disabled people not cut DLA as we have been promised this for years and where is it?</p> <p>*</p> <p>Trying to remove the lower care element is also just another cost cutting element who is going to help people do these things. I can no longer cut my nails being completely blind so I have a manicure and pedicure as someone does this. I also have my eyebrows shaped. I do not qualify for personal care from the council social services for just these things so I use my DLA. I have</p> |

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|                   |               | <p>had my bathroom adapted paid for myself from all my savings so I could be somewhat independent so I can wash myself. So on a good day this is possible. I also suffer from intractable epilepsy but that's another issue. However people with a visually impairment need help with simple everyday tasks that are taken for granted and if social services are not prepared to take up the mantle and they are already over burdened who is going to do it? Before reviewing this you need to put other systems in place first.</p> <p>*</p> <p>Where people do adjust and try to improve there lives slightly and get some degree of quality back into there lives by being able to socialise and gain a small bit of independence using technology these new guidelines then want to penalise them!!! What sort of society are we promoting for goodness sake. You want to encourage disabled people to stay at home out of sight and we'll keep paying you but if you start to gain a little independence we'll stop paying you. This is money they really need to survive. Absolute rubbish.</p> <p>*</p> <p>Assessments for each person are going to lead to wrong decisions, endless appeals and in effect more money. This is not going to save money it is going to cost more and is totally counter productive. Employing a corporate body to do a job that requires detailed knowledge is ridiculous and insensitive. We are not a target we are living breathing people and this is our lives that are going to be affected by this. I urge you to take action this needs someone to stand up and be counted. This is unjust and absolutely unfair.</p>  |
| EM236             | 17-Jan-11     | <p>1. What are the problems ...? Stereotyped Attitudes about disabilities and people/children with disabilities Discrimination, patronisation, ignorance, bullying. Socially Ostracized*</p> <p>Accessibility, physical and non physical ( mental, developmental)*</p> <p>Poverty or lack of any chance of financial independence of any kind as there are extra costs involved, eg- aids.Unemployment, and many many want to work.*</p> <p>People who are not disabled frauding the government- eg- fraudulent disability claims= less money for those who need it, or even just parking in a disabled bay when they are able bodied.*</p> <p>Waiting too long for essential care and too much "red tape/form filling" when applying for benefit/support.*</p> <p>Aids, supports, medical equipment and adaptionns are expensive, we are a "captive customer" as we needs these items.Lack of compassion, support, acceptance and understanding in society in general.*</p> <p>We are largely ignored and forgotten about.. Until it affects you or your family.*</p> <p>2. Is there anything else about DLA that should stay the same? Yes, I do not understand the DWP's need to reassess lifelong conditions and disabilities that have been diagnosed and are accepted. For example, I have EDS, it is genetic, I was born with it, it will not "change" in anyway other then become progressively worse as I age. So in to life long conditions that will not improve with time, why would the DWP need to continually reassess benefit levels?In my case, specifically, I was awarded that my benefits be continued "indefinitely" due to my condition as decided by an appeal panel. My genetic condition remains, so why does the DWP need to re-assess my medical condition again?*</p> <p>3. What are the main extra costs ...? The costs are varied and wide ranging, from supports, aids, adaptionns to the home, car as well as costs for personal support.*</p> <p>I believe many are like us and buy in their own support to help get into/out of bed, get washed and dressed, feeding, preparing a meal, toileting, overnight support, gardening, making and listening to a telephone call, writing letters, envelopes, working on the computer,emails or even surfing the Internet. *</p> <p>In our specific case, I am disabled and have mobility difficulties due to my genetic condition EDS, that literally can change by the day or even hour. My youngest son is High functioning Autistic Spectrum Condition as well as co-</p> |

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|                   |               | <p>existing conditions of ADHD, Post traumatic stress disorder and Obsessive compulsive disorder an he has my genetic condition, EDS. *</p> <p>My personal extra costs involve the aids and supports I need, some need to be replaced on a regular basis, others are larger items to be replaced less often, however all are a cost and can be expensive. Eg- wrist/finger supports, bandages, walking cane, special mattress, dexterity aids for the kitchen/home, writing and computer aids, treatments not covered by the NHS, medicines and other support/dexterity aids. As my condition worsens I will require more supports and more aids as well as possibly a personal "assistant" to help with personal care even more then my husband currently does for me.*</p> <p>The costs are greater in reference to my son's condition are far more varied. For example when he was much younger, the replacement of furniture and electrical equipment as they were continually broken by him as a direct result of his condition. We've had to replace his glasses, for example 4 times one year and after the first replacement we were responsible for the cost of replacing them. We have spent the a lot and continue to do so on supports, such as visual diaries, prompts, books and various other such items in direct reference to his condition. He also requires aids for writing and working on the computer, eg- homework, playing games. *</p> <p>Childcare is virtually impossible to find for a disabled child and we have had to hire independently. This is becoming more of an issue because for our son to access out of school activities he requires one to one support. He is getting older now and no longer wants his parents, us, to "perform" this role for him and rightly so. We will need to again hire someone experienced in his condition independently, which will be expensive, without some financial support we will not be able to afford this at all. *</p> <p>Those entitled and not entitled to social services support buy in their own support to help get into/out of bed, get washed and dressed, feeding, preparing a meal, toileting, overnight support, gardening, listening to a telephone call, writing notes, envelopes, walking the dog. *</p> <p>I'd also like to add lose of wages here as well. Because of my problems with dexterity and mobility as well as our son's condition of ASC, my husband has become the main carer of the family as we have no outside help, no extended family or friends that can help and he is required often to help and miss time he would be at work. He receives no support.*</p> <p>4. The new benefit will have two rates...? It should not as the rates need to be a reflection of the individual's personal needs and not be complicated to alienate those who do need the support.*</p> <p>What, if any, disadvantages or problems...? The main problem would be if those in need were "left out", no longer eligible and if it were not based on the disabled person's individual personal needs.*</p> <p>5. Should some health conditions....? I do not believe it that any of the NEW claimants of that new system should be automatically entitled to the new benefit unless they are terminal as it is in the current system. However, I do not believe it is right nor cost effective in any way to re-assess those already in receipt of DLA due to a life long illness. Those with disabilities or conditions such as myself (genetic EDS) and my son's ( ASC, ADHD) that have not changed or will not change should not be re-assessed. It would be detrimental as well to the well-being of those with the conditions as the inference is that they are not "believed" and this would be yet another stress and challenge to those who face enough daily.*</p> <p>The money spent paying the doctor's to visit and re-assess those with conditions such as I've mentioned, could be better spent further helping and supporting more who need it.*</p> <p>6. How do we prioritise support ...? Every day activities are essential, ones that able-bodied people take for granted. Getting in and out of bed, washing, going to the toilet, getting dressed, being able to prepare a meal, eating, taking and making a phone call, writing, working on the computer/internet/email, help getting around, mobility, having any sort of social life, being able to actually afford taking a cab. *</p> |

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|                   |               | <p>Because of my condition, some days it can take me 30-40 minutes to get out of bed. I can be completely immobile or I can be functioning at a reasonable level, which is still not the rate of an able-bodied person. I am increasingly losing dexterity so everything an able bodied person does with their hands, i am increasingly losing the ability to do. I can no longer drive more then 10-15 minutes and some days can not drive at all. It can often be difficult to take the tube or bus. This limits me socially.*</p> <p>Thankfully I am currently employed and due to my employer's awareness and support, I am able to enjoy a working life as well, though I am greatly limited.*</p> <p>All of these things are essential to even come close to having a full and active life.*</p> <p>7. How can we best ensure that the new assessment...? All Assessors need to be fully trained. When assessing fluctuating and variable conditions, the medical experts in those conditions must be consulted as well as those individuals with the conditions. The assessors need to actually meet those people with these conditions to become completely aware of the situations and difficulties those with them face as well as the support they need. This is particularly true in my situation as I was assessed when I first applied to DLA and the assessor had no previous knowledge of my condition nor my needs and my application was initially refused. I won on appeal and I was awarded that my benefits be continued "indefinitely" due to my genetic condition. This could have been avoided if the assessor was familiar with my genetic condition.*</p> <p>8. Should the assessment of .... aids and adaptations they use? Yes, definitely in reference to help in payment of them, as this is a great "hidden" expense to those who need the support. But in terms of what the person needs in terms of support aids/adaptions, I don't believe the assessors should be involved at all. The experts and those with the disability know exactly what they need, as I know what I need.*</p> <p>What aids and adaptations should be included? None, except the payment towards the aids/adaptions the person chooses to support them.*</p> <p>Should the assessment only take into account aids and adaptations ...? No, not in the supply of them as it may be unsuitable, unstable, have a waiting list to obtain or not be available in the local area. The assessment can not centre on the aids/adaptions used or needed. It can be used as a "reason" not to award the new benefit. If aids/adaptions are used/needed then the question should be "who pays for them?" only. *</p> <p>9. How could we improve the process ....? For example:How could we make the claim form easier to fill in? Have the application online in an easily accessible website with the ability to fill out "real time" as well as download to print and fill later and post or fill out on the computer and email it. It could also be accessed through a login and password to be worked on, updated and reviewed by the applicant before sending it. It could also be possible for the applicant to have an "on-line" account to track the progress of the application. It should also be in every communication form possible, eg-audio, large text and whatever other means possible.*</p> <p>How can we improve information ...to qualify? Possibly by listing the extra "hidden" costs they have. *</p> <p>10. What supporting evidence ...? The disabled person applying, family and friends to start with. Also included should be any carers, charities and others that also support the person and their family as well as specialists, experts and possibly previous DLA forms/awards.*</p> <p>11. An important part of the new process.... What benefits or difficulties might this bring? *</p> <p>Are there any circumstances ...? Those with lifelong conditions and disabilities that have not changed and are not going to change will wonder as I do, why they will have to go through the process again as many of us have been through these processes many many times. It is stressful. It can be frightening and very the applicant feels very pressurised. It is an unpleasant feeling as you may be having a "good day" which does not</p> |

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|                   |               | <p>truly reflect your condition/disability or your true needs. The assessor only sees you on that day, at that time and can not get a real true reflection of what your life is really like, not to mention if the assessor has no or little knowledge of the disability/condition generally. *</p> <p>It would be a great waste of time, resources and money if those with life long conditions that haven't changed and are not going to change were made to have yet another face to face meeting. I also believe if a person has reached the highest amount/level of benefit, it is tasteless, pointless and not in anyway cost effective to continually re-assess them *</p> <p>12. How should the reviews be carried out? The criteria should be set on if the person's condition will change or remain stable. If the person has a life long condition and it has not changed nor will change then they should not require review. If the person's life long condition changes purely due to deterioration and aging, then the disabled person should be able to request a review and possible the DWP to request reviews at periods agreed to with the disabled person. I believe the current system of review with "indefinite" awards for certain conditions/disabilities is appropriate. *</p> <p>13. The system for PIP ... circumstances? Reminder letters are most appropriate to remind people to keep the department informed. But most importantly, there should be no automatic removal of the benefit in any case except fraud.*</p> <p>14. What types of advice and information... process? The same information and advice that a specialist would ask the disabled person in relation to their disability/condition is exactly what is needed. The help with Care/mobility sections, though difficult for Variable/fluctuating conditions/disabilities, in the DLA form should still be considered and worked on to improve. The "how my condition affects me" section is imperative.*</p> <p>15. Could some form of requirement... ? No, in my opinion it could alienate people applying.*</p> <p>16. How do disabled people currently fund... I currently pay for any and all aids and adaptations as much as possible from the DLA recieved, though it doesn't cover it all as well as my son's DLA pays for his. It definitely should be an option for the disabled person to be able to chose the option of a one off cost such as an adapted vehicle or in-house adaptations.*</p> <p>17. What are the key differences ...children? The parents of children need to be considered seriously and listened to. They are the main carers of their children and know their needs. Much more consideration needs to be taken as many parents are the unpaid carers of disabled children. They often receive little outside support and little respite. They are often "left alone" to care for their child with little consideration or understanding of the physical, mental and emotional strain caring for a disabled child can take outside of the "normal" parenting. This affects the child and the family as a whole on many levels. *</p> <p>18. How important or useful has DLA ...? The mobility aspect of DLA has been helpful to those who require blue Badges. I believe the Blue Badge should be automatically given to those on high levels of mobility need. Other departments have based their criteria on the level of DLA received, such as Harrow Aiming High for Disabled Children, but I feel this is unjust and unfair. It does not look at the person/child's individual need. It gives a guideline of support and not a true reflection of need. I do not believe any other benefit, other then the Blue Badge for Mobility, should be based on Level of DLA or the new benefit system. *</p> <p>However, other departments should be able to access the information and evidence contained in the DLA/ new benefit application and folder to aid in assess needs. It is the fact that the DLA Level alone is used as a criteria by other departments that I object to as, as mentioned, it is not a true reflection of the individuals needs nor does it explain their condition/disability and the realities the person faces. The new benefit application and department could be a central data bank of individual records, information and evidence as contained in the application submitted allowing other benefit departments to access it for their own assessments.*</p> |

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|                   |               | <p>19. What would be the implications ... ? Unfortunately it would mean more "assessments" by the other departments, but if this means that the disabled person's individual needs were met, then it would be positive.*</p> <p>20. What different assessments ... ? Again, there should be a central "bank" of evidence, information and assessment that can be accessed by other benefit departments once the disabled person has made a claim to that department. They then can use this information as well as any new information supplied to them to decide to meet for a face to face assessment themselves. The disabled person should also be allowed access to this to update information or even add evidence, pending approval by both the DWP and the disabled person.*</p> <p>It is explaining and re-explaining as well as submitting forms, information and evidence and then resubmitting it to various different departments that becomes stressful, tedious and alienating.*</p> <p>21. What impact could our proposals have on the different equality groups ... policy? *</p> <p>As these groups (on page 28) are disabled and the new benefit is looking to cut costs as well and Not just better the lives of the disabled then i can only assume the impact will be great. I am also unsure of those working, such as myself, even part time will still be eligible. My DLA literally helps me to be able to work.*</p> <p>22. Is there anything else ... consultation? Again, I believe reassessing everyone is ineffective, costly and deeply flawed in ideology. It will alienate a group of people already discriminated against. We disabled are not fraudsters, we are struggling to live as "normally" as we can a full life as everyone else. We are usually poor, yet in the most need. It took a long time before finally made a claim for DLA, and many more do not even claim when they are rightfully entitled under the current criteria. We are not the ones trying to "con" the system and this proposal is making me personally feel alienated, stressed, concerned about my future, my son's future, our financial future and deeply disappointed.</p> |
| EM237             | 17-Jan-11     | <p>I have briefly read thru consultation and what changes the government are proposing to make to DLA. Personally I think it should remain as it is. Also it should be put that Fibromyalgia should be recognised as a long term condition. On the 10 December 2010. I went for a fifth DLA appeal. And I was turned down as I did not meet the criteria. Please make sure that Fibromyalgia is recognised. I know people who have Fibromyalgia and can get DLA. But I can't receive both components of the DLA. Also to make sure that the EMP are made more aware about Fibromyalgia and the impact it has on people with other conditions that come with Fibromyalgia like, Migraines, Fatigue, Tiredness, Widespread pain, Stiffness in my joints in the mornings, Depression, low mood swings. I also have osteo-arthritis in my hands, hips, knees and feet. How it affects my daily living, I need help with washing, dressing, putting shoes and socks on. help to unscrew push down bottle tops. I am unable to stand for long periods, I do not do any cooking due to the Raynauds in my hands and feet. I can't cut up vegetables. or prepare a meal from scratch due to the long standing. What medication is taken what the side effects of the medication. Please think of people like myself who have to live with this dreadful condition which changes on a daily basis, Please take the time to talk to people like me and others with this condition before you do any changes, as these changes will affect me and others like me forever.</p>   |

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| EM238             | 17-Jan-11     | <p>Being a paraplegic is very expensive for example in the last two years I have had to spend £32,000 on a wheel car adapted vehicle, £6,200 on a fully supportive wheelchair, £1,600 on a new adjustable bed. The only way this was affordable was to take out a mortgage on the bungalow and we use the high rate mobility component to help service this loan.*</p> <p>Although I agree that DLA does need radical reform because it is a relatively easy benefit to defraud but any reduction or a rapid increase in interest rates would cause financial hardship.</p>  |
| EM239             | 17-Jan-11     | <p>Our son [REDACTED] is [REDACTED] years old and has profound learning disabilities and severe physical disabilities. He has complex care and a range of medical needs. He is chronically epileptic, severely asthmatic, a wheelchair and oxygen user, is pump fed through a gastrostomy and needs frequent suction to keep his airway clear. He is also doubly incontinent with various other long term conditions. As he is non verbal we have to respond on his behalf.*</p> <p>We have spent many years putting together a shared care package that involves ourselves and two charitable organisations (one of which I am a Trustee for) funded jointly by the NHS and Lancashire Social Services. This keeps him largely out of hospital and living in the community - a x4 person staffed bungalow. As we are both on pensions we no longer receive Carers Allowance for the time he is with us. Our son currently receives Incapacity Benefit, DLA care component (for the time he is with us only) and Mobility Allowance (which we understand will be stopped next year as the time he is not with us is 'registered care'.)*</p> <p>The current proposals by central government to cut his Mobility Allowance and to change the DLA situation, coupled with capping council spending, forcing massive cuts in Adult Care Services, on top of the NHS cuts already in train are having a major impact on us and putting us in fear that his present 'excellent' rated service will be put at risk. It is critical that these changes be considered together, as together they are in danger of destroying complex and fragile care models for the severely disabled that have taken much time and hard work to put together.*</p> <p>We understand that this consultation is about DLA, but feel it cannot be considered in isolation as the reality is that from the disabled persons viewpoint, all these factors are coming together to destroy the * foundations for any sort of life for severely disabled people in the community.*</p> <p>Our following comments relate specifically to the proposed DLA changes -</p> <p>The proposal for yet another assessment is dispiriting for carers and disabled people. We have had many assessments in the past where we have been assured that because his condition will not improve, we will not have to go through it again. We are currently being reassessed by Social Services (and we understand this will be annual). Apart from * taking major amounts of time from his actual care, these assessments reinforce how little he can do and do nothing to motivate us or anyone else to consider how to get the best quality of life for him.*</p> <p>The assessments, though better than form filling, tick box exercises are being carried out by people, and will still be subjective. Pretending they are any more objective than what is there now is disingenuous.*</p> <p>Taking away allowances because someone is in 'registered care' misunderstands completely what this is. The 'registered care' situations that many disabled people live in, particularly those with complex care needs and/or learning disabilities are usually small scale houses embedded in the communities, mainly with less than 5 residents. They are not large hospitals or nursing homes. If these changes are implemented without any care for the impact they will/are already having, much of the progress achieved since Care In the Community was brought in will go into reverse, with only large institutions being able to afford the economies of scale that allow them to do things like run vehicles etc..*</p> |



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|                   |               | <p>The test for disability indicates that it will take Aids &amp; Adaptations e.g. wheelchairs, into account when assessing things like mobility. This assumes that things like a wheelchair gives a disabled person as * much mobility as a non disabled person. The reality is that wheelchairs help, sometimes a lot, but they do not put people on a level playing field with everyone else. It took us two years and the threat of a DDA * action to get our local swimming pool accessible for our son - it was nominally accessible before. We are still unable to use the local bus service (which has wheelchair adaptations) and the wheelchair bus * service has been discontinued to save money. Forcing us onto 'universal services' effectively means taking these services away.*</p> <p>Reducing DLA and other existing benefits will undermine the fragile financial models that many care services are based on. These benefits underpin the viability of care arrangements and changing them, * particularly reducing them, will force people out of their current care and housing situations. The care providers, particularly in the voluntary sector, will no longer be able to sustain these services and * they will become unavailable. Care will by default only be provided informally by family, many ineligible for even Carers Allowance due to age. Quality of life will be reduced as transport is taken away due to * lack of Mobility Allowance and the disabled will be forced into extreme poverty by having their already meagre benefits further reduced. The risks of abuse to the disabled and despair to carers will be massively increased. Inadequately supported carers have already committed suicide with their disabled children, unsupported people with learning disabilities will starve when they are unable to shop for themselves.*</p> <p>We do not feel that the impact of these changes has been thought through and ask that these cuts and changes be reconsidered. On the ground it feels very much that we, the disabled and their carers, are being targeted for cuts in the hope that we will not be able to answer back. Please reconsider and do not go ahead with these cuts.</p> |
| EM240             | 17-Jan-11     | <p>I am writing to express my concern over the planned overhaul of Disability Living Allowance, set to go through on 14th February 2011. I am very concerned that this benefit, which supports the most vulnerable in our society, is coming under such attack. The coalition government maintain that they wish to protect the most vulnerable in our society, but proposed cuts like this make it difficult to believe this. It is well known that it is difficult to be awarded DLA and that (probably as a result) the incidence of fraudulent claiming is very low –in fact, 99.6% of claimants are not fraudulent. As a result, cuts of 20% will * mean that thousands of people who really need and rely on DLA will lose it. Also, as DLA is not income based it does not discourage people from working as they will not lose it when they start work. In fact it allows people to work who would otherwise not be able to, thanks to the Motability Scheme, for example.*</p> <p>The cost of living with a disability is higher than the cost of living without. It's a fact. There is often a drop in income as well as higher costs. If I could work in my chosen profession, which I was advancing in well, our household income would far surpass what I receive on DLA with my husband's modest income. I am concerned that a PIP will not be an adequate replacement of DLA as no one knows me like my doctors do, and the medical assessments coming into place would be undertaken by a civil servant with a computerised tick list and no room for a fluctuating condition like mine, not taking into account how my illness affects me over the long term. With my DLA application I sent many supporting letters from various HCAs including my lung consultant which described the effects of my condition. A medical assessment from a stranger on a certain day would not relay all the realities, for me and thousands of others in my situation, for example those with conditions such as MS and epilepsy. The removal of DLA equals the removal of dignity from people who did not ask to be disabled and would rather not be.*</p>   |

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|                   |               | I hope you can see why I am concerned. Please have a cold hard look at how many people will be affected by these changes. How many parents would struggle to do the best for their disabled children. And how many people with disabilities that are not so visible on the outside would actually be prevented from living a normal life if they lost their DLA and become dependent on means tested benefits as a result. I also would like to register concern about taking the mobility element off those in care homes. This could leave people who have been able to be more independent, just as the reforms seem to propose to want, sitting on their own doing nothing all day and becoming more depressed as a result. I am worried that this reform, despite its intentions, is striking at the most vulnerable in society, those unable to argue back or make their voice heard.  |
| EM241             | 18-Jan-11     | I am responding to your proposals for reform of DLA. As a recipient of DLA for a condition that varies and fluctuates, I am extremely concerned that conditions such as mine will not be fully taken into account. I found the whole process of applying for DLA humiliating. Initially, despite letters from my consultant I was denied the award after a healthcare professional came to assess me at my home. Undoubtedly, one wants to play down the extent of one's disability so as not to seem totally inadequate. However, this can be interpreted to the detriment of the applicant as it proved in my case. On appeal, in front of a panel of experts, I was granted the award indefinitely. Now although my condition is degenerative, I find I may have to go through the whole humiliating process again. The thought fills me with horror. I fear it is simply a money saving venture and the real needs and feelings of the individual will be ignored. I therefore request that those with varying and fluctuating symptoms who have already successfully applied and been granted the award on an indefinite basis be exempt from the humiliating process.  |
| EM242             | 18-Jan-11     | <p>I attach a response to your document. You may find it helpful to know by way of background that , before retirement, I was the Chief Executive of a Metropolitan Authority and prior to that a Finance Director of more than one authority. I also served for five years as the chair of trustees of a charity that provided care in the community for people with learning disability. However, my main qualification in the subject is that of a parent of a son with severe learning disability.His disability take the form of serious behavioural disability as well as learning disability.*</p> <p>You will not find my limited response flattering. It is limited because I have already spent a considerable time responding to the call for evidence by the Commissioners looking into the wider issue of the future of social care and I do not feel that a decision on DLA should have been taken outside of the conclusions of that enquiry. To do so is simply not joined up thinking.*</p> <p>My response takes the form of a reply that I have sent to the Chief executive of the charity for which I was previously the Chair of Trustees. it is quite short so I urge that you do me the courtesy of reading it.*</p> <p>*</p> <p>"Thanks for letting me see this consultation document.*</p> <p>Frankly, I found it utterly depressing. It is difficult to believe that the authors (as they say in the forward) are truly concerned about the most disadvantaged in society and most of the proposed changes are about overtly reducing spending.*</p> <p>There are problems about seeing the issues in the round. The call for evidence by the commission looking into social care is more rounded and worth a read, although even that document is highly influenced by the parameter of saving money.*</p> <p>As personal budgets become more common place, there are obvious questions about the difference between these and the care element of DLA. In one sense it does not really matter as, because of the cuts in local government, local authorities are increasingly likely to take account of 100% of dla in assessing charges ( including charges for personal budgets). So the real impact on a reduction of dla and its replacement by a lower</p> |

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|                   |               | <p>independence payment is likely to be loss of opportunity by local authorities to fund adult care through charging.*</p> <p>However, some of the financial analysis in the call for evidence by the care Commissioners is worth a read. I suspect that there is an imbalance between spending on adult care and spending on social security and the care commissioners are probably right in asking the question as to whether there should be a switch from social security finance to adult care finance. However, I doubt, if DLA spending is reduced by the new independence payment, that any of the saving will find its way into increased spending on social care. It will merely be used to reduce the totality of public spending and mop up the current deficit. For any rebalancing to be genuine, it would need to be supported by increased rights of the individual in need to access adult care (and probably the abolition of fair access to care regulations) and also by the ring fencing within the local government finance system of any of any switched monies from social security to adult care. I cannot see any of this happening.*</p> <p>Overall, my personal view is that it is probably not worth responding to this consultation, but maybe I am back into my "half glass empty mode"*</p> <p>If I were to respond, I think that the most important comment that I would make is the inappropriateness of a medical person to be involved in the assessment of people with learning disability. I have yet to meet a doctor who has the least understanding of the needs of people with learning disabilities or even the manner in which to communicate with them. I would push very hard for the assessment process re entitlement to the new benefit for people with learning disability, to be made by a multi disciplinary special panel of people who have real understanding of the issues of people with learning disabilities and how to communicate with such people.*</p> <p>It may be just worth you as an organization responding to the consultation on this point but that is a matter for the Board members and not me.*</p> <p>If you want a copy of my response ( bit lengthy I am afraid) to the Care Commissioners call for evidence I can let you have it. It is however a personal view and many people with disabilities may disagree with it."</p> |
| EM243             | 18-Jan-11     | <p>I am a carer of a young man with severe learning difficulties. I believe that it is important to be reviewing the DLA benefit. At present it is mainly benefitting physically disabled people or individuals with long term illness. I believe that people with learning difficulties miss out on the higher benefit because the mobility element is judged on one's "ability to walk". I agree that a new system where individuals are assessed on their ability to get around, interact with others , manage personal care and access food and drink will be a much fairer assessment. There are a number of people who might well be able to walk but do not have the capacity from a personal safety point of view to walk alone. These people always need to be supported by someone else so need to spend money on paying for carers. *</p> <p>There needs to be more of an understanding about individuals mental capacity and more of a differentiation between physically disabled needs and mentally disabled needs. It should be focussed on accessing a full and active life and the ability to achieve this. [REDACTED]</p>  |
| EM244             | 18-Jan-11     | <p>We are parents of a young lady who has Autism,Epilepsy and Learning Difficulties and we do not think the changes in DLA will be of any benefit to her at all.Based on the current difficulties we are experiencing with Social Services who are using the Mental Capacity Act to change our daughter's circumstances we do not have any trust or confidence in any new legislation.They have chosen to ignore a report from the [REDACTED] Hospital and their own 2008 Assessment of Needs document to rush through their own in house MC assessment which is completely inaccurate but will enable them to reduce costs and achieve their own targets. *</p> <p>We believe if we do not stand up for our daughter rights as a person with specific needs we feel the future will be extremely uncertain and will lead to additional issues that us as caring parents will be left alone to handle</p>  |

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| EM245             | 18-Jan-11     | <p>This response to the consultation on the reform of the DLA is submitted in my personal capacity. I have worked for over 30 years with people suffering from various forms of disability and have been the carer for a disabled person for over 20 years. My starting point is that with proper support a disabled person can live a life in which both employment and a reasonable social life are achievable. The important words being "with proper support"*</p> <p>1. Depending on the level of disability the two components that create the greatest disadvantage are caring and mobility. My own personal experience is with someone whose major problem was mobility and my comments will be mainly focussed on that aspect. *</p> <p>Even relatively low level disability can make transport a major issue and one that has a major effect on employability. Access to public transport is not easy for disabled people in most places. Physical access to buses etc is not always an option, changing trains buses etc can become a major undertaking. Inability to move freely between different places acts as a barrier to work and to social life.*</p> <p>2. My own view is that keeping DLA with changes to the complexity and application process would have been an easier and cheaper option. One point I would make is that continuing the payments post 65 is likely to be beneficial not just for the recipients but for state and government. Few disabilities disappear in old age, most commonly the effect becomes more noticeable, people with limited mobility are more likely to lose rather than gain as body strength is lost, other illnesses intrude etc.*</p> <p>Putting at risk the payments will create a climate of fear and concern among some of the most vulnerable in society, increase costs as assessments will need to be done, and I guarantee, lead to a high a number of successful (politically damaging) appeals *</p> <p>3. Travel costs are a constant and sometimes underestimated factor. In a world where the majority of people use a car it is sometimes assumed that provision of mobility is almost a luxury. There is a major difference in car usage for those who have other options. Someone with full mobility can walk to the nearest shop, can walk to the pub, and can nip between two work sites a few hundred yards apart. For someone who has to use a car for even the smallest journey and cannot choose the public transport option the cost is a continual incremental strain. *</p> <p>While the availability of scooters has helped some, even there a cost is incurred, not just for purchase and maintenance, storage facility etc but also the cost of recharging batteries which with increasing energy charges removes much of the financial benefit of this as an alternative for short journeys. *</p> <p>Care costs. A variable depending on need but one that for even low level support quickly becomes a large and frightening cost element.*</p> <p>4. There are good arguments in favour of 2 rates as the level of disability has an impact on the extra costs incurred. The major risk is that if cost cutting is treated as a priority there is the possibility that the lower rate will be awarded for financial reasons rather than as a reflection of the actual needs of the applicant. *</p> <p>5. The phrasing of 5 worries me, as the word "circumstance" is one that could have many meanings. If assessment is carried out on a case by case basis for all disabilities then when the circumstances change there could be real hardship caused unless there is a guarantee of immediate re-assessment. For a number of disabilities where degenerative conditions are present the circumstances are likely to change faster than the system can respond.*</p> <p>There are also some conditions where circumstances will not affect the reality of additional costs. Someone born with no lower limbs will create extra costs and an automatic award is probably going to create a cheaper and more effective response.*</p> <p>6. This paper at times skirts St Thomas's territory with concerns about the number of angels on a pinhead, this question being a case in point. Is there a serious suggestion that we are going to start assessing intangibles? Will</p> |

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|                   |               | <p>someone with a strong will, a good general education and a willingness to suffer a degree of pain receive a lower award than someone who is inarticulate, unmotivated and risk averse? The logical conclusion of the statements leading to this question raises that possibility. There is also a high level risk that those who choose to exaggerate their condition will receive awards whereas those who adopt a positive attitude will be rejected. *</p> <p>7. I have already expressed concerns about the problems of reassessment trailing far behind the changes in circumstance. There needs to be an automatic trigger system, for example, set in motion by a letter or contact from a GP that leads to a guaranteed reassessment within a fixed time period. *</p> <p>8 The idea of taking into account an aid of variable benefit, such as a wheelchair, will have two results, one increase the likelihood of unfair decisions and secondly provide a motivation for disabled people to be less independent that they could possibly be.*</p> <p>The fairness factor would arise from the reality that a wheelchair has a different value in increasing mobility based on the location of the home and the places to be visited. Using a wheelchair in a city with paved level streets and ramped pavements, is a very different matter from using one in the Welsh valleys where every street is at a steeper incline than the last. Similarly someone whose mobility may be reasonable in the street where they live would be limited by the problems likely to be encountered when visiting less accessible areas.*</p> <p>If there is an honest intent behind the reforms then any aid that is of a variable benefit bases on location, such as a wheelchair has to be discounted. A wheelchair is of vastly differing benefit based on the areas in which it is used and any attempt to factor in the benefit of a wheelchair would be inaccurate unless every potential place the user was likely to visit was considered. Any claim at an "objective" measure of its contribution to mobility would be by its very nature dishonest.*</p> <p>If the aim is to create a context in which disabled people have as much access to a full life as possible then taking into account an aid such as a wheelchair is a backward and destructive step. *</p> <p>The second factor is that if a disabled person thought that being able to use a wheelchair would reduce potential benefit then there is little incentive to encourage and support such use (or any other movement toward greater independence.) Any reform should take into account the fact that greater independence reduces other costs and makes movement into work etc far more likely. *</p> <p>Apart from my work related experience I am married to someone who had a leg amputated 20 plus years ago and who was enabled to carry on working until retirement as a result of the mobility aspect of DLA. While competent to use a wheelchair on level streets and inside a building there is no way that she could have accessed the various places she had to go as part of her job using public transport, with or without a wheelchair. (Something she was quite capable of doing before her amputation).*</p> <p>Visiting local shops, the doctor's surgery, visiting friends would also have been impossible. *</p> <p>With reference to other aids and adaptations a number of points have to be made. If aids and adaptations contribute to mobility then in many cases those aids have to be purchased, repaired, replaced etc. That itself is a cost factor. A stair lift in a relatively small terraced house will cost £2,000 to £3,000 and require repair and renewal. Unless Santa gets busy the aids mentioned will need purchasing.*</p> <p>The term "easily obtained" is not one that we come across very often when trying to access aids and adaptations. Typically a delay of 12 to 24 months is not uncommon between assessment of need and the fitting of aids etc by Local Authorities and there is every sign that the delays are growing. Exactly how are such aids "easily obtained"? *</p> <p>Aids and adaptations being fitted to a home are not standard processes and</p> |

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|                   |               | <p>in some cases cannot be used due to problems with room size, stair type etc. Unless there is an intention to carry out a full scale survey of all homes, a full OT inspection and assessment as well as the "objective assessment" of the individual there is no fair and honest way of assessing the contribution any aid can make to an individual's mobility or care needs. .*</p> <p>Again such an approach, i.e including aids and adaptations is likely to have the unintended consequence of making people less likely to actively improve their situation if a cash loss is a likely result.*</p> <p>9 Both this and following sections appear to make an unexpressed assumption that the GP of the applicant is not an appropriate person to make an assessment of their needs. If the "circumstances" of an individual are to be considered then the health professional who has the highest level of continuing contact would appear to be an obvious option to take. *</p> <p>There could be objections raised as to the "independence" of the family doctor but the increased degree of personal knowledge of individual and circumstances allied to a stringent monitoring system should be sufficient to address those problems. The involvement of the GP would also increase the likelihood of the benefit being applied for by those with actual need and through a relatively "user friendly" route.*</p> <p>If GP's are to be trusted with the majority of the National Health budget I would have thought allowing them to asses their own patients' level of disability was a reasonable step to take, if the aim is fairness and not a pre determined attempt to cut costs whatever the harm done. *</p> <p>One problem with independent experts is that they have a high level of error (I think I saw 39% of appeals against ESA decisions were upheld) *</p> <p>10 From the above answer it is probably clear that the GP of the applicants is the person whose views and recommendations I would regard as being most trustworthy and relevant *</p> <p>11 People lie. Unfortunately the lies are not as simple as exaggerating problems, a larger cause for concern is that some people are more likely to understate the difficulties they face. In my work setting I am used to people who lives are a constant struggle, caring for spouses with dementia while facing serious health issues of their own and responding to the question "How are you?" with a smile and a "can't complain".*</p> <p>Having the main assessment being carried out by someone with minimal knowledge of the applicant, in a setting where many ordinary people would be nervous will result in a high percentage of wrong or challengeable assessments and decisions.*</p> <p>12 There needs to be scope for two types of assessment and once again the sensible route would be through the GP. When there is a sudden and unexpected change in circumstance then there needs to be fast track decision making option to allow immediate response. There should also be a regular review carried out automatically to take into account the more "ordinary" type of change. This latter option could be either deterioration or recovery and once again the GP is likely to be aware of such changes without the need for another level of bureaucracy. This review could be carried out annually and one relatively simple form could cover all the information required. *</p> <p>13. The majority of cases I have come across where information has not been forwarded to the relevant department are the result of ignorance rather than malice. The use of the GP as a referral and review point would remove a large part of the risk factor.*</p> <p>14. I hate to sound like a cracked record but the use of the GP would address a number of the problems associated with these issues. A simple requirement for each GP to have a contact point locally for advice ref aids etc before an application is submitted would allow effective local advice (Something that could not be centrally provided without a ridiculous investment of time) *</p> <p>15 Putting the onus on the individual would be unfair and counter productive if the aim is to improve the service rather than simply save money. Avenues of advice and support vary by geography, have different names, and have</p> |

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|                   |               | <p>very different levels of availability and access. A significant percentage of the most vulnerable would not be able to seek or find help and consequently be barred from help.*</p> <p>16 The funding of aids and adaptations is a lottery. In some council areas there are good and responsive services, other are disgrace with long waiting periods and delays.*</p> <p>The charity for which I work gives grants for aids and adaptations (as do charities such as the RBL) The majority of people though do not have access to such grants making charities and are reliant on family, savings or the "do without" option.*</p> <p>If it is accepted that one off grants should be seen as an extra source of help and not a substitute for help then they would be a good addition. However if it is thought that a stair lift or wheelchair would make someone totally mobile and no longer in need of further mobility financing that is just not the case for the reasons mentioned under Q8.*</p> <p>17. I have no experience of working with children with disabilities so will not comment.*</p> <p>18/19 The passporting of benefits is an important benefit of DLA, At a time when there is a major change in lifestyle caused by the onset of disability it is essential that people have the minimum added burden of bureaucracy and paper barriers to having the help they need. *</p> <p>The more barriers created and uncertainty in the system the greater the burden on the individual and carers. Additionally if there was no automatic connection then service providers would find it far harder to estimate future demands, which on past experience would mean a lower than necessary allocation and increased delays and confusion.*</p> <p>20 To repeat once more, if the main assessment was through the GP then the amount of duplication and redundant bureaucracy would be minimised. There would also be a far higher likelihood of accurate assessments that addressed all needs in one relatively simple process.*</p> <p>21 The more complex the process and the more forms and information requirements then the greater the probability that those with specific issues around literacy and command of English will suffer a disproportionate disbenefit. *</p> <p>22. If this is not simply a cynical cost cutting exercise then the aim should be to make initial assessment more accurate and fairer. *</p> <p>There is probably a general acceptance that some revision and reform of DLA is necessary but honest reform is a very different matter from cost cutting as an aim. Too many of the comments and questions appear to support the view that those who are honest and self motivated should lose benefit while those who are better at playing the system and who accept the consequences of disability, without attempting to overcome them, will gain. *</p> <p>A serious and honest attempt to improve the quality of life for one of the most vulnerable and disadvantaged groups is a worth while exercise, attempts to penalise and target that group is unjust and likely to have a number of unforeseen, and damaging, consequences.</p> |
| EM246             | 18-Jan-11     | <p>Hi i know my opinion wont probably count for much but i feel very strongly about all of these reforms to disability benefits.....I do have to say first of all that there is a need for some sort of reform as to many people are claiming these benefits fraudulantly and some people with disabilities can work... But this is all hitting the wrong people the genuine people who should be getting these benefits are being turned down daily yes it is also helping those with a disability who want to work but those who are fraudulantly claiming know how to play the system so are still getting the benefits.*</p> <p>i myself have had fibromyalgia/chronic fatigue for 15 years this year also now have pernicious anemia, plantar fascia and diagnosed with bi-polar disorder 3 years ago and also if you read up on fibromyalgia most of the associated conditions that come with it and yes i do work i want to work for as long as i possibly can i dont want to be a burden on society yet i keep coming up against brick walls constantly all aiming at the end result of me having to leave work... my work place are constantly putting pressure on my</p>  |

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|                   |               | <p>sick leave saying they cant sustain the levels despite the fact that in the 8 years i have been there my sick levels have drastically improved even though my condition is worsening as i push and push myself my self. daily life is work and thats it i get home i cant cook or do my housework i need help getting out of bed washed and dressed and back into bed again helped... i cant go to unfamiliar places alone as i panic and end up a total mess i struggle with public transport unless someone is with me i could go on but i really dont want to bore yyou with my ailments..... i have been getting DLA for around 8 years now having to renew it regularly and only last year did i get it indefinatley which believe me has taken a great deal of stress and pressure of me (which i must add flares my conditions up) i dont know what i would do with out this extra help it enables me to get to help in a lot of ways. and also helps me stay in work.....under this new reform i know i would definatley be turned down if people who are claiming ESA are getting turned down when they have terminal cancer (and yes i do know this is a Fact and would be willing to discuss this with you) what chance are people like me going to have. The trouble is you dont speak to the people who matter or know first hand you just bring in a set of rules that everyone must qualify to get these benefits people should be treated individually as everyones needs are different and we dont always fit into your strict criterias as these are always aimed at people who are totally incapacitated... Plus the fact not all employeers understand people with disabilities or wont make adjustmants or sustain someone having to have more sick days than the average person... i have a friend who has cerosis of the liver and not through drink she actually doesnt drink alcohol but when she goes for a job and tells them this she never gets a job ever.... the one job she did get she didnt tell them when she had some time of sick and they saw what was on the sick note they asked why she hadnt told them she explained was told we would of employeeed you then proceeded to terminate her contacrt from permanent to tempory.... why does every goverment pick on the disabled people singel parents ( yes not all are genuine) but what about people claiming as couples surely one of them could get a job but there never picked on like we are.....* i finally get my Dla permanent feel all the pressure has been taking of me to find out a few months later i now have to start worrying again worrying how i will cope with out this extra help..... you really need to start talking to real people consulting organisations doctors ect... i know and appreciate you need to cut public spending and seek out the fraudsters but at what cost... putting people who genuinly need help into more poverty... as in my case and also others i know taking away that help we need to keep us in work to keep us of state benefits*</p> <p>please feel free to contact me if you want to know anymore or of any help i can be i,m writing to you as an individual who is so scared that your new rules will take away from me help that i genuinly need</p> |
| EM247             | 19-Jan-11     | <p>Hi my name is [REDACTED], and I currently get DLA, I have schizophrenia and panic disorder and am on very powerful meds, im frightened that im going to lose everything with these changes coming. Who are the vulnerable that will be looked after. I spoke to my doctors and they said It will all be fine, just another name and as im deteriorating as the years go by, I may forget it all. Sorry for this jambualled email I just scared.</p>  |



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| EM248             | 19-Jan-11     | <p>I am writing to submit views on the above consultation.*</p> <p>To reassess all cases will be very expensive and certainly should not be done in those cases where an indefinite award has been given.*</p> <p>Reducing the Care Component to two levels rather than three may be a cost cutting exercise and may reduce support to those who need a lot of care at night as well as during the day.*</p> <p>Most people have jumped through many hoops and filled in very long &amp; complex forms to obtain their DLA. It is very unjust to make these existing clients jump through even more hoops to retain their benefit or to receive the new benefit. It is already very difficult to get DLA – this process should not be made even more difficult and existing clients should not have to go through even more red tape when they have already been assessed once.</p>   |
| EM249             | 19-Jan-11     | <p>This consultation cannot be filled in online? Your proposals, rather than making life simpler for disabled and carers, is suggesting a system even more complicated than the old one. An amazing achievement.*</p> <p>It also makes the usual mistake of really thinking of disability as being of a physical nature and that a lot of people just need a nice modern piece of technology and they are suddenly independent. It gives very little space to providing for those with severe learning difficulties. Although they can physically walk normally, they cannot be allowed out on their own or left alone in the house for one minute as they have no idea of personal safety, or anyone else's either. They are incapable of holding down a job.....even if anyone would take them on....as they cannot sustain interest and are dangerous to themselves and others. How many people with severe learning disabilities does your Dept employ, for example? I can imagine the answer.*</p> <p>Cutting the benefit for those in hospital is also an indication that you simply do not know the reality. Parents/carers of sick children usually live in the hospital with the child, usually sleeping on camp beds and sharing limited facilities with numerous others. They carry out the non-medical care of the child, for the day and night, and often the medical care too if appropriately trained. They have given up their job, they have to eat in canteens, family have travel costs, phone calls....etc. They have to pay childcare costs for the siblings. They save the NHS a fortune. I speak from experience. So it is not cheaper to have the child in hospital, it actually costs more.*</p> <p>I am also concerned that you want the doctors to assist with the assessments. They haven't got time, they are busy making people better. Also, as in our case, which Doctor would you choose? My daughter goes to see several consultants for all her various problems. Although all expert in their field they have little knowledge of what life is like for the family; they do not live with the disabled person day in day out. If a problem is short term it may not pose too much of a problem as people will help out on a temporary basis. This doesn't happen when the problem is lifelong.*</p> <p>It is disappointing that Mr Cameron is showing disabled people and carers such scant respect. There is much to solve in this country at the moment and picking on the most vulnerable seems to be the priority. Many have said to me that because he had his beautiful son who was disabled he would know where we were coming from. It is quite clear that rather than supporting families who are struggling to look after their disabled person, he is attacking us. Improving support for disabled and carers would have been a nice thing for him to do in memory of his son. He is showing through his early proposals that he hasn't a clue what it is like for ordinary people. He will have had the money to pay for help whenever it was needed and no doubt did not have to fight tooth and nail for help at school for his child or to get a break for his wife. It is dealing with bureaucracy that exhausts us as much as caring for our disabled child.*</p> <p>We are being attacked from all sides. Adult Social Services here have declared they want families to do more!!! with less money, less support. And the Short Breaks money which was previously ring fenced is no longer ring fenced so councils are seizing their chance to siphon it off to other things. So now we get no break either.*</p> <p>Change the form filling, yes. But make it simpler, not even more complicated.</p> |

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|                   |               | The money snatched from the disabled person will be spent on yet more bureaucracy. I am sure lots of us would be very willing to help you to design a form more fit for purpose which would target the money better without having to reform the whole system.  |
| EM250             | 19-Jan-11     | <p>I am an individual in receipt of DLA for which I am very grateful. I have Multiple Sclerosis and depend on carers for my personal care, household tasks and for miscellaneous outings to the doctor, dentist, opticians, hospital appointments, etc. I am in receipt of my state pension of £520. per month, plus a private pension of £50 per month. I do not receive any other benefits. All expenses relating to the services provided by my carers are paid for from my DLA. If my DLA was reduced there is no way I could afford to have the level of care I now receive and depend upon in my daily life. *</p> <p>You say there need to be changes taken into account with regard to disability in society now. Of course, attitudes towards disability have changed and there have been many improvements with regard to disabled people looking for work and support in the work place but these changes won't help those people who cannot access public transport and who rely on a Motability vehicle paid for out of their DLA. If their DLA is reduced then they won't be able to afford an adapted car or be able to fund the cost of taxis to work, thus forcing them to rely on state benefits which would be counter-productive in reducing the welfare bill. *</p> <p>I am age 62 now and was very reluctantly retired on medical grounds a few years ago. I would have loved to have carried on with my job but needing 24 hour care isn't exactly a plus point when submitting one's CV. *</p> <p>Please, please think very carefully before implementing changes that could affect so many disabled people living a worthwhile life, whether in work or housebound. What an able-bodied person takes for granted, like having a shower, can be a luxury for a less-abled person.</p> |
| EM251             | 20-Jan-11     | <p>i just hope this government or any member of their family need to care for any one.as most carers do,with out mobility allowance..and disability allowance ..my husband might just as well give up..this money isnt used on smoking drinking or holidays as such,but being able to pay for help getting out and about.other wise wede be house bound ..i still wouldn't trade places with you,i've not got a guilty conciouce.as you who voted for this should have.</p>   |
| EM252             | 20-Jan-11     | <p>We deal with blue badges so can only complete the questions 18 &amp; 19 which I hope might help:*</p> <p>Question 18 – What information about the disabled person could we share with other services or government departments to stop the disabled person having to tell lots of people the same thing?*</p> <p>If the person qualifies for the higher rate of DLA at present they receive the badge immediately but we do require written proof from your department therefore if we could get an immediate answer that would speed up the issue of the badge. Sometimes the condition can improve with surgery etc and it would be useful if we could be informed if the award is amended in any way.*</p> <p>Question 19 – How would our ideas for the new benefit affect different equality groups? For example, the equality groups looking at disability, age, race, gender, sexual orientation and religion and belief.*</p> <p>I can't see any reason why this would change as this is not applicable to their mobility.</p>  |

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| EM253             | 20-Jan-11     | [complex table - can't reproduce in Excel]  |
| EM254             | 20-Jan-11     | If you take my child's DLA away, you will destroy my family. As she has autism, a 'medical assessment' will not see it / pick up on it, unless that person is to be as expertly trained as our developmental paed and hns entire team at the Child Development Centre who diagnosed her. Please do not do this to us. We will fall apart.   |
| EM255             | 20-Jan-11     | <p>DLA reform applies to everyone, every single person could be just one step from disability themselves.*</p> <p>These proposals could mean poverty for the disabled and their families in this country. It could leave some in residential care completely isolated from their families and support networks through the removal of the mobility component. Removal of DLA then means that Carer's Allowance is removed, which could leave vulnerable people without support from their families. Taking into account aids and adaptations does NOT take into account the fact that not everywhere has access to these things.*</p> <p>The current system has one of the lowest rates of fraud and makes an effective support system for a great many people. The mental health organisation Mind is opposed to the 20% cut and seriously concerned about some of the proposed changes announced in this document.*</p> <p>I hope that the reform of DLA is reconsidered and that vulnerable people are NOT further marginalised by the loss and removal of important benefits and services.</p>  |
| EM256             | 20-Jan-11     | I am shocked that dla is going. I feel I don't get the right level for my level of disability as it is, that is another story. I am a single parent with multiple physical problems due to hms, to children with the same condition. I have no family help and their father is not in their life. I have had depression and anxiety problems also due to recovery from emotional abuse. I am getting under £20 per week in dla, and I have not been able to walk most of last year. Please do not get rid of dla, because some people play the system, how they do it is beyond me, when I feel I barely get the right level. I suggest more requests to wistle blowing!  |
| EM257             | 20-Jan-11     | <p>Question 1 Disabled people are unable to perform everyday activities at home, at work and in social situations, due to their disability, that most healthy people take for granted. *</p> <p>I comment from experience. I've had Rheumatoid Arthritis for 40 years, since I was aged 6 or more probably since birth. The disease has restricted all aspects of my life. I cannot take part in sports, dancing, other social situations etc. I have to plan carefully all my trips out. I prefer to have someone with me for various reasons - if I drop my car keys I cannot bend down to pick them up. If I need to use a public toilet, it would need to be a high seat with rails around etc. *</p> <p>My disease is unpredictable, I don't know from one minute to the next, from one day to the next, which parts of me will be painful, stiff and achy or how unwell the disease will make me feel in myself. Other non-disabled people do not understand how my disease affects me, unless they see me move stiffly, or see my disfigured hands, feet etc., they assume I'm "normal" and can do "normal" activities. They do not see the pain and fatigue. It takes time and energy that I don't have, to explain to non-disabled people what's wrong with me and how I might be feeling. My best friends are ones with disabilities themselves. They are the only people who really understand what its like to be disabled. *</p> <p>I managed to work for 22 years as a secretary but had to stop when I</p> |

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|                   |               | <p>developed cervical myelopathy and underwent urgent neurosurgery to fixate my spine. Two years prior to retiring, I successfully took my employers, a firm of solicitors, to Employment Tribunal for Disability Discrimination in 2000. My colleagues and employers claimed they did not understand my disease and how it affected me. They never made any reasonable adjustments which made my life so difficult I had to leave my job. *</p> <p>All the above makes me very wary of "joining in" with non-disabled people and I feel like I just want to be left alone to enjoy whatever life I have left, as much as I can. *</p> <p>More recently, disabled people and welfare benefits have been in the news a considerable amount. I find some of the reports extremely prejudiced against genuinely disabled people. If the DWP performed their role competently, there would be no benefit cheats.*</p> <p>Question 2 Higher Rate Mobility Component to enable the physically disabled to get out and about. Without my Motability car I would be housebound. I am unable to use public transport. I live in a village and would end up feeling miserable and depressed if I had no way of getting out and about. I would not be able to attend my medical appointments. My husband would not want to risk his job by having time off to transport me around. I would have even less quality of life without my own transport which now that I cannot work, would not be able to afford without Higher Rate DLA and the Motability Scheme.*</p> <p>The care component of DLA is fine as it is. I envisage people currently on the lower rate would not qualify under the new proposal to have two rates for PIP and would lose out.*</p> <p>Question 3 Aids &amp; Equipment – I have had to buy various things – long-handled grabber; kettle tipper, electric can opener, walking sticks, high seat chair, electric rise and recline chair etc. *</p> <p>Prescription Drugs. I have been on prescribed drugs for 40 years and have had to pay for them since age 16. It is not fair that some long term medical conditions qualify for free prescriptions and other chronic conditions don't.*</p> <p>Adaptions to their home – wetroom shower bathroom conversion etc., *</p> <p>Adaptions to car, petrol and diesel. The disabled with lower limb disabilities have reduced walking ability and rely on their cars to get around, even for short journeys. They cannot use public transport.*</p> <p>Eye Test – my prescribed drug "Hydroxchloroquine/Plaquenil" requires me to pay for annual sight test. I am unable to get this free.*</p> <p>Podiatry treatment – My spinal fusion and bilateral hip replacements make it impossible for me to bend to reach my feet. I cannot cut my own toe nails and care for other foot problems I have and have to pay a podiatrist. I asked my GP to refer me on the NHS but was told there is no NHS podiatry service in my area. If I did not receive DLA I would not be able to afford this and don't know what I would do.*</p> <p>Gas and electricity to heat home. It is unfair that pensioners receive winter fuel payments and cold weather payments when some pensioners are physically fitter than a lot of physically disabled people who don't. I am unable to move around as quickly and often as able-bodied people and need to have my heating on more. *</p> <p>Prepared foods, i.e. vegetables because I am unable to peel and chop etc. *</p> <p>Question 4 I agree that the current DLA application form is long-winded and lots of questions repeat themselves.*</p> <p>If reducing the care component to 2 rather than 3 parts is the Coalition Government's way of reducing the amount of money it pays out in disability benefit to the genuine disabled, then yes, I do see it as a problem. It would depend what the new PIP rates are going to be and whether the current 3 rates of DLA care component will be included in the new 2 rates of PIP.*</p> <p>Question 5 Yes, I think certain health conditions and disabilities should be paid automatically, i.e. chronic diseases, e.g. Rheumatoid Arthritis, Multiple Sclerosis etc., where the disabled person's GP, Consultant, Surgeon or other medical professionals can show that the person is a genuine case and will have the disease for the rest of their lives.*</p> |

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|                   |               | <p>Question 6 By listening to disabled people and their own medical professionals, rather than some agency doctor with little knowledge of the disabled person's medical history and being paid a commission for rejecting claims. Also by not using statistical information to deprive genuine disabled people of benefit. *</p> <p>What activities or actions are the most important to live an independent life? *</p> <p>The right to quality of life. A disabled person's life is restricted enough and it costs more to live as a disabled person. Being able to live in one's own home and spend disability benefit on whatever the individual chooses to make their lives more comfortable and healthy. *</p> <p>Question 7 If the applicant has been diagnosed with a progressive chronic disease, its inevitable the person's health will deteriorate and that person can contact the DWP to request an increase in payment, if he/she doesn't receive full benefit already.</p> <p>If a person has a health condition that could improve, then that person should be reviewed by the DWP more frequently than someone with a progressive, long-standing chronic illness.*</p> <p>Question 8 Absolutely not! A disabled person does not choose to walk with a stick, or use a wheelchair and it would be grossly unfair if he/she were judged using any such aids. Just because a disabled person uses an aid doesn't make their lives as easy as for a non-disabled person – its still not a level playing field. With lower and upper limb disabilities, when it rains, I cannot walk holding a walking stick in one hand and umbrella in the other. I either have to get wet or not go out. Someone who uses a self-propelled wheelchair cannot use all public transport. Even with aids, disabled people still face lots of hurdles in everyday life. *</p> <p>What aids and adaptations should we take into account? *</p> <p>None.*</p> <p>Should we only take aids and adaptations into account if the person already uses them? Or should we take aids and adaptations into account that a person could use and get hold of easily? *</p> <p>Surely if a disabled person required a walking stick, crutches or wheelchair to get around, then they would already be using them? *</p> <p>Question 9 The current DLA form is very long and repeats itself, but its not difficult to fill in. The main problem with claiming DLA is the DWP assessor not understanding the nature of the person's disabilities and/or not taking on board what medical professionals have said, ignoring the facts, resulting in the applicant having to appeal the decision - an unnecessary waste of tax payer's money! I speak from experience. My DLA claim for an increase was rejected initially despite producing substantial medical evidence from GP, Rheumatologist and physios. On appeal, the DWP requested a report from my surgeon. I was awarded full DLA as a result – I consider this a complete waste of tax-payers' money - the surgeon's time and NHS &amp; DWP budgets. *</p> <p>• How could we tell people about the new benefit so that they know what the benefit is for and who is likely to get the benefit?*</p> <p>DWP website, Directgov, CAB offices, Law Centres, GP Surgeries etc. It was a Community Physiotherapist who told me about DLA in 2002, before then I wasn't aware of its existence and did not claim.*</p> <p>Question 10 The disabled person's own medical professionals.*</p> <p>What information will we need to make it clear what the person can and cannot do? *</p> <p>Information from the disabled person, their GP/Consultant/other medical professional. However, I considered it a waste of tax payer's money when a DWP assessor ignored my GP, Rheumatologist and Physio's reports and ended up requesting a report from my Surgeon – another waste of tax payer's money and NHS &amp; DWP time.*</p> <p>Question 11 What good things and bad things may this bring? *</p> <p>It would be a bad thing if the independent person was encouraged to refuse the applicant based on his/her commission payment from the Government for refusing. *</p> |

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|                   |               | <p>An independent person would not know a person's medical history as well as his/her own GP and other medical professionals, the interview would be brief (say an hour), resulting in more appeals and waste of tax payers' money.*</p> <p>Is there any time when it would not be right to say that a person had to meet an independent person face to face, either in the person's own home or somewhere else?*</p> <p>The disabled person should not be made to feel they are being ordered to meet with an independent person. We do not choose to be disabled and deserve to be treated with respect. The DWP should understand the nature of their health condition or disability results in them sometimes always not being able to keep appointments, or attend appointments at certain times or certain places etc. There should be a degree of reasonableness about meetings. *</p> <p>Question 12 Take into consideration the disabled person's type of health condition, whether it is a progressive chronic disease; or something which may get better over time and how long the person has been afflicted etc. E.g. someone that's had 40 years of Rheumatoid Arthritis and numerous surgeries is likely to be more disabled than someone else diagnosed just 5-10 years. *</p> <p>Should the way we look at a claim again depend on the needs of the person and their health condition or disability? *</p> <p>Absolutely, the same health conditions and disabilities will vary from person to person, e.g. someone who has had a Rheumatoid Arthritis or Multiple Sclerosis diagnosis for, say, 5 years is unlikely to be as disabled as someone who has had it for 40 plus years. In the case of a 5-10 year diagnosis maybe an annual review would be appropriate and for 10 years and over a 3 or 5 year review. *</p> <p>Question 13 How can we get people to tell us about the changes in their lives?*</p> <p>Whether or not the new PIP will be easier than DLA to understand is as yet unknown. I would assume any changes would be reported in the same way as for DLA.*</p> <p>Question 14 Help with understanding and completing the new PIP forms.*</p> <p>Would it help if we told people to get help and advice and where to get it from? *</p> <p>Yes.*</p> <p>Question 15 By paying for them themselves out of partner's earnings or DLA. *</p> <p>Should disabled people be allowed to use the new benefit to pay for a one-off cost?*</p> <p>Yes. Disabled people should be able to use the money for whatever they like to accommodate their disability. By one-off cost, does this mean claim a whole year's entitlement in one go to pay towards something such as a home adaption or mobility scooter? That would be a good idea. Disabled people cannot afford to pay interest on loans.*</p> <p>Question 16 Ensure the child will get the benefit and not the parent.*</p> <p>Question 17 Apart from Warm Front Scheme and recent Digital TV Switchover, I haven't been told about any other services or benefits in the 8 years I have claimed DLA. *</p> <p>What can we do to make things better?*</p> <p>At the moment people who get Disability Living Allowance automatically get help from other benefits and services, like the Blue Badge scheme and the Warm Front scheme. *</p> <p>What would it mean to disabled people if they did not automatically get help from these other benefits or services?*</p> <p>A waste of tax payers' money unnecessarily duplicating the application process; another application, another hurdle to overcome ..... Disabled people face not only a life-long battle with their illnesses but a life-long battle with the DWP and other Government Departments. *</p> <p>Question 18 Medical history? Surely this is shared already?*</p> <p>Question 19 If the new PIP benefit is going to be a way of reducing the</p> |

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|                   |               | <p>number of genuine claimants then the idea would be a breach of the right to quality of life, the Human Rights Act 1988.*</p> <p>Question 20 I dislike the way the media are portraying disabled people to be benefits cheats and the like. *</p> <p>Every time I have applied for benefits I have provided substantial medical evidence and been thoroughly investigated. I cannot understand how some people manage to cheat the system. If the DWP carried out their job properly, there wouldn't be any, or very few, cheats. My benefits get reviewed from time to time, surely the benefits cheats get reviewed as well? Unless the DWP do their job properly, I am sceptical that any new DLA benefit will reduce this problem but place an additional burden on tax payers</p>   |
| EM258             | 20-Jan-11     | <p>Dear DLA Reform team, After learning about the possible removal of the DLA on the BBC Breakfast Programme I was most concerned about the possibility of losing my Disabled Living Allowance. So much so I wrote to my member of Parliament [REDACTED] MP; and he kindly took the matter up with Maria Miller MP. Minister for Disabled People at the Department for work and pensions.*</p> <p>In her response to [REDACTED] and to myself the Minister suggested that I should e-mail you direct with my concerns which I am now doing. I start with my letter to my member of Parliament [REDACTED] MP;*</p> <p>*<br/>*<br/>*</p> <p>08 January 2011*</p> <p>*<br/>*<br/>[REDACTED] *</p> <p>*<br/>Dear Sir [REDACTED] *</p> <p>This morning, Saturday January 8<sup>th</sup> I was watching the BBC Breakfast programme and on their News Headlines, they were discussing DLA, Disability Living Allowance. *</p> <p>*<br/>It appears that this Government has it in mind to stop the allowance and replace it with something else.*</p> <p>*<br/>In 2001, I was diagnosed as having Spondylosis between five of my lower Disc's and this causes me problems when I walk.*</p> <p>*<br/>If I walk more than about 15 paces without a break, I get an angina pain in my chest causing me to stop, I take out my Glyceryl Trinitate spray and spray two metered doses under my tongue. After a while I can then carefully begin walking again.*</p> <p>*<br/>In 2002, I was declared as being disabled and awarded the Disability Living High Rate Allowance and in 2005, I received this letter, Copy attached, telling me that I did not have to keep applying for the allowance as the date was now from the 21/07/2004 Indefinitely.*</p> <p>*<br/>I applied for and was granted a Motability car, the Car lease lasts for three years and then it is replaced with another car if I still need one and in April 2011 I am due to get another car, my fourth*</p> <p>*<br/>Living in North Northumberland where public transport runs about every two hours I would find it difficult getting on and off a bus. Also waiting around for a return bus in a draughty bus station would not be very pleasant so the Motability car which is paid for by my weekly DLA allowance has been a wonderful asset to me.*</p> <p>*<br/>It also allows my wife and I to go to Alnwick to do our shopping without the need of asking friends and neighbours for help.*</p> |

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|                   |               | <p>*</p> <p>I would imagine that if the DLA, Disability Living Allowance was withdrawn many other people like me in North Northumberland, who are also disabled and regular visitors to local hospitals some, over fifty mile away, would have to rely on Ambulances to get us there and back. For instance when I visit the Alnwick Infirmary for my Endoscopy Procedure every year it costs me £40.00 a time for a Taxi, which is quite an amount when taken off my old age pension.*</p> <p>*</p> <p>Sir [REDACTED], all I ask please is that if there is a debate in the chamber could all the disabled people in North Northumberland rely on you to bring my comments above to the appropriate Minister. *</p> <p>*</p> <p>Yours sincerely, [REDACTED] *</p> <p>*</p> <p>*</p> <p>*</p> <p>*</p> <p>*</p> <p>Dear Reform Team, I am conscious of the Governments need to save monies at the moment but at what cost. I have always paid my National Insurance claim on time and also my taxes. I have worked all my adult life and until I developed Spondylosis in my spine I am certain I never missed a days work through illness. I am prepared to answer any questions you may have for me, Yours sincerely,</p>  |
| EM259             | 20-Jan-11     | <p>It is vital any change in the benefit will not result in are duction as ever the current system falls well short of covering the extra costs of disability,extra heating,extra transport costs*</p> <p>special dietary requirements among many other things It is also important entitlement to housing and council tax benefit as well as free prescriptions and eye tests this must be made clear and quickly*</p> <p>the example set by the appalling handling of the work Capacity Assessment which the government's own review has shown to be not fit for purpose yet millions of existing claimants will still be subject to because it is to be rolled out un amended in APRIL2011*</p> <p>IT IS SCANDALOUS THAT DISABLED PEOPLE SHOULD BE SUBJECTED TO A HUMILIATING UNFIT FOR PURPOSE ASSESSMENT WHEN DWP AND LOCAL AUTHORITIES ALREADY HAVE THE INFORMATON THEY REQUIRE*</p> <p>HOW PLAIN STUPID IS IT THAT PEOPLE WHO RECEIVE CARE PACKAGES TO HELP THEM WASH AND DRESS SHOULD BE SUBJECTED TO AN ASSESSMENT FOR FITNESS TO WORK THE ASSUMPTION DISABLED PEOPLE DON'T WANT TO WORK IS A SCANDAL MANY OF US DID BUT CAN NO LONGER IT IS AN UTTER WASTE OF TIME AND MONEY it should be made clear peiople with care packages should be exempt from the WCAdisabled people are being left in limbo in fear of losing benefit because we , we may be wrongly assessed as able to work and further left in limbo as a resultof unclear mixed messages regarding DLA reform*</p> <p>the whole thing is a cuts orientated mess which will lead to hardship and illness if the position is not made unequivocally clear currently the WCA and DLA REFORM ARE CLEAR AS MUD AND AN ENOURMOUS WORRYSOME BURDEN ON THOSE WHO WILL BE EFFECTED AND NOBODY SEEMS TO GIVE A TOSS*</p> <p>[REDACTED] (sorry accidentally hit capslock didn't mean to shout)</p> |



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| EM260             | 20-Jan-11     | <p>Hi, My name is [REDACTED], im 28 years old about to turn 29 in a few months, four years ago i lifed a box at work and my life changed forever. It has taken 4 years of fighting to get a formal diagnosis, mainly because of my age too young. I am still to get DLA but i do fear these changes will remove my benifits when i do get them. These changes are to a degree fair, things do need to change in a big way.*</p> <p>I dont agree with constant reassessment, i struggle with forms all the time as it is without increasing them. This will put off a massive number of people from even applying due to the amount of work involved in getting it then keeping it. Yes there needs to be reform, to include how the condition affects day to day but aids shouldnt mean the person is put off from them, or from apply as a result. I need a mobility scooter if i was to go back to work, something i couldnt afford with out DLA money. To loose that would be the end of me possibly going back to work, or even end the work i might be doing at the time.*</p> <p>For me the greatest thing you need to change is the doctors that do the assesment, dont farm us out to jo blogs who have no speciality. Who put us through various tourtures and even though they go yeh this person has a issue you still fail them. You need to put more work into winning over specalists - mine wont reply to dla letters, they just forward the last letter which for you guys is useless. Your medicals need to be specalised to the problems the person has. So they know about these things, what is normal level of issue, what the result normally looks like.*</p> <p>I belive the changes in DLA and in other benifits is needed but the way the plan is coming out makes me fear many people will lost the independence this provides. The ability to interact with the general public, hold down jobs, be a beneficial memeber of society. These changes might drive people to suicide, to becoming homeless to worsening there condition. You need to change but at what cost this cost is too much.</p> |
| EM261             | 20-Jan-11     | <p>To whom it may concern. Please register my objections to cutbacks and reforms in the way Disability Living Allowance is allocated. People applying for DLA either for themselves or for those they care for, are already living in a highly stressful situation. This is because either because their disability means that everyday tasks such as dressing, washing, eating are more difficult to acheive or because their time is taken up supporting another person to perform these tasks. To these people, DLA means the difference between meeting basic needs (such as food, water and shelter) and Esteem needs, essential for a person to feel secure and happy (ref: Maslow's hierarchy of needs, 1943). Thank you for your time and consideration.</p> <p>Regards</p>  |
| EM262             | 20-Jan-11     | <p>Good afternoon. Speaking as the wife of a disabled person -with multiple health issues; I am seriously concerned that those who are entitled legitimately to the benefit will be penalised because of the rogues/spongers behaviour and outright lies.*</p> <p>DLA mobility award - allows us the vehicle without which we would be completely abandoned in a small village that has no bus service and thus we rely heavily on the vehicle for regular hospital, doctor, food shopping; as social visits are limited by reason of the extortionate cost of fuel; thus we keep our motoring as low as we can to ensure that we have fuel in the car in an emergency (two 'blue-light' calls have been necessary in the past year and obviously I need to be able to follow the ambulance and get back home again at 3 in the morning) As you must appreciate without the mobility vehicle; we are completely isolated - indeed more so than most - as our neighbours are also in their late 70's/80's so cannot assist us.*</p> <p>DLA care component award to my husband allows for personal help; ie chiropodist etc and such like; as he unable to reach his feet, even to put his socks on; also I sometimes need assistance when he falls - which he does on a regular basis -and as I myself have had a stroke albeit a mild one; I have still been left with limited use of my right side; so outside assistance is essential. Our son is miles away and is in any event in the forces; so is not</p>  |

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|                   |               | easily available in any event. Loss of these benefits will impact on us tremendously and in fact my husband has already said that if we lose this; <b>we might as well top ourselves;</b> as being a burden on others (god knows who) is not living merely existing.  |
| EM263             | 20-Jan-11     | <p>Hello Can you tell me how this is going to affect deaf people. We are a group that is normally ignored by everyone, because we are difficult to assess and our needs are so very different from the majority of disabled people.*</p> <p>For example, I contracted Meningitis at age 7 and now have 100% hearing loss, I was brought up orally with lipreading, and in my 30's learnt sign language because my sight was not as good as it used to be, and now rely very heavily on sign language. Sign Language interpreters are expensive, and for a great number of things we cannot get funding to pay for them, therefore we have insurmountable communication difficulties.*</p> <p>I am socially isolated, because I cannot do what every other hearing person does 24hours a day , 7 days a week, 365 days a year, throughout my life, and that is to hear, to socialise with others and to have conversations, to learn, to listen and pick up. There is no way of overcoming this barrier unless a sign language interpreter was assigned to me for 18 hours a day 7 days a week, and I know that the cost of such a thing would be horrendous.*</p> <p>I would challenge anyone to go without hearing for a month and say that it is not a very severe disability. I would therefore ask that when you are setting the new PIP, you very carefully consider deaf people, the fact that their communication needs are an insurmountable barrier, and will be for the foreseeable future unless science expends to such an extent that peoples hearing can be restored (I do have a cochlear implant, which is absolute rubbish, it just gives me a load of unrecognisable pain and noise , that one cannot distinguish anything from).*</p> <p>In an Ideal World I would hear again.. and I regularly pray to God this will happen, but apart from a miracle, or a huge scientific breakthrough, I do not foresee my insurmountable barrier being removed.*</p> <p>So please, please do seriously consider us deaf people, who are all alone in the world, many of us with unrecognised mental health problems, as we are just labled deaf, and no consideration is normally taken into account by doctors of how deafness affects us mentally (most social workers just pass it off as "oh they are deaf", which undermines us and makes it look as if there is no problem! Thank you for taking the time to read this email.</p> |
| EM264             | 20-Jan-11     | <p>Dear Sir / Madam, I wish to make the following comments as a disabled person who has been receiving the higher rate of DLA from an early age:*</p> <p>Firstly please do not stop any payments to current recipients while they go through the assessment process, as many of us rely on this as part of our "income". Surely it is also legally wrong to remove something before the assessment procedure has been done?*</p> <p>The term "independent, full &amp; active life" means so many different things to different people!*</p> <p>The barriers we face are many and varied and are continuously changing, so to define exactly what all these are I'd argue is virtually impossible! *</p> <p>Extra costs! – Heating. Equipment, most not "free" for all of us e.g. chairs, adapted vehicles and communication aids. Travel. Specialist foods. Restrictions in many purchases due to access e.g. shopping / leisure activities / holidays. Paying for PA's to accompany us anywhere! *</p> <p>Being a disabled parent should also be considered, with all the extra costs involved there.*</p> <p>Why two levels? Why not 1 or 10! Disabled peoples needs are so complex.*</p> <p>Personally I think too many people get awarded a Blue Badge!*</p> <p>DLA is a ticket to other benefits, which needs careful consideration.*</p> <p>I don't get the redefining of mobility and consideration of equipment! Much equipment is overpriced and we pay for it ourselves! You cannot say that the ability to "walk" is compensated by a prosthetic or a chair etc!*</p> <p>Most social workers have an extremely limited empathy of disability and do</p>  |

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|                   |               | <p>not built up lasting professional relationships with us. I think this could / should be a role for the Independent Living Fund, which has a far better understanding of disabled people and independent living!*</p> <p>There is loads more to say but can't get my head around it all in a short time and would have liked the opportunity to discuss with others! ---- Many Thanks</p>  |
| EM265             | 20-Jan-11     | <p>Dear Sirs Please find following a post, taken from my blog and transcribed into email, that sums up my feelings about the proposed DLA reform: The cutting edge.*</p> <p>Posted on January 20, 2011 by [REDACTED]*</p> <p>*</p> <p>Yesterday, I added a few comments to this Guardian article. This morning, I tweeted the link to that article, and [REDACTED] retweeted it and blogged about it too.*</p> <p>*</p> <p>As far as the proposed cuts to DLA are concerned, I am largely an ostrich. I don't get DLA. I did once try to apply for it, out of desperation and panic, and I'm apparently in the system to have my claim reconsidered on appeal, although I've not heard – from either the Benefits Agency or the Welfare Rights worker who is supporting me – for some time. The truth is that, when the appeal date does finally come through, I may decide to cancel it. Such is my present intention, but I am acceding to my husband's request that we wait and see how I am at that point.*</p> <p>Because, slowly but surely, things are getting worse for me, and it is impacting upon his ability to work and earn enough to support us all. But I have talked to people who have been through this process and I know how humiliating and ghastly it is. Even with support, I am not sure that I can face it. I'm not sure I can talk openly to hostile strangers about the sometimes degrading, always distressing, things I have to go through.*</p> <p>My doctor believes I should receive DLA. So does my occupational therapist. So does my support worker (Welfare Rights is a subdivision of Social Services). I don't believe it – not because I can't accept that I am disabled enough to need practical help, but because I have read many stories of people far, far worse off than I am, and I simply cannot see, even though I clearly do fall within the criteria for the receipt of DLA, how I could possibly accept it when those others are denied it*</p> <p>.Read the One Month Before Heartbreak website and you will quickly see what I mean.*</p> <p>I can't solve the dilemma in my heart and mind, so I stick my head in the sand. Truthfully, I am hoping that, by some miracle, I will start to earn enough money for us to manage without it, so that I can avoid the issue completely.*</p> <p>Because, let's say I do get awarded DLA... I would feel obliged to send it back in protest – at the pending cuts; at the whole governmental attitude to disabled people; at the injustice of the entire welfare system. But how could I do that to my husband? He works so hard every single day and then has to come home and pick up the pieces of the things I haven't been able to do; he has to care for me <i>and</i> our children when I am not well enough to care for myself.*</p> <p>It's just not something I can bring myself to think about.*</p> <p>But then there's the whole 'experience' of living on benefits. I used to get incapacity benefit. I decided to go back to work, even though I was technically too ill to do so, and it proved disastrous. But it taught me what I <i>can</i> do – work freelance from home – and I am still willing to do that even now. I don't usually describe myself as brave, but it has taken courage and determination to persist through all of this. And yet the Daily Mail saw fit to portray me as a wilful scrounger; a leech; a criminal.*</p> <p>Which is how so many disabled people are portrayed these days. Never mind the fact that, even if they wanted to work, the playing field is not level and there is little support available to them to get and keep a job.*</p> <p>If I were to receive DLA, I'd be forever looking over my shoulder. I don't, for</p> |

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|                   |               | <p>example, customarily go anywhere alone. The last time I tried to travel further than my home town was over six months ago and it was such a distressing experience that I swore I would never do it again. But there are a few places where I feel safe, because I know the staff and where the toilets (to hide in) are. Would I feel that I have to check that I'm not observed before going to one of these places without my usual assistance (in the form of one of my older children).*</p> <p>Yes, I would. That's how I felt when receiving incapacity benefit. Because people assume that the slightest instant of normality means that your life is normal. And then they judge you. Or they try and report you.*</p> <p>My life is not normal. I wish it were. But you can't necessarily see that if you should happen to bump into me, one daughter or the other hovering close by.*</p> <p>To a certain extent, my children are my carers – even, for God's sake – my eight-year-old son. Their lives are not normal either. We are trying to survive, not to live an extravagant or pampered existence. I would rather have support in finding work than DLA, but things are as they are and the stark fact is that no-one wants to employ an incapacitated homeworker when they can have a fully-functional office worker instead. Even if the homeworker is more talented/dedicated/hardworking/focussed etc etc etc. (Yes, I'm making an assumption here, I know, but forgive me the frustration that has lead to it.)*</p> <p>I wrote yesterday that I feel as if the government is merely reflecting public enmity towards the disabled. I would like to apologise to all the lovely people who support me every day for that remark because, speaking in anger, I failed to be specific enough in making it. I should have recognised that there are many, many people who do not read the Daily Mail and who are sympathetic and concerned and justly horrified by what's going on. But I do stand by the essence of my comment – which is that our current society tends to want to believe that all disabled people are scroungers who deserve to have the pathetically threadbare rug of support that is available to them dragged out from under their feet. Or is that just an illusion created by the vindictive, ill-informed, often illiterate commenters on the Daily Mail's website?*</p> <p>No, the DLA cuts will not affect me. But the government's attack on the less wealthy and fortunate – the removal of EMA; the rise in tuition fees; the benefits' cuts; the restriction of child benefit – these things all tell me that as a woman; as a mother; as a low-earner; as a person with disabilities; I am inconsequential, unimportant, insignificant.*</p> <p>But I am not. And if I feel disturbed and victimised and frustrated and infuriated – and I do! – then God alone knows how it must feel to those without all the blessings that I have. My heart in particular goes out to [REDACTED], the mother who has been forced into contemplating the unthinkable.*</p> <p>So, please... Tweet this post – or another of the links above. Add your thoughts to the Guardian article. Email David Cameron (camerond@parliament.uk – or – privateoffice@no10.x.gsi.gov.uk) with your opinion. Whatever you do, please just do something.*</p> <p>So, please... Just do something.</p> |
| EM266             | 20-Jan-11     | <p>Dear Maria Miller, Re: Disability Living Allowance reform*</p> <p>I am writing to urge you, as Minister for Disabled People, to recall the Public Consultation on Disability Living Allowance (DLA) reform, and to cease work on reform of this benefit, due to serious flaws in the consultation paper. As such, the consultation questions are deeply skewed and any answers will be likely to support wholesale reform. This is both unfair and unwise, and will cause hardship for many disabled people. *</p> <p>Your case for reform has been criticized, and then completely demolished, by the various disability rights groups fighting reform. They accuse the DWP of building their argument without sufficient evidence, and I am inclined to agree. The claims that DLA can act as a barrier to work, in particular, are</p>  |

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|                   |               | <p>robustly questioned. Questions are also raised concerning the accuracy of the representation of supporting data. *</p> <p>Most devastating to your case for reform is the critique of proposed amendments, leading one to ask whether augmenting DLA might not be a better, cheaper way of improving employment opportunities, rather than launching an entirely new benefit. It would seem that the costs of such rebranding are only justified when savings are made by cutting the DLA caseload by 20%. This figure is, in and of itself, questionable – how is it possible to know that this many people can be removed?*</p> <p>The Personal Independence Payment (PIP) appears to be a case of cuts dressed as positive reform. Disability rights groups and charities have uniformly condemned the proposals, warning of dire consequences. The list of those affected includes: people who are mobile with aids; people with disabilities so severe that they are unable to be very active; care home residents; those who receive local authority care packages. Most other disabled people will suffer through needless reassessments upon the introduction of PIP, and re-testing every few years even when a condition cannot be treated.*</p> <p>There is a strong feeling amongst people with disabilities that the Coalition Government have declared war on us, with a continual ratcheting of pressure on us since the Emergency Budget in June 2010. Announcements on Employment and Support Allowance, Incapacity Benefit, and Disability Living Allowance have made us feel that the Government is scapegoating us and removing the support on which we depend. Iain Duncan-Smith's comments to The Sun newspaper [01/12/2010) suggesting that Incapacity Benefit claimants were partly to blame for a large fiscal deficit caused by a recession, a bail-out of the banks and quantitative easing. The only way that you can convince people with disabilities that you are not hostile towards us is to halt the current process DLA Reform. Whilst there may be ways to improve DLA, they do not involve replacing it with a new benefit, and neither do they involve removing anyone from the claimant caseload.</p> |
| EM267             | 21-Jan-11     | <p><u>DLA and the particular needs of people who have been diagnosed with a severe mental health illness*</u></p> <p>I have been a carer for my son who is diagnosed as schizophrenic for some 12 years and I would like to highlight some of the problems with DLA he and other vulnerable similar people face.*</p> <p>Firstly I would like to point out that he is lucky to have us to watch out for him as many people do not become ill till later in life after they have been perhaps independant for some considerable time and have lost contact with relations or acquaintances who would take on a caring role for them but I am sure as in the case of my son when he has severe psychotic symptoms he is not capable of any rational responsibility for dealing with his own affairs and as I have had to deal with several severe episodes over the years I can assure you that there is not the infrastructure in place for any 'body' to take on this role for them . This is something that needs to be addressed. For example he is in hospital at the moment and no one has asked him or us if we need help with sorting out his DLA or any other benefits for that matter. This has been the case on several occasions in the past. Many <u>assumptions</u> are made conveniently by professional bodies responsible for his care. For example who or what has taken on the responsibility of getting this questionnaire to these vulnerable people? I only came across it by accident when I was looking for something else so how can it be a fair reflection on what people think. When I had to inform the DLA office that he was in hospital I asked about this consultation and no one there had heard of it!!!*</p> <p>In the consultation there is not much encouragement to hear the views of carers, and while they are not the person in receipt of the benefit they play a crucial role when supporting someone who has a severe mental health diagnosis.*</p> <p><u>Cessation of DLA when someone with mental health problems is admitted to hospital for a considerable period*</u></p> <p>When a mentally ill patient is in hospital for more than 4 weeks DLA</p>   |

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|                   |               | <p>payments stop and I would like to outline why this is unfair. In theory it is because they are being cared for away from their home but part of their rehabilitation is to get them back in to the community as quickly as possible and this can consist of very quickly, even when they are under section, getting out of hospital for considerable periods of time on a daily basis, and as DLA is only paid for nights spent out of hospital why is this the case? Surely if payment is made because they need help and support when they are at home to sustain independent living this should still be the case when they are outwith hospital confines? At the moment my son is only allowed out accompanied and that usually means us, and all the expense that that involves. For example collecting him from hospital, providing meals while he is with us etc. At one stage he was allowed out from 9 in the morning to 9 at night in our care! Just because he is in hospital doesn't mean he will not have the usual bills to pay to keep his house running. This is very different from someone with a physical illness who goes in to hospital for treatment as they remain in hospital until deemed fit enough to go home. Surely then a fairer way of looking at this would be to keep an award pro rata for periods spent outwith hospital? We have often had to meet the shortfall out of our own pockets to support and sustain him through these periods. I would like acknowledgement and feed back on this and look forward to receiving a reply. Many thanks*</p>   |
| EM268             | 21-Jan-11     | <p>Dar Sir, I am in receipt of DLA and it is of great benefit. It also opens up the component of Motability which keeps me mobile and without which I could not afford a car. If I lose this allowance I will not be able to afford a car again.*</p> <p>I ask the consultation panel to look carefully at withdrawing this benefit from people like me who are double amputees and over sixty years of age, as if it is withdrawn, I will not be in a position to work and earn money again to provide a car to keep me mobile. It also helps to pay my carer who is my wife and without whom I could not cope. regards</p>  |
| EM269             | 22-Jan-11     | <p>I am responding as an individual on behalf of my son who lives in a care home and is unable to communicate. *</p> <p>I would like to respond to Question 6 ...How do we prioritise support to those people least able to live full and active lives? Which activities are most essential for every day life?*</p> <p>Answer. The most vulnerable people in our society are people with a profound disability. Profound means unable to do anything or hardly anything for yourself. These people are unable to live " full and active lives." Children with a profound disability become adults with a profound disability. You think its hard looking after a disabled child, well of course it is, but you cannot imagine how hard it is when that child becomes an adult. I know, I did it for 28 years and had to make the heartbreaking decision to place my beautiful son in a care home. He is dependent on carers for all his needs and cannot make decisions for himself. That said, he is an intelligent young man with a great sense of humour who takes a great interest in the world. He needs to be around people both in and out of the home. He needs to come home to his family to know that he is still very much loved by us all and hasn't been deserted. These "activities" are essential for his every day life otherwise he becomes withdrawn and depressed. His "activities" require a specially adapted vehicle without which we would not be able to bring him home.*</p> <p>You can prioritise support by not taking away the Mobility Component for people in care homes, without it many of these peoples lives will not be worth living.*</p> <p>Maria Miller says on page 1 "It is not acceptable for anyone to be trapped in a cycle of dependency". For your information Ms Miller, many people certainly are trapped in a cycle of dependency and always will be because of their disability. I don't think that the EXTREME minority have been considered at all in this reform. Extreme minority means people like my son who will never be able to walk, talk, sit unaided, dress or feed himself, read a</p> |

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|                   |               | book, voice his opinion etc etc etc. I'm sure he would dearly love to be able to work and contribute to society, its a pity you view his kind as a drain on resources. This makes me so angry I can't believe it is even being considered. It makes me ashamed to be British.   |
| EM270             | 23-Jan-11     | <p>Dear Minister Maria Miller, We have a phsical and learning disabled daughter in shared care (home 2 nights because of her special needs to be part of the family and in residential the rest) and ofcourse this document is extemely important for meeting her need of the here and now and the future.*</p> <p>In response to your forward document which appears to protect vulberable people but as you read on the document states contradictory statements eg: Para 14 of the document states that "mobility is about walking". This is incorrect, mobilty is about being able to get from A to B. Mobility is about Mobilty in which ever way helps them to get mobile, often/always requiring someone else to accompany them .*</p> <p>Then Para 21 - says that those living in care homes do not qualify for mobility component this is unfair, discriminatory an punitive. If anything living in a care home requires more assistance than living at home. At home individuals usually have 1 -1 care but in Care Homes this is never achieved unless the person is profoundly disabled with multiple needs. To stop mobility component to people who live in care homes, especially younger learning disabled people, is returning to old provision of people being trapped in the care home environment.*</p> <p><u>My response to some of the questions in section 5 are*</u></p> <p>Question 3. Because the variety and levels of disabilities, the degree of financial help cannot be generalised but has to be dealt with on and individual basis. All needs, need financial help to cover living, mobility and supervisory and indepence costs to a level which gives them a lifestyle acceptable to parliamentarians.*</p> <p>Question 5. There are some conditions which will never change for the disabled person which prevents them from living an independent life. They will need care and supervision for the rest of their lives and so therefore will require automatic entitlement for life.*</p> <p>Question 6. All disabled people should have the necessary help provided according to their needs. It is paramount that govenment looks after those in great need before providing help to those who do not need this help.*</p> <p>Question 8. The aids and adaptions should only be taken into account if by the state paying for them the person has overcome their disability completely.*</p> <p>Question 9. The Questionnaire must be short and in a clear, simple and unambiguous language.*</p> <p>Qestion 11. People who are unable to understand the question or to be aware of the consequences of their answer must have a parent, carer or advocate of their choosing with them.*</p> <p>Question 16.. Long term disabled people who do not have private insurance cover should have their aids and adaptions paid directly by the state. PIP should be for regular outgoings to aid the standard of life.</p> |
| EM271             | 23-Jan-11     | <p>Yet another way of hitting the most valnerable in our society? And at what cost? The figures will finally show a saving but will not show the cost involved. The paperwork to be distributed, the staff to assess the completed forms, the appeals, and appeals, and appeals.... .... *</p> <p>Please someone use some common sense. If you think the system isn't working bring in a better system but don't spend vast amounts of money trying to fix the existing system. Draw a line, leave it as it is for those already claiming and start new with a better system tomorrow.*</p> <p>Look carefully at the mobility componant. What is it for? If it's to enable disabled people to go to work then it should stop at retirement. If it's to enable disabled prople to get around because they are disabled then it is age discrimitary because it can't be claimed by the sixty fives but if you claim it at 64 and 11 months you have it for life. How is that fair?</p>  |

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| EM272             | 24-Jan-11     | <p>1. They are as wide-ranging as people's impairments, but in a society where almost every transaction is mediated by money, money is one of the biggest obstacles. You can tell bus companies to put low-loader buses on routes and get the authority to put in raised bus stops, but neither is much good for someone who can't walk unless you give them the money to buy a wheelchair or put the money in someone's budget to issue them one with (and NHS wheelchair vouchers don't cover anything like the full cost). Major cutbacks to social services and parts of NHS services mean that DLA is paying for things that most people would assume that people who are disabled get automatically. People with mental illness that once would have been able to rely on a CPN or a social worker or a crisis team to visit them when they were struggling find themselves discharged to primary care and relying on their DLA to pay for care that once the NHS would have provided. In theory, you could take away DLA and say that the NHS should provide continuing care and social services should provide social care, but we all know that there are areas such as mental health that get a very low priority.</p> <p>*</p> <p>2. I think that having payments to people that they can spend how they want so as to use the money flexibly is important. So much help and money from so many sources comes with bureaucratic conditions attached and it is the DLA money that enables people to plug the gaps. *</p> <p>For example, I get some of my health care by doing favours for others and this can be a multiway thing. For example. there is someone I know that we'll call A. A asks me to help out with some of the charity and community work she's involved in. I have legal drafting skills and I can do this in my own time and at my own speed. This frees up some of her time and she then gives me lifts to places and helps to feed me. However, in order to do this sort of thing, I need a computer plus a printer plus ink plus paper. If I were to get money in the way that local authorities issue direct payments so that I had to account for the money spent, it would be easy enough if I were paying A so much an hour for her time, but there's no way she'd do what she does for the amount that a local authority would pay anyway (she couldn't pay someone skilled enough to replace her for what the local authority would pay a carer). On the other hand, if I asked the local authority to pay for ink, paper, electricity and depreciation on a computer and printer, they'd probably tell me to get lost. So I'd lose my care. Yet because I use my money the way I do, I'm able to afford a lot more care/mobility than I would otherwise do.*</p> <p>Being flexible this way also means that the money goes further. If you add up the amount of care that a person needs to the care element of DLA (at the various rates) then if you simply paid an agency, say £15/hour (which is about the going rate), it wouldn't go very far, would it? Just how many hot meals a week do you think you could have prepared for you for £20/week? But do a few favours using that £20 and people will give you a lot more care for that.*</p> <p>3. A massive range of things from electric wheelchairs to someone to encourage and support. Non-disabled people often seem to have some starry-eyed notion that everything is provided by social services and the NHS. However, more and more local authorities are restricting social care to the "critical" category, or, if you're really lucky "critical" or "substantial", which leaves out an awful lot of people who currently get some DLA. The reorganisation of the NHS is supposed to make massive savings, but I haven't heard any suggestions that it will enable the NHS to expand the services it provides. As the drug companies charge ever more for wonder drugs and the media highlight individual stories and clamour for drugs that will keep people dying from cancer alive for another six months, less money will be available for less areas of need less likely to sell newspapers such as support for people with severe mental illness/learning difficulties and for people with chronic but boring conditions such as CP or arthritis.*</p> <p>Disabled people also face costs that the benefit system doesn't really cater for very well. Over the years, I have heard politicians saying they don't need</p> |



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|                   |               | <p>to fund all sorts of things because people have DLA. There appears to be a common myth that it is for heating bills, for housework and for shopping, just to give three examples. People passported to premiums may well get extra money for these things, but people not passported have to find the money out of their other income or savings. In reality, DLA may get used for things other than what it is intended for, papering over the gaps in service and benefit provision. This then can leave the disabled person with less to spend on what the DLA is there for, but sometimes it is better to have help with buying in food than to have a wash or better to have the heat on a bit higher and do with fewer trips out of the house. The government can use this as a reason for cutting DLA, after all if people spend it on things other than what it is intended for, it can be argued that they didn't need it for what it is intended for, but then it leaves some very nasty questions as to how people do pay for these things.*</p> <p>4. What happens to the many people currently on lower rate care? Will you abandon them? They certainly won't get any help under most local authorities' criteria, and CMHTs don't have the resources to help people with mental health problems who need that level of support.*</p> <p>5. I think that some conditions should lead to automatic entitlement. It seems to me to be absurd to duplicate sight tests carried out in eye hospitals and to try to evaluate whether one SVI person needs more help than another. You can send them to a medical and ask lots of questions, but can you actually determine whether one person needs more help than another with it? Further, if you do that, with some conditions, again let's use the example of SVI, you would deter people from doing what they could to improve their position. Suppose you said that one SVI person who'd had long cane training couldn't get mobility but another who hadn't could, then where would be the incentive for the second person to learn to use a long cane? I'm already reading on websites people saying that they should get rid of a guide dog or not get one in the first place because of the revised ESA descriptors due to come in later this year.*</p> <p>I think that people who cannot mobilise without a wheelchair should automatically get a mobility payment to cover the cost of a decent wheelchair because NHS wheelchair services are a joke and simply don't provide the sort of wheelchairs that people actually need.*</p> <p>6. What's wrong with the things you already support, like eating, personal hygiene, social activities etc? Having said that, it seems absurd that you go through DLA to get help with these things, but social services to get help with cleaning and shopping. Why not combine what are now social services direct payments with DLA and include an element for shopping and cleaning? This could be assessed just as easily as part of the DLA process. The money all comes from central government anyway.*</p> <p>7. It would have to do better than the ESA assessments do, so that's not a model to copy, and it would help if the form was better designed. It asks how many days of the week you need what sort of help but not how many months of the year. What if you have a condition like bipolar disorder and have totally different needs according to whether you are manic, depressed, or in between? When I submitted my last form, I converted months of the year into days of the week and explained that that was what I'd done, but it would help if the form allowed for this. No wonder so many people get advised to fill it in as if it is their worst day. People just don't know how to explain that their condition is variable other than from day to day.*</p> <p>It is also difficult to fill the form in if your needs at different times are different. For example, you may find that at some times, you need more help with cooking and at other times you need more help with washing and at other times you need more supervision to stop you harming yourself. The form simply doesn't reflect that. Perhaps a daily chart with space for several variables, and something to say how often it is like that. You could list needs down the left hand side and then columns to enter length of time, with totals at intervals. That way you could reflect differences in need without having to have pages galore asking questions. If you had a couple of pages first</p> |

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|                   |               | <p>explaining in simple English how to fill in the chart, plus some blank pages afterwards to add further information, you could do away with a lot of pages, whilst gathering the information the Decision Maker actually needs as to how much help you need and how much of the time you need it.*</p> <p>8. The trouble with taking into account aids and adaptations is that it doesn't factor in people using their money to pay for them. If you say that someone doesn't need money for mobility because they can get around in an electric wheelchair, but you don't give them the mobility component, how are they going to buy that wheelchair that you use to stop them getting that component? I think that if you're going to include aids and adaptations, you have to include a DLA component to pay for them, which includes paying for training to use them.*</p> <p>9. You could explain to people what the criteria are in simple everyday terms. A friend of mine recently got her renewal form and I sent her a single side of A4 in bullet points with the basic criteria, taking into account case law defining them. You could do that. See also my suggestion above about a simple chart.*</p> <p>You could ask the questions in a way that addresses what the criteria are, including the case law, which seems to get conveniently missed out. There are things that you can get DLA for that the form doesn't indicate that you can. The Decision Makers may know this, but unless they seek legal advice, the claimant won't, so they won't mention them. An example would be 'thinking' as a bodily function. Since the government is taking away legal aid for benefits, which will hit law centres and CABx, people aren't likely to be able to get this sort of help in future unless they pay for it.*</p> <p>10. I think that it's important to take information from a variety of sources. With cutbacks in some areas of the NHS and social services, many people will not have a consultant, a specialist nurse, an OT or a social worker to provide professional evidence, and their GP may not know much. When I last reapplied for DLA, I phoned my GP and asked to see him and he said "don't worry, I know you". Well, yes he has known me for twenty years, but we've never discussed my care or mobility needs. He carries out an annual assessment, but he isn't interested in very much except a brief set of tick-boxes on a computerised NHS form.*</p> <p>I submitted several statements from people who know me including employers, colleagues, friends, relatives etc. That sort of evidence is important. It's not the doctor, be that the GP or the one from Atos, who's there at 3 in the morning when I need help urgently.*</p> <p>11. I think that a lot of the problems that there have been with the ESA WCA would pop up. It would be very easy for the assessment to involve indirect questions, be brief, be carried out by someone without the relevant area of expertise and be intimidating. It's also virtually impossible to get Atos to consent to an assessment being recorded, so that's a problem. At least with evidence in writing, the assessor can't pretend it says something it doesn't. *</p> <p>I think that it would be very important to enable the applicant to choose the gender of the assessor, especially if there's any need to undress or if there are mental health issues. You have absolutely no way of knowing whether the applicant has been raped, molested or ill-treated or if they have any personal or religious objections to an examination by a particular gender. *</p> <p>I think that it is important always to allow the claimant to have someone with them and for what that person says to be taken into account unless the claimant objects. *</p> <p>12. I think that it would be nonsensical to review someone when they have an irreversible condition. I appreciate that there are great advances in medical science, but a gamble can be taken on, for example, the chances of a cure for total blindness in the next few years or the likelihood of a previously severed spine regrowing. I cannot for the life of me see the point in reviewing someone with something like Parkinson's or Motor Neurone Disease unless the person hasn't been awarded the highest rates.*</p> <p>I think that frequent reviews can be extremely stressful and can interfere with recovery for mental conditions.*</p> |

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|                   |               | <p>13. Tell them in plain, simple terms what the criteria are. At present, people haven't a clue. They think they can get it for medical conditions not need, they think they can get it for shopping and cleaning, they think they can only get it if they need care every week or they think they can get it if they need care occasionally. Be explicit and up front. Some people may use this to exploit the system but those people would find a way of doing so anyway.*</p> <p>14. See above for information. For advice – you could try overturning the government's decision to withdraw legal aid from welfare work.*</p> <p>15. Independence would be crucial, but who's going to provide that advice and support now that the government's taken away legal aid from welfare work and social services are cutting back staff right, left and centre? I would be concerned that if the advice and support were to be provided by the DWP, the NHS or social services, it would not be independent and might be as interested in persuading people to get help elsewhere than to get DLA.*</p> <p>16. People get a bit of money here, a bit of money there. They add up money from all sorts of sources, doing without one thing in order to have another. They already use DLA to meet major costs such as electric wheelchairs. *</p> <p>17. What are the key differences that we should take into account when assessing children?*</p> <p>18. It's essential for getting premiums on means-tested benefits, which can make the difference between affording heating bills and not affording them. It provides access to free bus passes. *</p> <p>One thing that you could do is to draw people's attention to them. Someone on, say, contributions-based ESA may not realised that they could get an income-based premium on top.*</p> <p>19. It would be an easy opportunity for the government to cut back on things such as premiums and bus passes. Already, local authorities are cutting back on bus passes where their arrangements have been more generous than the national minimum requirements. The more people you withdraw DLA from, the easier it is for the government and local authorities to reduce eligibility for bus passes and blue badges. *</p> <p>People also get a range of services from the private sector based on DLA, such as free or cheap tickets.*</p> <p>20. To judge by what I've seen shared between different bits of the NHS and between social services and the NHS, any further sharing will need a lot of safeguards built in. At present, it is virtually impossible to get errors corrected on a health record, and the only way to escape from them is to transfer to a different NHS trust for your care. Police records are even worse because they're national and you're stuck with all the inaccuracies on them unless you can actually prove that they're wrong. Heaven help us if there's more sharing of anything except basic information. *</p> <p>Further, I think that it's easy when looking for some sort of economy by combining assessments to forget that they're for very different things. Should an assessment for fitness for work actually have anything to do with an assessment for care needs? I don't think so. Should an assessment for what care a local authority is going to provide have anything to do with an assessment as to whether someone should have any money for their care from elsewhere? It all sounds like there are too many conflicts of interest.*</p> <p>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?*</p> <p>22. The thing that matters most to me about DLA is the flexibility. I don't want the services delivered to me by social services, not least because their criteria make it almost impossible to get any services or payments (you have to be in the critical category here – even the severe category isn't enough) but also because going through them is bureaucratic. I don't want any sort of system that's bureaucratic.*</p> <p>I'm concerned that a revised system will not provide for people with mental illness, who will be seen as less in need of help than people with physical impairments. I'm concerned that it will take away provision from people that</p> |

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|                   |               | <p>cannot walk but can use a wheelchair, leaving them without the money to pay for that wheelchair (which I'm sure the government thinks that someone else will provide but which they don't – you're lucky if a wheelchair voucher will cover a third of the cost of an ordinary wheelchair, much less an electric wheelchair).*</p> <p>I'm concerned that there will be a cascade effect whereby people will lose DLA, then will lose premiums on their other benefits and will lose their concessionary bus pass and their blue badge and their rail pass etc. There are all sorts of discounts and help available elsewhere that people will lose. In theory, you can ask service providers to provide you with the same services/concessions without DLA under the DDA, but in practice, you're usually asked to prove that you're "registered" disabled.*</p> <p>I'm angry about DLA mobility being taken away from people in residential care. I believe that this is in breach of the international treaty on the rights of disabled people that this country is signed up to, and is in breach of European law. I think that the people in government should hang their heads in shame. To think that a person in an open prison can have more freedom than a disabled person in residential care is a disgusting indictment of this government. I hope that as many people as possible challenge this and also that as many people as possible challenge the decision to care for them in a residential home and insist on being cared for in the community where they can get their DLA mobility restored. In the meantime, like many others, I am spreading the word far and wide in the non-disabled community about how it is not true that local authorities pay for mobility for disabled people in residential care, they don't pay for the cars/wheelchairs/scooters/taxis/escorts that enable them to go to work/church/the shops/college/community groups/friends' houses/the GP/the dentist/the optician/the chemist/evening classes etc. They don't even pay for communal minibuses, much less drivers to take all the residents everywhere they want to go (and what do you do if resident A wants to go to work at the same time as resident B wants to go to the dentist?)</p> |
| EM273             | 25-Jan-11     | <p><u>Question 1</u> Many of the barriers which exist are social barriers. For example people with mental health problems often encounter stigma, prejudice and discrimination across society. The symptoms of a mental health problem are themselves problematic but sometimes the treatments simply compound this with serious side effects which themselves lead to impairment.*</p> <p><u>Question 4</u> There is not much finesse involved in tailoring the rate to the individual circumstances. It is not clear as it has not been specified what these rates will be. Is it the case that lower rate will be lost completely or are all the rates being changed. Who will lose money as a result? The paper does not outline who is likely to be excluded from the new benefit, only that those most in need will be targeted for help. Does that mean that those who are still in need but are perceived to have lower needs will simply have their needs unmet? Which rates will act as qualifying rates for eg. extra tax credits?*</p> <p><u>Question 5</u> Yes some conditions should mean an automatic entitlement to benefit. These include the conditions which already come under that category and other serious impairments eg. profound deafness. I would make a case for severe psychiatric conditions such as schizophrenia and bipolar disorder to be included in this category. Although people with these conditions may have needs which fluctuate frequently, the level of support must be continuous and consistent. The very fact that symptoms can change suddenly demands that a high level of support be in place at all times. The high rate of suicide amongst eg. people with bipolar disorder and the fact that medication must be managed often with suicidal thoughts puts people at a high risk of death if not adequately supported. This is the tip of the iceberg in terms of the dangerous situations that can arise for people with bipolar disorder during episodes of both mania and depression.*</p> <p>As a side issue related to paragraph 21, psychiatric patients often spend long periods eg. 3 or 4 days in the week out on pass. They must support themselves and make their own care arrangements during this time. I think if</p>               |

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|                   |               | <p>this situation prevails you should consider treating their claim as though they were not in hospital. Perhaps you should set a number of nights in the week which would count as full time inpatient treatment.*</p> <p><u>Question 6</u> Not enough account is taken of the necessity for clear thought and mood stability in order to be able to function on any level. Every aspect of everyday life is affected by the inability to achieve these due to severe mental illnesses. There is too often an emphasis on physical and sensory impairments as these are easy to see, measure and quantify. The less tangible but no less disabling aspects of mental illness need to be given equal weighting.*</p> <p><u>Question 7</u> A medical assessment will not adequately capture the range of symptoms and varying degrees of severity experienced by someone with a cyclical, episodic condition such as bipolar disorder. It is only a snapshot on one day and typically people with bipolar disorder experience many different, extreme mood states. As it is ever changing, that in itself is very difficult to deal with and very disabling. If a medical assessment must be part of the process, equal weighting should be given to getting information from the professional person best able to give a true picture of the person's abilities and challenges. This person should be chosen by the individual claimant concerned.*</p> <p><u>Question 9</u> Be clear about the criteria, the assessment process and transparent about any scoring system.*</p> <p><u>Question 10</u> Evidence from the professionals who support that person. It should be the professional of their choosing who is asked to give this information.*</p> <p><u>Question 11</u> When someone has a severe mental illness it is a lottery as to whether that person will be well enough to attend and participate in a medical assessment. If they are having a good day they will likely be penalised in their claim as this snapshot will be taken as a true indication of their general health. This may be far from the truth. On a bad day when unable to attend and participate, they will be penalised for not turning up. It is a classic catch 22 problem and you can alleviate this problem by not insisting that people with variable, fluctuating conditions attend medical assessments.*</p> <p><u>Question 12</u> Account should be taken of how long that person has had the condition or the impairment, without substantial changes to their overall condition. The longer this is, the longer the period between reviews should be.*</p> <p><u>Question 14</u> Details of organisations covering these issues, eg. disability, mental health, specific conditions. Information on things you can also claim after an award of benefit eg. extra tax credits.*</p> <p><u>Question 15</u> A requirement is more than encouragement. It is patronising, paternalistic and coercive.*</p> <p><u>Question 18</u> This has been very important and useful. In the past many of the additional things have only been available to those on middle or higher rate care. If the new benefit will be targeted at those whose needs are greatest, perhaps consider ensuring that recipients of both new rates can qualify for things such as extra tax credits.*</p> <p><u>Question 19</u> It would mean a lot of extra assessments and some of these additional benefits may simply be lost as new arrangements may not be put in place or it may not be clear what you can apply for and how to go about it.*</p> <p><u>Question 20</u> Different assessments could have different criteria, and perhaps should have different criteria, and would not benefit from all being brought into line with the new PIP criteria. In general I am opposed to sharing sensitive information across different agencies. The information people will be giving when they claim is extremely personal. It opens the door to sharing information with agencies which have no business knowing this information.*</p> <p><u>Question 21</u> As already stated, DLA was always weighted towards physical and sensory impairments and the questions didn't readily fit those with mental health problems. It would be good if the new benefit assessment</p> |

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|                   |               | process could be geared up to deal better with mental illness than its predecessor. I think this is worthy of consideration under the Equality Impact Assessment.*  |
| EM274             | 25-Jan-11     | <p>This looks like reform for the sake of it once again. There seems to be a way of thinking that means that things have got to be changed, reading through the Paper it looks as if there is very little actually being changed apart from the Title of the benefit and the fact that instead of three levels of mobility and care components there are now going to be just two.*</p> <p>The present system allows for a spread of benefit granted to be matched to different levels of Disability.*</p> <p>This would work if the breakdown of the recipients was under Specialised Group Headings, say,*</p> <p>1) Temporary Disability - those able bodied but disabled through injury etc, that will heal and they will then return to employment.*</p> <p>2) Semi-Permanent Disability - those have a disability, either from birth, age or illness, who will always have their disability but who can still hold down employment.*</p> <p>3) Permanent Disability - those have a disability which cannot be cured or removed and means they need much more care.*</p> <p>In my own case I fall into the last category, I developed Spinal Osteo-Arthritis in 1980, which deteriorated to the extent that in 1992 I could no longer earn a living, I have had two Major Spinal operations which left me with permanent nerve damage and severe walking difficulties.*</p> <p>So now I ask the question - Why should someone like me have to re-apply, fill out more forms, see more Doctors, see more Benefit Assessors. Why should I be submitted once again to the rigours of face to face consultations with those who do not know anything of my condition. My existing DLA was granted and my forms were seen by Doctors, Consultants, and DHS Assessors, the letter which confirmed the granting of my DLA, states that this is for 'life'. I take it that that means that it is accepted that my Disability will not go away it will just deteriorate, I have already had to live with this for thirty years, and consider that I should not need to be submitted to the rigours of further assessments.*</p> <p>The paper states that there is no control over the system at present, changing the title won't bring that control, we hear of so many cases where people are caught fraudulently claiming, so it is obvious there is some kind of control already in existence, it also means that those who did the assessments of these individuals were not good at their jobs. I remember being asked to demonstrate how my disability affected my everyday life, I was asked to bend and pick things up, I was asked if I could down on the floor and get up again, in fact, the assessor was very insistant about the things he wanted me to do, things that I could not do and felt that I should never have been asked to do in the first place; if this Assessor had read my file and my Consultant and Doctors comments he would not have been so dismissive of my disability.*</p> <p>If things are checked in the correct way then the controls should be there !!</p> <p>The other point that is made in the Paper is there should be more sharing of information between departments, this already happens, I know that the Departments of Income Support/Pension Credit, Housing Benefit, Council Tax Benefit, DLA etc know all about my current situation, how much more information can they need or get.*</p> <p>I feel that these proposed changes are going to put a lot of Disabled People under a tremendous amount of stress, these are probably the most vulnerable people in the community and to subject them to this stress when they are already trying to live and cope with all their disability entails is very thoughtless and in some instances cruel. We all accept that there needs to a tightening of belts and there are things that can be done to help the economy but hitting the most vulnerable individuals is not the way. The Disabled Community is vast and if the Government keep puuting them down, they will lose the votes of this community.*</p> <p>I hope that those involved in this decision making will make sensible and</p> |

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|                   |               | considered decisions to ensure that none of those who need this Benefit most, will be put in the position of not receiving it.*   |
| EM275             | 25-Jan-11     | <p>Introduction and Context*</p> <p>I cannot believe it is an objective of this benefit reform to reduce expenditure by 20%. I cannot see this written anywhere in this consultation document, so I do not know how bias ministers will be in deciding changes to the benefit. This support is vital to the most vulnerable members of society. I do not see how a cut to the expenditure will help those vulnerable members of society the government says it is its mission to protect.*</p> <p>1.1 <u>The belief that decisions are subjective and inconsistent.*</u><br/> There are objective, legal benchmark criteria that determine what rates of DLA an individual can receive. It is better training of decision makers that is required in order to remove any inconsistencies in awards given.*</p> <p>1.2 <u>Resources to be focused on those with greatest need*</u><br/> Resources should not be taken away from <u>anyone</u> in need. DLA is the only support disabled people receive. No tier should be taken away from anyone who is currently deemed to be disabled.*</p> <p>Taking away this vital support from anyone currently deemed disabled will be in violation of the government's mission to protect the most vulnerable in society.*</p> <p>1.15 <u>In just eight years, the numbers receiving DLA has increased by 30 per cent.*</u><br/> I do not see how the government can support its mission to protect the most vulnerable in society and talk about cutting expenditure on the benefit. You consider how much the London 2012 Olympics – something unnecessary - was originally estimated to cost and the spiralling costs in reality! The principal of the NHS is accessible healthcare to those who <u>need</u> it, and disability benefit should be the same. If it is needed to protect and support the most vulnerable in society, the government should allocate sufficient funds to provide that support. The estimated costs when the benefit started had not considered rising population from birth rate and immigration. A long term model for welfare should cap immigration and encourage couples to raise small families, not deny the support to those already here and in need of it.*</p> <p>1.16 <u>The 11 possible different rates of the benefit also make the benefit complex to administer.*</u><br/> DLA comes in two components – Care and Mobility. Each component can be awarded without considering the other. Care has three tiers and Mobility has two. Middle rate Care is having care needs during the day <u>or</u> the night. High Care is having care needs during the day <u>and</u> the night. Low Mobility is difficulty getting around due to a sensory impairment. High Mobility is for a physical impairment, such as pain. As a disabled person with mental difficulties, I do not find this difficult to understand.*</p> <p>The low tier of Care can be satisfied by the 'main meal' test. That is, a person's ability to perform the vital independent task of preparing a cooked main meal for themselves. This amount is currently £18 a week, given to those who are incapable of cooking food in order to feed themselves. You will appreciate that in times of MPs expenses scandal, MPs get considerably more than this a week for food allowances when they are perfectly capable of cooking. It is criminal to consider removing this tier of Care. With the increased cost of living, it doesn't cover 'meals on wheels' services, and those are in short supply with council cuts. In rural areas they don't exist at all. How can you justify taking away a level of support?*</p> <p>The maximum amount a disabled person can receive for having the highest tiers of both component is around £100 - that's total. Trust me, that is not enough to bridge the gap between disabilities needing day and night care and help with getting around, and living independently.*</p> <p>1.17 <u>Two-thirds of people currently on DLA have an indefinite award, which means that their award may continue for life without ever being checked to see if it still reflects their needs.*</u></p> |

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|                   |               | <p>I would like to know where the 'two thirds' statistic comes from and how old that statistic is. I had to undergo a review of my DLA every 18 months which added unnecessary stress to my life for having no financial security. Imagine if every job contract only lasted 18 months! Awards should be for at least 3 years to remove unnecessary stress from the life of a disabled person.*</p> <p>I would like to clarify that an indefinite award is not an award for life. The indefinite award is given when it is unlikely there will be a change in the condition of the disabled person. For example, missing limbs and blindness. If there is a change in the law, a renewal pack is sent out in order to check the person's disabilities meet the new legal criteria. I find this method of renewal to be resource friendly for the government and stress reducing for the claimant.*</p> <p>The New Benefit: Our Proposals*</p> <p><u>Question 2. Is there anything about the benefit that should stay the same?*</u></p> <p>Yes. At least three tiers for Care and at least two tiers for Mobility. To remove the lower tier of either Care or Mobility will devastate the person it is taken away from in their ability to live independent lives. Removing one of the lower tiers also sounds like a cynical way of cutting costs by taking support away from those who – by the very fact they are disabled – cannot fight back.*</p> <p>I cannot believe it is an objective of this benefit reform to reduce expenditure by 20%. I cannot see this written anywhere in this consultation document, so I do not know how bias ministers will be in deciding changes to the benefit. This support is vital to the most vulnerable members of society. I do not see how a cut to the expenditure will help those vulnerable members of society the government says it is its mission to protect.*</p> <p><u>2.16 Reducing the Care component to two tiers instead of three and retaining two tiers of Mobility*</u></p> <p>See 1.16*</p> <p><u>2.17 Qualifying Period*</u></p> <p>Given the government wishes a person to be disabled for 6 months and anticipated to be disabled for a further 6 months, this should impact on their decision on the frequency of reviews of the claimants entitlement to the benefit. It's only fair if the qualifying period is increased that the length of awards is also increased.*</p> <p><u>1.19 Automatic Entitlement*</u></p> <p>Illnesses affect each person differently. I support an assessment on an individual basis instead of automatic entitlement based on health conditions. I am aware of people that have sensory impairment that struggle to get around more than those with physical impairment and feel they should receive the High Mobility because of the difficulties they face.*</p> <p><u>2.22 Application Form*</u></p> <p>The form for DLA needs to change. The questions it asks is often not the information it is asking for. For instance, one question is how many days a week a person needs help to bathe. If a person has a bath three times a week and they needed help each time, they would write 3 time a week on the form. This would not be considered towards any care award as it is below the criteria. What the form should ask is, "Every time you bathe, how often do you need help?" The person would answer 100% of the time. This answer would be considered towards a care award.*</p> <p><u>2.27 Aids and Adaptations*</u></p> <p>As with automatic entitlement, aids and adaptations should be considered on an individual basis. Just because someone can get around in a wheelchair should not mean they are not entitled to the Mobility component of DLA. It might be that they need someone to pay them to push them around as they are incapable of doing so. The cost of running motorised scooters should also entitle such users to the Mobility component. Wheelchair users should not be denied access to the Motability scheme and other assistance vehicles, as it is their right to travel wherever they choose and someone may not be inclined to push them great distances.*</p> <p><u>2.30 Independent Healthcare Professionals*</u></p> |



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|                   |               | <p>Of course, the best source of information of how a person is affected is the person themselves. No review should be considered without a personal account.*</p> <p>I'm slightly concerned at the government's consideration of 'approved doctors or occupational therapists' in the gathering of evidence. Surely every doctor takes an oath that is for the greatest benefit for their patient? A GP for example is the person that is likely to know the disabled person best, and is in a strong position to offer evidence as to how the disabilities affect the claimant.*</p> <p>My personal experience of 'one-off' face-to-face assessments has been stressful and unrepresentative of the extent of my disabilities, for both the assessment conducted in my home and when I had to attend one in an external building.*</p> <p>I also hear horror stories of people being assessed for Employment Support Allowance being turned down after the medical exam, and later having a successful appeal and receiving the correct level of benefit. I sincerely hope it is not the same company that will be doing the disability claimant assessments as this will be unnecessarily stressful for the claimant and expensive for the government.*</p> <p>The only beneficial thing about an independent assessor is accountability i.e if the assessor fails to document the extent of the disabilities if the claimant goes on to have a successful appeal against it, the assessor can have a black mark on their record. Having been through the Tribunal process, I know there is currently no such accountability to remove poor decision makers and assessors from the system.*</p> <p><u>2.31 Periodic Assessment*</u></p> <p>There is currently a systematic review of claimants. It involves a lengthy form when the award period expires, or when there is a change in the law and the form is sent to those with indefinite awards to see if they meet the new legal criteria.*</p> <p><u>2.35. Penalties to ensure compliance*</u></p> <p>If the government was worried about people not reporting improvements in their disabilities, penalties should ensure compliance in prompt reporting.*</p> <p>I'm concerned that the government insists on giving control back to the people and yet insists on frequent and stressful reviews to ensure the right level of benefit is being awarded. How about a little bit of trust?*</p> <p><u>2.36 Information on sources of support*</u></p> <p>Everything I've learned about my entitlements I've been told by my local health condition support group. Having government sources to support me in being aware of my entitlements would be appreciated.*</p> <p><u>2.38 Carers*</u></p> <p>Currently carers are paid a slave wage to look after a disabled person. The minimum hours of care provided a week to be entitled for Carers Allowance is 35 hours. At £60 a week, this is £1.71 an hour wage, well below the minimum wage. The benefit doesn't stack with other earning replacement benefits either, e.g. state pension. Effectively the government is saying a person is no longer sick when the person looking after them receives a state pension!*</p> <p><u>Delivering the New Benefit*</u></p> <p><u>3.4 Passport to other Support*</u></p> <p>No 'passport' that DLA provides to other levels of support should be removed. They are all vital to ensure the most vulnerable members of society receive the necessary level of support. To do so would threaten the Human Rights Act to a person's right to a normal life.</p> |
| EM276             | 25-Jan-11     | <p>This is a change that has not had any thought put into.*</p> <p>To reassess people that have received this benefit for alot of years is totally unfair.*</p> <p>People with a learning disability do not get better overnight, they simply deteriorate.*</p> <p>This benefit helps with their care. *</p> <p>Family cares can only do so much</p>   |

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| EM277             | 25-Jan-11     | <p>I am responding as a private recipient of the DLA mobility and Care. *</p> <p>I think the proposals are utterly appalling. *</p> <p>It has been a national scandal that for years cheats and liars have abused the system, not only the DLA but the Blue Badge. I know people who boast of going to their GPs wearing their surgical appliances, or using a stick and fooling the GP AND the DLA assessors. They go to hospitals wasting the time and resources of the NHS to get equipment and services which are not necessary. Particularly galling to myself who had polio at age two years old and will NEVER recover.*</p> <p>So the government takes the easy option of reassessing all disabled people, and typically will also introduce reassessment to people 65 and over.*</p> <p>I am thankful and very grateful for the DLA. It helps me lead an existence that may be full of pain and discomfort but at least gets me onto the road, at least gets me living a life that is not ideal but at least acceptable.*</p> <p>If it had not been for the laziness of many GPs to fail to spot the cheats, had it not been the encouragement of people to claim they are disabled because of minor physical problems, the DLA would have remained a proper and encouraging system to protect and enhance the lives of the genuinely disabled.*</p> <p>Whatever the proposals, I doubt if the 'period of consultation' will mean that the disabled will really get any say. But for the life of me, never, ever, please let the care allowance fall into the administrative hands of elements of the incompetent, negligent and completely ignorant hands of the Local Authorities. That way will lead to madness, and we have enough of that already!*</p> <p>Sort out the cheats. Open up a disability cheats reporting line and <u>ACT</u> on information given. Leave the genuine ones alone.</p>  |
| EM278             | 25-Jan-11     | <p>1. Disabled people do not have the same abilities to enable them to participate in society on equal terms. These disabilities can be physical, mental including mental health, understanding and awareness of what is going on around them.*</p> <p>With government cut backs and large numbers of local authority redundancies it will be even harder for disabled people to find employment. An awful lot of disabled people are capable to do some kind of work, the shameful reality is that they are not given the opportunity. Many disabled people are vulnerable and are exploited. There may be legislation but this does not stop the daily bullying and exploitation that is happening to individuals.*</p> <p>2. I believe that the different rates should remain. There are different people (individuals) who have different levels of needs, all of which in a 21<sup>st</sup> century civilised society should be met.*</p> <p>If the government are prepared to top up wages because employers refuse to pay a living wage, all disabled people should be provided with the means to cover the extra costs incurred to help them live full and active lives.*</p> <p>3. Support to live full and active lives in their communities, this will be different for each individual. Often this is the assistance of another person on a day to day basis to ensure they are safe, along with assistance to carry out tasks that most people do without thinking. Taxis are often necessary as public transport is not always accessible or convenient. Our 21<sup>st</sup> century society is geared up to car drivers which the majority of disabled people are not. Disabled people can require help to find and visit new places as well as new people. It can be very daunting to try and engage/integrate, even within your local community when others see you as different.*</p> <p>4. Having the current different rates allows those whose needs are lesser than others acknowledged and in some part met. They should not suffer because uptake of this benefit has been underestimated by the government.*</p> <p>It needs to be acknowledged that for various reasons, including advances in medicine, more people are surviving at birth and other illnesses and accidents but are often left 'disabled'. Very often giving a small amount of</p> |

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|                   |               | <p>support is enough to keep someone from slowly or very quickly going into crisis and needing greater support and resources than otherwise. Decisions should be taken whilst looking at the long term.*</p> <p>5. I believe some health conditions and disabilities should be allowed an automatic entitlement to benefit. It is distressing enough to be disabled without having the uncertainty of being able to afford the much needed help.*</p> <p>Having some claims automatically allowed will also ensure a quicker service for all?*</p> <p>6. Ensure that the process is straightforward and accessible to all with well defined criteria. Let people know what qualifies and what does not, it saves everybody's time.*</p> <p>It is most important for disabled people to be treated with dignity, allowed to make their own decisions and given the opportunity to be as independent as possible. Activities and actions will vary from person to person, all of whom are important and need to have their disabilities acknowledged. *</p> <p>7. Base the claim on the worst day and review annually or bi-annually.*</p> <p>8. Yes, do take into account any aids or adaptations that are in use*<br/>Other aids and adaptations should be suggested where appropriate and taken into account if they are later used. Not everyone will be able to afford or feel comfortable using aids and adaptations and therefore should not be penalised if they do not use them.*</p> <p>9. Give a simple and clear criteria for receiving the benefit. Ask straightforward questions that are not ambiguous. *</p> <p>10. The individual, their family and professional people who support them are the best able people to provide supporting evidence.*</p> <p>The evidence needed will vary greatly on the individual but no doubt it needs to be based on the help they need in order to live full and active lives in their communities and be as independent as possible.*</p> <p>11. There will be many preconceived ideas and suspicions as to why a meeting is to take place. Stress levels will be high for both the individual and their carers. It may seem like they are being judged and/or have to pass a test.*</p> <p>Positively it could be an opportunity to discuss needs and possible strategies to meet them.*</p> <p>There are some conditions that professional evidence would make a meeting unnecessary, especially if this would cause stress to the individual.*</p> <p>12. Evidence from a doctor or similar professional could state that an individual's condition is unlikely to change and therefore frequent reviews would be a waste of resources.*</p> <p>All claims could be reviewed on a 5 year basis with shorter periods for those whose conditions may be temporary or changeable.*</p> <p>13. Send an annual letter reminding individuals that they need to report any changes.*</p> <p>14. A clear criteria for what qualifies for payment.*</p> <p>I am sure applicants will be looking for help to complete forms, therefore information giving help and advice on what is available and where and how to access this would be very useful. It could also be useful to be able to discuss individual situations with someone who understands the criteria and the implications of being disabled. Not all helpline staff have an insight into disability and how it can affect individuals in different ways, there is not a one size fits all.*</p> <p>15. I do not think there should be a requirement to access advice and support.*</p> <p>16. One –off costs could be met from a different stream of the benefit, I see this benefit as an ongoing payment for ongoing expenses.*</p> <p>17. I do not think that because a school may support a child during school time that this can be considered as meeting a child's needs. Obviously children are more dependent and rely on a parent or carer to meet their extra support needs. The people who provide their support also need support. *</p> <p>Reports used for determining special educational needs could be used when</p> |

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|                   |               | <p>making a claim but I do not believe the two should be combined. School/home, night/day are very different.*</p> <p>18. Receipt of DLA is very useful in enabling other services to be accessed.*</p> <p>As there are no longer payment books, a card would be useful as a means of proof of receipt.*</p> <p>19. Vulnerable people would go without services that are valuable to them if the benefit no longer allowed access. Disabled people by the very nature of their circumstances are more in need of these services and are the least able to access them without assistance.*</p> <p>20. I thought the government already did this?!*</p> <p>Social work assessments could be standardised and combined with the new assessment.*</p> <p>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?*</p> <p>22. Please cut the bureaucracy, paperwork and systems that nobody understands*</p> <p>Train and pay staff a decent wage so that they enjoy their work and take a pride in what they are doing.*</p> <p>There are many disabled groups who provide training on working with and providing a service to all their customers. *</p> <p>Who says it is justifiable that those with lesser barriers to leading independent lives should have their benefit taken away and given to those with greatest need? Very often giving a small amount of support is enough to keep someone from slowly or very quickly going into crisis and needing greater support and resources than otherwise. Decisions should be taken whilst looking at the long term.</p>   |
| EM279             | 25-Jan-11     | <p>I am an MS sufferer and as such am in receipt of DLA which provides welcome top up income to assist with my care and mobility. I am also a believer that the current system is being abused and reform is a necessity but not merely because the country sits uncomfortably in the mire of debt. A reform to ensure equitable distribution would be more beneficial.</p> <p>Unfortunately, I fear that there is still minimal understanding of MS, for example how pain and fatigue affect individuals and how different this can be from one MS patient to the next. How are the OT's to take this into consideration?*</p> <p>In my case, I suffer from continual neuropathic pain which the majority of medication does little to nothing to alleviate; I suffer from fatigue and then extra fatigue which is a side effect of medication. Fortunately, my poor cognitive abilities to retain and recall information has been tested and proven but who sees and understands the difficulties this causes and the associated frustration caused. How can anyone fully appreciate the cause and effect of my mood swings on my life? These are just some of the hidden aspects of MS that in my experience, the majority of GP's and Neurologists do not fully understand. Therefore, how are these issues to be addressed by the reforms and subsequent assessments? *</p> <p>I would start with those in receipt of the Blue Badges before embarking on a blanket reform which will inevitably lead to cuts in every current recipients benefit. This would be a useful basis and would replenish the Govt coffers before they move onto the next phase of cuts. It is not just those in care that require such a benefit but those living at home with families that provide care; those that need their Independence and wish to be free of the constraints of their disability and environment. *</p> <p>I just pray that you are not using this easy option to penalise those most in need when there are thousands claiming non disability benefits that should be brought to task first. Regards</p> |
| EM280             | 25-Jan-11     | <p>This country and it's government seeks to punish those who have a genuine need for health support to be put through a totally wasteful process of out of date forms that are pages long and then a face to face with so called experts</p>   |

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|                   |               | <p>who much of the time score on the basis of zero medical knowledge. Is this right and fair?*</p> <p>Whatever is decided it's always the weak an vulnerable that suffer as they have no voice. It's not all about saving money. Why don't these processes ever rely on the consultant who is more qualified than any system this government will set up.*</p> <p>Of course none of these emails or feedback will help, it's just another wasteful process and use of public money. It's simple contact the dr and obtain the medical history and stamp it and pay out. Sent from my iPad</p>   |
| EM281             | 26-Jan-11     | <p>it is yet another change to benefits for the disabled - having just had a medical for ESA you sound like you will repeat medicals again for this why not use your ESA medicals to gage who is entitle those qualifyiing for support level would qualify for the new benefit automatic (save a lot in admin ) and those in work / working group Of ESA have to apply or ESA screening used if they would qualify for a lower level - children and the elderly being worked out by education assessments ( statements of special needs)/ health reports(occupational therapist /physio) or in the case of elderly (geriatric assessment / occupational therapy) the concideration of appropriate equipment sounds great to an able bodied person - but being disabled i have leg braces to stop my knees giving - but wearing them for more than around 30mins causes full thickness blistering where the brace gos at the sides of my knees and a sublux / dislocation of the knee causes them to come loose and fall off - my crutches make problems with my arms - i have a shower - but without wrist braces cant dry myself properly - equipment dosnt solve everything there isnt appropriate social housing - if you want to make disabled people feel fairly treated - dont keep attacking the genuine ones I pay for all the help i need with my DLA - I see thousands of others you could save money on by making the jobs advertised 16 hrs instead of 15 so people qualify for tax credits if they take them then say find one or get a choice of 3 dont do it your money stops (if they do it garuntee they wont be worse off ,) youd not need to pick on people who are having to come to terms with living with chronic degenerative conditions knowing they will only get worse</p>  |
| EM282             | 26-Jan-11     | <p>I have just read the Reform document three times and it fills me with dread. You obviously intend to introduce it so there is little point in responding, but in the tiniest hope that you may listen to the electorate THOSE YOU SERVE NOT VICE VERSA here goes. Firtsly the whole Benefit Scrounging Scum/only 6% of IB claimants are genuine propaganda fed to the Daily Mail and others is a disgrace. You have successfully tried to turn people against the most vulnerable members of society, This is obviously a policy document drawn up by people who have no real knowledge of life in the real world for real people with real mental and physical disabilities and is littered with platitudes and hidden measures. My husband is chronically ill with Parkinson's Disease is in a wheelchair, incontinent and unable to wash himself and yet was passed fit to work by that pioneering reform of yours,ESA. Introducing face to face medicals – which will probably be incentivised to fail claimants like the ESA bonuses do is completely deluded. ESA reform is shambolic and not fit for purpose – just look at the number of Appeals pending and awarded to the claimant. This DLA reform if it goes ahead, and I pray it doesn't, will be the same. You pretend to consult the disabled and the public and will then go ahead and do what you wanted to anyway. I had to fill in a 56 page DLA form for my husband, the DLA got full INDEPENDENT reports from his GP, his 2 Consultants, Physical Disability Social Worker and Social Services Care Plan and his Carer. He was awarded a lifelong DLA Award. It was the one break we got as we thought at least we don't have to go through all this again as well as deal with the relentless difficulties his illness presents. How wrong was !! An 'Independent' government doctor just won't provide accurate and detailed information such as the type the existing DLA get through independent consultations.*</p> <p>The new plan must cost £10s of millions to administrate. Like ESA you</p> |

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|                   |               | <p>barely mention the mentally ill – the paranoid schizophrenics who are currently passing ESA tests! We disabled people live in a constant state of extreme anxiety: as well as trying to cope with chronic problems every single day of our lives caused my husband's disability, the increase in food and fuel prices and just scraping by each week, you now want to reassess a severely disabled person and put him through all that stress again – it has a massive effect on already fragile and vulnerable people who have no other means of income. Quite literally mentally ill people are committing suicide over the chaos that is being caused by ill thought out changes. You are a disgrace to humanity with the policy think tanks that cause train wrecks in peoples lives and should hang your heads in shame at this barely disguised attempt to get as many people off disability allowances as possible.*</p> <p>Why not just cut out the middle man and just the mentally and physically ill straight to the gas chambers? It would save you a fortune and us a lot of heartache and stress.*</p> <p>If you are taking votes on this 'Consultation' please markmine and my husband's (who cannot use his fingers so is unable to write for himself) as a BIG FAT NO! KEEP DLA!</p>   |
| EM283             | 26-Jan-11     | <p>Please find attached my comments as an individual who has a disability and worked 20yrs for and with disabled people in Citizens Advice Bureaux and the local authority Adult Care Services. I'm not sure what other details you might need but if you do require more detail please do email me.*</p> <p>*</p> <p>This will be greatly different for many disabled people. Generally society forgets that many aspects of daily life will impact and or impede on disabled people, e.g. stairs, heavy doors, poor lighting, holding / using electrical items, holding / using domestic utensils, getting around unfamiliar places, transportation, carrying various items and so on. There are then the individual or personal problems or barriers e.g. dressing, undressing suitably for the activity participating in society, eating, drinking, toileting especially away from the home, washing, bathing. People with mental health issues / learning disabilities will experience attitudes and prejudice, combined with their own difficulties to comprehend / understand thus creating barriers to participate. People with sensory impairments experience a community that probably has some useful and helpful solutions, but not every place in our communities offer or have solutions. Also receiving various services that meet the needs of disabled people at an affordable price. *</p> <p>Disabled people may themselves be a barrier as they feel inadequate, incompetent, ineffective and generally quite negative in their approach to their lives. These feelings and emotions are compounded by society and therefore the attitude of the disabled person can prevent positive action. *</p> <p>*</p> <p>The assessment must be one that is not just of the medical model of disability but that of the social model. It is more often the social aspects of disability that creates the barriers or problems. The new PIP must continue to take into account the care needs / difficulties in social activities. The needs outside the home are just as important as the needs within the home. The assessment therefore must take into account the desires and aspirations of the disabled person and decision makers must understand the barriers that prevent or reduce these desires and aspirations.*</p> <p>*</p> <p>Usually equipment that is not available from the Local Authority. Technology is continuously improving at great speed. This can be helpful but also unhelpful as this is often expensive. A very simple way to overcome barriers is to secure assistance from carers. Sometimes these exist within the family unit but independence still remains uppermost in the minds of disabled people but that independence can come at a price. Generally the extra costs can be fuel costs, replacement of items because of extra wear / tear, but also the costs of achieving a task / activity that was made achievable by technology, equipment and/or carers. For disabled people to be in and remain in reasonable health, both physically and mentally, the costs are</p> |

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|                   |               | <p>those care tasks that are not always covered by the care assessment either by the DLA or Adult Care Services. Domestic cleaning is the typical example but others can be leisure activities (not just day care centres) or social inclusion. *</p> <p>4.*</p> <p>This matter may well be seen to be unfair. Once components are introduced there must therefore be applied criteria as to what sort of disability or care needs fit each component. The difficulty to measure the needs of an individual requires belief and understanding that the disability does impede ability. People with disabilities that do have a need might have a small level of need, yet others with greater need might still only be entitled to the same rate component. This fosters a belief of unfairness. The administration process includes decision making. How to ensure that the right decisions are made, should each amount of care be prescribed points and so the higher the points the higher the award? Employment and Support Allowance has a similar process but how successful is that?*</p> <p>5. *</p> <p>Are politicians wanting a sympathetic approach or not? My experience in assisting disabled people has seen a perception of unfairness. People have pondered how an individual could be entitled to DLA when they appear able to perform most daily living tasks, when compared to someone who receives the same level of DLA but experiences greater barriers to independent living. Conditions that have fluctuations in difficulty do cause people to have perceptions of disability that may not be accurate, both good and bad. Disability benefits generally are awarded because of the assessed needs of the individual. The exception must be terminally ill people as an assessment may be not be sufficiently timely for the claimant to benefit for an award. But why should not those disabilities that are never going to go away be included in the automatic entitlement test. Someone with a loss of limb/s are never going to regrow a limb. But then such a person may find ways of overcoming their disability to a degree. I then ponder as to what is being measured is it the actual disability or the manner in which a person copes with their disability. This automatic entitlement can be linked with the administration of the allowance. If every disabled person is to be assessed then costs and time will inevitably increase. It must be reasonable to accept that certain types of disability will always require care and carers supporting them. It is possible that those people with those types of disability may reduce the need of support and become more independent and take a more active and healthy approach to their lives. After all that is the governments aim. But to then expect those individuals to have the allowance reduced or removed seems not to make sense because their disability remains unchanged. What has changed, is it their abilities or is it that technology or better services that has assisted in their lives to create a better, happier, healthier and fulfilling life? . It has been said to me many times "why do disabled people always have to justify their disability". This phrase is born out of frustration of having to explain many times their disability, but quite simply I respond, this is tax payers money.*</p> <p>6. *</p> <p>This question is probably the most difficult, because every person is different. What would the individual want to do if they hadn't the disability? What help would enable that individual to achieve various life tasks? These two questions should identify every aspect of the individuals needs. Any assessment for the new PIP must enable the claimant to understand what type of care need or equipment causes the claimant to achieve a given task. So if equipment / adaptations are needed it would seem perverse to disallow the achievement gained. A person may be enabled to get around outdoors without the need for others by using a wheelchair. The wheelchair may in itself cause other barriers outdoors like high steps to be overcome. But without the wheelchair they are disadvantaged. The level of care needed may be small and often, this causes people not to identify a level of need simply because it seems insignificant. Yet if that care was removed, their</p> |

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|                   |               | <p>difficulties are increased significantly. Those disabled people who need small amounts of care (that is care that is for just a minute or so, e.g. fastening the coat when it rains) should also receive priority support as these levels of care are just as important in creating a full and active life as care that is more substantial in time. Those people with significant disabilities and are least able will require a higher level of support. This maybe identified simply by health / social care workers providing written support as to the level of support. The difficulty here is that may just part of the disability as there are other types of support given by other agencies and family. As for activities in everyday, the list is potentially endless. So what should most humans do day to day? Rise from bed, breakfast, wash, hygiene, dress, move around, travel, work, eat /drink again, socialise, leisure / keep healthy, preparation of meals, household duties, enjoy relationships, purchase products (food, household goods etc), relax, sleep. Each of these activities can be divided up to show what help is needed to achieve the goal. Some activities may only require minimal help whilst others may require significant help both in time and effort. *</p> <p>7. *</p> <p>This appears to be a medical question, therefore one that is answered by the medical profession. The assessment must enable the claimant to identify the fluctuation and the degree of care needed when experiencing difficulty. Accounting for the variability in this way causes a medical approach which may have differing opinions. Areas in the levels of pain suffered by the individual are very difficult to determine. Nationally agreed guidelines would assist in this area. This aspect of measurement creates a 'line in the sand' which means at what point does the claimant qualify. Further appeals are inevitable. *</p> <p>8. *</p> <p>The use of aids and adaptations do indeed assist the disabled person to achieve more and to continue their lives with dignity and provides a positive health promotion. I have met disabled people in my work who would make the conclusion to not pursue aids or adaptations as it would prejudice entitlement to disability benefits. Severely disabled people are not likely to be affected by this issue as they still will need carers to assist in using such aids. For people whose disability is not quite so severe, but whom are unable to achieve or participate in the community without aids / adaptations, may well create discouragement in using such aids which may also inhibit further improvement in health. To take a greater account of the successful use of aids etc in my view is counterproductive. It creates a culture of disincentive to use aids over the level of benefit. This in turn causes reduced health, reduced motivation to achieve in their lives and ultimately creates dependency on society and government. The measurement of disability should be based on the person only. Another issue here is the costs of aids / adaptations which are not always provided for by government. Disabled people will experience reduced earnings and any PIP awarded may well be saved to cover costs of aids etc. Currently people use the DLA mobility component to help towards the costs of a motor vehicle that enables better independent mobility. *</p> <p>However, there is, in my view, an issue of temporary disablement. Equipment may well cause increased abilities and quicker recovery to complete health and 'ablebodiedness'. The area of being virtually unable to walk caused many people confusion as to what exactly that meant. On their own two feet the walking was difficult but with an aid like suitable walking stick they were able to achieve a greater ability to walk. Having a dressing aid can give people greater independence in dressing themselves. *</p> <p>9. *</p> <p>People generally hate completing forms. To establish claims one needs to complete a form. The longer the form the greater the hatred towards that form. Disability benefits must surely establish whether the claimants meet the criteria. Disabled people do find the current DLA form long and the questions seem to be repetitive and focuses on inability rather than ability.</p> |



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|                   |               | <p>In my work once people understood the reason why and how questions were asked the hatred of the form was reduced. The repetitive aspect was overcome by explaining that the question isn't repeated it's the answer that's repeated and that it was okay to give the same or similar answer. People need to be better informed about why the form is formulated and designed in a particular way and the principles about the benefit written simply. Lord Denning in his summary of what was considered to be personal care made a list: toileting, washing, drying, eating, drinking and so on. Could the claimant look at that sort of list and describe their difficulties and care needs. In my view it is very important to keep the self-assessment process as this allows the disabled person to express what their needs are arising from the disability. Yes this is seen to be a negative approach but then the point of DLA is to target those people whom are least able and thus the greatest needs, consequently the greatest difficulties. *</p> <p>There are of course other factors that cause claimants to dislike form completion: poor English, poor education, inability to express their circumstances. Local agencies are usually available to assist. *</p> <p>10. *</p> <p>Medical evidence is sometimes needed to confirm that a disability is apparent. But evidence from social workers, carers, physiotherapist, mental health care managers, psychiatrist, supporting housing staff and many others including family members is just a valuable and probably more informative. However, for claims that are refused the relationship between the disabled person and those mentioned above can be polluted causing poor communication and distrust. *</p> <p>The evidence should focus on the social needs of care and disability.*</p> <p>11. *</p> <p>The healthcare professional should be impartial and not biased in any way. They should be able to ask appropriate questions that create a positive environment so relaxes the claimant. This can achieve a better outcome on the assessment of disability and care needs. But, talking to a complete stranger about aspects of difficulty can 'close down' the discussion and little information is gleaned. Also an inappropriate account of the disability can be created, that is people do under explain their disabilities because of pride and embarrassment. *</p> <p>It would seem inappropriate for a face-to-face meeting for claimants where the disability clearly causes the need for help. Also there should be no meeting where security is an issue.*</p> <p>Claimants should not see the meeting as a 'checking on you' exercise, but should be seen as the decision maker is not sure as to whether to make an award or not because the claim form has insufficient or incomplete information.*</p> <p>12. There are disabilities that are almost never going to change the care needs, e.g. learning disabilities, loss of limbs, permanent loss of use of limbs, illnesses that have no cure but can only be decelerated in respect of the progression of the illness e.g. dementia. These people and others may well be identified from the medical professionals. *</p> <p>The medical and healthcare professionals should be in a better position to set different time scales to review awards for those people with disabilities that should improve with appropriate healthcare intervention. Different disabilities may create a shorter or longer time scale for the review of an award. *</p> <p>PIP awards must not discourage individuals from becoming as independent as they can simply because there is no or very little healthcare or social care professional assisting or the criteria for professional help is so high that none can be provided. The needs for care or assistance must be the principle aspect being considered. *</p> <p>13. *</p> <p>It's a bit like watching your baby grow; you don't see the growth over a year. But another person sees your baby and says "my goodness haven't they grown".*</p> |

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|                   |               | <p>Similarly with disabilities, people become used to receiving money and use that for many circumstances. People can become acclimatised to disability and so hold a belief that they will always be disabled as they are unlikely to be seen as 'normal'. Their disability remains but the need for care or mobility decreases and so what is there to report? People hold a perception (wrongly) that being in work means that their disability has reduced or gone completely and may then report the change. To have a gradual percentage reduction in PIP benefit over some weeks may give the necessary space to adjust. *</p> <p>14. *</p> <p>People whose disability may last for 3-5 years may want advice and information as to what kinds of assistance is available in their community or nationally. Having this information from the DWP may appear cajoling, insensitive, 'how quickly can the DWP get them off benefit'. However, the DWP should be encouraging people to seek independent advice and information. There are many agencies that have offices in localities but certainly via telephone, libraries and the internet. Could the DWP pass on claimants details to the adult care service in the locality for that service to contact for advice and information. How does one balance interference with assistance? *</p> <p>15. *</p> <p>As mentioned above, it may help if the DWP could provide the adult care services with details of the claimant so that the adult care services can then offer advice and information with potential for assessment to services and support.*</p> <p>I'm not clear if Data Protection Act causes difficulty. This also may create evidence for periodic reviews and awards. To be avoided is the conclusion by a decision maker that having little or no care services does not mean that the award must be terminated. The services offered by the adult care services in the locality may not be to a good standard or the authority have increased their eligibility criteria that causes reduced or no service. Yet the persons disability remains the same. Is it appropriate for the DWP to be making their customers seek services from a poor service provider? *</p> <p>16. *</p> <p>Do people separate the DLA from their normal finances? I'm not sure they do. DLA may become part of their every week household expenses. However, any aids identified is paid for from their normal incomes. I do not believe that people account for their disability related costs; they can identify what their care costs are though. To use the DLA to fund or partly fund aids costs appears reasonable as it would be an interest rate free short term loan repaid via their DLA. Politicians need to understand that many people who become disabled expect such aids / adaptations to be good quality and free of charge. So to be encouraged to use their DLA may be a surprise.*</p> <p>17. *</p> <p>I am not able to comment here. But perhaps behaviour may be differently assessed than that of adults. Also it may not be appropriate to meet with children together with their parents . *</p> <p>18. *</p> <p>DLA increases income support, housing and council tax benefits. DLA allows carers to claim Carers Allowance, DLA can give access to disabled parking permit. There may well be other passporting arrangements. If the claimant has a successful award then could the DLA systems send that information to other departments of DWP and possibly local authorities HB/CTB using a 'tell us once' process. *</p> <p>19.*</p> <p>We should not see the passport to other premiums or allowances be removed. The implications as I understand it is extra claiming for higher levels of premiums that support and enable people to pay for a decent quality of life. Disabled people are very dependent on benefits especially if their earnings capacity is significantly reduced. Society should, must, support those people who are most affected by their disability and</p> |

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|                   |               | <p>consequently need a higher level of care and support.*</p> <p>20.*</p> <p>This could be problematic as different benefit have different rules and criteria. To be assessed for one benefit does not necessarily cause entitlement or disentanglement for another. DLA is available to disabled people in work, yet ESA is for people who are incapacitated. Some of those assessments may assist the other but equally some parts of the assessment may have contradiction and confusion with the other. So similar benefits that have very similar criteria would be helpful. *</p> <p>21.*</p> <p>I am not sure on this question. But Attendance Allowance is for those disabled over 65yrs. There is no mobility element nor are there three components to the care element. Why are the elderly treated differently when their situation is more likely to require greater needs. Should allowances take account of different cultural approaches towards disability. *</p> <p>22. The use of prosthesis does not always assist with improvements in well-being and care needs, in fact these can be more problematic. *</p>  |
| EM284             | 26-Jan-11     | <p>Hi, I am writing on behalf of someone who is seriously visually impaired and receives DLA. The DLA is a great benefit to them and the care allowance and the mobility allowance make a great deal of difference to the quality of life that they have.*</p> <p>The DLA gives them the ability to use the allowance in ways which specifically meet their day to day needs.*</p> <p>I am concerned that they will have to undergo more assessments and worry that they may lose a valuable aid which helps them cope with their disability.*</p> <p>Surely if the test is objective then medical evidence should play a large part in the process.*</p> <p>Please do not make it harder than it already is to be disabled and to have to cope with a disability. Some reassurance for people like this and in similar positions should be given as the DLA gives them a significant increase in their quality of life.*</p> <p>Serious visual impairment requires special needs which the DLA allowance helps to meet and is of great benefit to help maintain independence.</p>   |
| EM285             | 26-Jan-11     | <p>Hi I am replying to this consultation as an individual. I am concerned that many of the people this reform is intended for might not be able to read such a lengthy document. I am struggling with it myself and have answered some of the questions below: *</p> <p>Question 4 The new benefit will have two rates for each component: *</p> <p>Reducing three levels to two levels will have serious disadvantages, those on the middle levels each time whether mobility or care are likely to lose out. How do you decide on the care component between a child/person totally dependent on carers both day and night and one who doesn't require nighttime care yet is unable to cook, wash, etc for themselves? do you put them in the upper level or reduce them to the lower level on a 2 level system and in that case where do you put the person whose mobility is not impaired but a disability means that they are unable to cook safely. How can you equate the two?*</p> <p>Question 8 Should the assessment of a disabled person's ability take into account any aids and adaptations they use? *</p> <p>The individual needs to be able to say what aids and adaptations they have but also how often they are used as part of their daily life. eg Prosthetics. A prosthetic leg can be supplied but the individual may only be able to wear it 4 days out of 7 and 4 hours a day. Therefore it doesn't make them fully ambulant just because they have a prosthetic.*</p> <p>Aids and adaptations should only be taken into account if they are currently in use when applying for the benefit. If you include those they might be eligible for etc then surely that is a change to their circumstances. What would the follow up be to check that the easily obtained aids had been</p> |

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|                   |               | <p>obtained?*</p> <p>Question 9: How could we improve the process of applying for the benefit for individuals and make it a more positive experience? *</p> <p>Thinking/talking/writing about your disability and what you CAN'T do is never going to be a positive experience so please don't patronise us. Acknowledge that it won't be enjoyable BUT that the individual MUST remember when filling in the form that the person reading it knows nothing about them. Therefore they need to describe accurately every aspect of their disability and the impact it has on their daily life.*</p> <p>Question 10 What supporting evidence will help provide a clear assessment of ability and who is best placed to provide this? *</p> <p>Firstly the individual or their advocate, secondly it will vary greatly depending on whether they are under a Specialist Service or their GP.*</p> <p>Question 11 An important part of the new process is likely to be a face-to-face discussion with a healthcare professional. *</p> <p>My GP has always declined to look at my amputation stump and has never seen it, who will these healthcare professionals be? Will they be tailored to the disability?*</p> <p>Claimants should be given the choice however the assessment centre should be fully accessible, with disabled parking and patient transport facilities.*</p> <p>Question 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? *</p> <p>New DLA to act as a 'Passport to other benefits, possibly through access to DWP. Does the individual not have a right to Data protection, should they not be requested by the secondary 'benefit' to allow the information to be called for?*</p> <p>Claims process for re assessing existing DLA recipients says that they MAY gather additional information which MAY be from the individual. The individual should be able to contribute to the assessment procedure if they are able.*</p> <p>Regards</p>                                       |
| EM286             | 27-Jan-11     | <p>attached is my response to the DLA reform Please contact me if your unsure of any of my answers or need clarification Yours [REDACTED] *</p> <p>There is a basic stigma against people who are disabled against getting housing, social care, work or having a relationship or family. People who are disabled are victimised for being different or a scrounger. Seen as a drain on the national health – where in reality, they are the poorest most deprived group in society. The media hold a responsibility in this. Socially excluded from birth to death. We have come a long way since locking people up in poor houses and mental asylums but not far enough. Hidden disabilities are one of the most difficult to assess but can be the most challenging to support. Having good understanding from your peer group can be worth a lot more than having a nurse or paid carer sitting with you for hours just in case. Starting at grass roots, where a child is born or is diagnosed with a disability, where is the careers advice? How can a parent plan for the future if they are in mourning for the child that could have been? I once heard a lady speaking to a woman in a wheel chair and a baby “who’s is that baby?” when the woman replied “he’s mine.” She replied, “Don’t be silly, you can’t have a baby, you’re in a wheel chair” this lack of education in the general public need to be tackled before people who are disabled will be full active members of society. That is just a person with a physical disability, the public are even less understanding when the parent has a learning disability or mental health problem. *</p> <p>Making sure that carers allowance is paid for people supporting people on DLA. That people who have absolutely no hope of getting better with all the support, aids and medical help in the world, have DLA for life. This is for people who are born with severe and multiple disabilities meaning they will never be able to communicate, walk, eat or drink without help, are doubly incontinent, are visually impaired, have brain damage etc. Look at all the</p> |

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|                   |               | <p>people who have DLA for life and don't stress out the parents / carers by making people who live in these conditions, come out and apply again for DLA. Also people who have no cure for a condition such as Autism and no medical help will change this, as stated before, hidden disabilities are the hardest to diagnose and the most challenging to support, especially in the condition Asperger's Syndrome or Bi-Polar where the person is highly intelligent and has trouble accepting their diagnoses. The peaks and troughs of these conditions are immense and need the stability of support from carers and benefits. Just knowing that there was going to be a benefit reform on incapacity benefit put one person I am aware of into a fugue state and ended up being sectioned for 6 months.*</p> <p>Paying for the basics when you don't have a job, year after year after year due to not being able to get a job if your born disabled or losing your job when you become disabled. When a child is born with a disability, a parent probably won't be able to go back to work after their maternity leave. This will put the household into financial hardship. If one of the parents has a hard time accepting the diagnoses then the parents might split up. This may mean the parent supporting the child will be on benefits. If the parent is young then they might not have the ability to advocate effectively on behalf of their child. As stated before the parent might be grieving for the loss of the child that they should have had.*</p> <p>After this there is the extra cost of physical adaptations of the home for the person who is physically disabled or washing clothes and bedding due to incontinence or drooling. Repairs to property if the person has violent outbursts, cost of wheelchairs due to local social services poor one size fits all policy. The cost of decent incontinence pads for children and adults, extra water and heating the water for cleaning the person, adapted shower and kitchen units in houses for people to bathe and cook for themselves. Clothing that are easy to put on a person who is dressed rather than dresses themselves, the cost of heating and cooling for children or adults who are incapable of regulating their own body temperature, the cost of leaving hoists on 24/7 or they don't work properly, the cost of transport if the person can't drive or lives with someone who can't drive. Giving people bus passes isn't the answer for physically disabled wheelchair bound people, most wheel chairs can't get on the bus and even if they can, spaces are being used by buggies. Special dietary requirements such as gluten free food. When a person has autism, they have sensitivity to light, sound and touch. This can cause extra cost due to buying different lighting or products to clean yourself or clothes to wear / in some extreme, having to live in a shed in the garden due to the house being too warm or noisy etc.*</p> <p>When a person becomes disabled in adult life, they might lose their job due to it not being possible to adapt. EG. A nurse in their 40's, who looks after people in recovery from operations being diagnosed with MS. If someone who is employed has a boss who is ignorant of disability law and so is the person with the condition, the person could be let go. Getting a job when your disabled is next to impossible, due to fear of the employer thinking that the person will need special help or adaptations in the work place and loads of time off to go to the hospital. *</p> <p>People who are on DLA are on it due to being born with a disability where in the past, getting a job was for other people, your only future was special school (which to be honest, doesn't give you any qualifications or life skills) then the day centre. If you become unable to work in adult life, chances are you will lose your job, due to depression of discovering the condition or the accident you had, lose your home, and struggle with income changes and trying to navigate the system of adaptations, social housing and benefits.*</p> <p>4. What support? A lot of people on DLA don't get any support at all due to the different eligibility criteria, and some people are happy and only want unpaid family support not paid care. Also some people have nearly all their DLA taken off them due to the charging from social care. When all the cash is taken off them to pay for care they have no money left to do anything when they go out. Make sure that carer's allowance is payable for anyone</p> |

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|                   |               | <p>who is on DLA or PIP.*</p> <p>People who have indefinite DLA awards already as they have passed enough tests, assessments and people who support them have a very stressful time filling in the forms. Where a baby is born with a condition that is obviously very life limiting and debilitating then this should be automatic, * I think you're getting a bit confused as to what DLA does. DLA is money to help people decide what they want to do for themselves, it's the council and social services that provide support for people to do activities. Give a person with a disability enough money to go out and make sure everything in society is accessible and you won't have to prioritise support for the most disabled group in society.*</p> <p>How can we best ensure that the new assessment appropriately takes account of variable and fluctuating conditions?*</p> <p>8. Should the assessment of a disabled person's ability take into account any aids and adaptations they use?*</p> <p>As long as it doesn't mean that if a person can move across a street in a wheel chair then they are less disabled and is entitled to less help/money. A true assessment has to see the person without any aids or adaptations because if you don't, and the aid they have breaks down, and using the passport system, how can they pay for a replacement or get the appropriate help. If a person is in a wheelchair with speech aid, doubly incontinent and can only move 1 finger to guide the chair, is this person less in need because they have with adaptations ability to move even though they need 24/7 care. *</p> <p>9. How could we improve the process of applying for the benefit for individuals and make it a more positive experience? For example:*</p> <p>The form will always be difficult to fill in unless the condition is a passport to benefits automatically. *</p> <p>Unless you have people who make the decision impartial, and the people want to help people get the benefit rather than worry about the 2 % who try to defraud the system, certain conditions should automatically be easy to say yes to. For example, autism will soon be diagnosed with a brain scan. As it is a lifelong condition, put someone diagnosed on the low rate automatically and if the parent/carers feel they need more support then they can then apply for the higher rate. The same with cerebral palsy, no cure for this condition but is diagnosed as a baby or small child. Follow the system that child benefit has.*</p> <p>10. What supporting evidence will help .....?*</p> <p>If a baby or small child is diagnosed with a condition, surely this is enough for the assessment to show they are eligible for benefits. With all the doctor and hospital appointments, why pay more assessors to do a worse job than the professionals at the hospitals. With this kind of condition, diagnosed at the time of the discovery this is when the benefit should be paid at the low rate automatically. I know of people who have been diagnosed with various conditions and never had DLA. This should be a form filled in by the person who has diagnosed you with the condition. The people filling in the forms should have a list of automatically agreed conditions. This would save money not cost money due to the lack of proof needed as the diagnoses had already been made. This should be the same in an adult setting, when a condition has been diagnosed, rather than leave it to the person to suddenly understand about benefits, overloading the 3<sup>rd</sup> sector with enquiries, wasting time and money.*</p> <p>11. An important part of the new ....*</p> <p>If you sort the system out there won't be need for another assessment, as the benefit will be paid automatically when the diagnosis is made. A doctor should have the forms with a list of conditions, explain that this is an automatic benefit and sign the form there and then. As long as the condition is lifelong and debilitating, especially when it's a child, the form can be sent off and the benefit can be paid, making the passporting to other support easier. It is because the benefit isn't sorted at source that you have this massive governmental machine to run and support.*</p> |

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|                   |               | <p>12. How should the reviews be carried out? *</p> <p>If it is a lifelong condition, that has no hope of improvement like Profound and Multiple learning disabilities with brain damage, one assessment should be enough for life. The Paediatrician's diagnoses should be enough. When the condition has a time limited impairment like a stroke then that is when you need regular reviews. *</p> <p>• Should there be different types of review depending on the needs of the individual and their impairment/condition?*</p> <p>Yes, but why again do you double up the process, why have unqualified staff deciding when someone should get a benefit when a doctor has already told the person they have it. You are always relying on the disabled person to have good writing skills or be able to get good advocacy. *</p> <p>13. The system for Personal Independence Payment ... *</p> <p>If you make the system easy and fair then people will be honest. When you promise to increase the payment when you are more poorly then do it. It should be as easy to increase it as decrease it. At the moment to increase it you have to fill in the 32 page DLA form again, but to get it decreased only takes a nosy neighbour phoning the office reporting the person for going for a walk without their walking stick. If you want trust you have to trust people to be honest, for example, one lady I know was given a letter from the Job Centre promising if she went to work and then had to leave again due to ill health, that she would automatically go back onto the same rate of benefits she was on before, when she was unable to work, the DWP stated that letter is not recognised by us and she ended up fighting to get any benefits for over a year. She lived on her son's benefits as he is disabled too. Also you need to join up the system so people don't get letters informing them of a benefit cut due to incompetence at the Jobcentre plus, example a person has a DLA renewal and the Jobcentre write to inform you of you benefit dropping due to not getting DLA anymore. You then get awarded DLA at the same rate as before and when you ring to inform the Jobcentre, they tell you that they already knew and had auctioned this, a week later you get a letter informing you of the benefit cut again. If the Jobcentre staff can't understand or work the system, how do you expect a disabled person to ?*</p> <p>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? *</p> <p>15. Could some form of requirement to access... *</p> <p>If you mean drug users or alcoholics then yes, cash for recovery rather than cash to spend on drugs and drink. If you mean autistic people refusing to attend behavioural therapy to be like everyone else then no, this would not be acceptable, but be careful with this one, as a person's human rights could be infringed. If you make deaf children have cochlear implants, a blind person have a chip in the brain, a fat person have a band, then it will cost more to fund the NHS. Then you go down the road of if you don't have this spinal operation then we won't give you your PIP money anymore. What about people with mental health problems, if you make them take medication that causes them to feel unwell or refuse to give them money if they don't have electric shock treatments!*</p> <p>16. How do disabled people currently fund ...*</p> <p>Yes this is an excellent idea. If the government fund it rather than the local council then its less likely to rely on a postcode lottery.*</p> <p>17. What are the key differences that we should take into account when assessing children?*</p> <p>That the carer is the person giving the information and they may be in shock and mourning, they have had a body blow and life will never be the same again, also they are probably never going to be able to have the career or life they expected. The child will probably live in poverty and if they have mobility problems then the cost of adapting the house will have to be taken into consideration or the moving of the whole family. If the child lives in a rural area then this is compounded as care brought in to help the family might be nonexistent. Also the family may have other children who are not</p> |

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|                   |               | <p>disabled. This has to be taken into account when transporting to school is discussed. In Peterborough the cutbacks have been so that free bus passes are given to parents to bus their disabled but not in wheelchair children to school but no consideration is given to the non disabled siblings. If a parent requires a break and the parents have split up, there needs to be funding available to provide either movable hoists or doubling up of equipment so parents can share the responsibility. Make it easy – If a child is born with a lifelong disability or has a condition diagnosed in early childhood, then some kind of immediate entitlement to DLA with the diagnosing paediatrician signing consent should be enough. *</p> <p>18. How important or useful has DLA ... *</p> <p>If you make it that anyone on the high level of DLA can get as much help as they need from services, rather than having to fight for them, this would be great. Wheelchair services, respite for unpaid family carers, adaptations to houses or cars. Have some type of credit card style passport showing that they have the high level of DLA and this entitles them to services required to make them as independent as possible.*</p> <p>19. What would be the implications ...? *</p> <p>Each benefit or service will have to have their own criteria, forms, paperwork, officers, offices, money to pay for the afore mentioned. People will get missed, children will die, adults will end up in residential homes instead of living independently, and the BmE community will be the most disadvantaged group due to the pockets of ethnic areas in the country.*</p> <p>20. What different assessments for ...?*</p> <p>When a person is diagnosed with a condition then this should be on the person's electronic health record. If you make a specific page available to benefit agencies without infringing a person's data protection rights, this would make it easier and quicker to process and stop a person who has been through a traumatic event having to repeat again and again what has happened to them rather than trying to get well or cope with a massive change in their life.*</p> <p>21. What impact could our ....?*</p> <p>If you can start at the preschool children and make sure that all children, regardless of ability has the opportunity of work experience, invest in schemes such as project search instead of funding the revolving doors of independent living courses at college. Worry less about the people already on benefits and consider how to avoid more people becoming disabled. Invest in prevention and education of the general public so they can see the many positive aspects of people who are disabled can make to society. "Thousands of people saw the apple fall from the tree, but Isaac Newton asked why" He had Asperger's Syndrome. *</p> <p>22. Is there anything else you would like to tell us about the proposals in this public consultation?*</p> <p>You need to be very careful that you don't force people who are now living in the community due to having DLA, and other help and benefits but are unable to work due to lack of work, suitable jobs, transport or geography, into residential homes or with families who are not able to care for them, and that all the good work to get the long stay hospitals closed down, and the mental institutions from 30 years ago gone, by not creating something similar to save money due to a small percentage of people highlighted in the media.</p> |
| EM287             | 27-Jan-11     | <p>In the case of children like my daughter, living in a semi-rural area with limited public transport, the use of a car is essential. As is, in my own particular circumstances, the taxi to enable her to access her special-needs school. But without Motability, most disabled adults and children would be trapped in their homes, isolated from most, if not all that the rest of us take for granted. Children like my daughter can only travel in a wheelchair accessible vehicle.*</p> <p>I think it is important to include a middle rate and not reduce this to two rates in the future.*</p> <p>The extra costs that a child and his/her family face as they become bigger is that equipment has to be replaced. You can't buy something only once! My</p>   |



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|                   |               | <p>daughter has cerebral palsy and much of what she needs is not always provided by the NHS. For example my daughter wears night shorts in an attempt to keep her hips in place (she has had three operations on her hips) and these cost my family £240.00. Our house has had to be adapted with a wet room and ramps and hand rails. I spend a lot of money on petrol to enable my daughter to attend a large amount of appointments. Limited amount of continence aids are provided by the Council and extras have to be paid for by my family. I pay for a carer to take my daughter to Brownies and this is an additional expense for our family budget. My daughter is not continent and so I have to pay for specialised care for her, which is expensive.*</p> <p>I think it is important to include a middle rate component, because many disabilities are complex and often there are additional conditions and disabilities.*</p> <p>I think if a person has complex needs and has major health issues they should automatically be entitled to this benefit.*</p> <p>Activities which everyone wants to be involved in are social groups, outings, education, church, mosque, synagogue and being able to leave their home and their city, town, village with assistance.*</p> <p>I think a person who receives disability living allowance should have their NHS number on a central computer and this should flag up every time they enter hospital or visit their doctor. It should be the doctor's responsibility to inform of any changes.*</p> <p>I think all aids being used at present and in the future should be taken into account. Why is this relevant to claiming disability living allowance?*</p> <p>Claiming should be made easier with a smaller document to complete. Much of the present document is repetition. Parent Partnerships should remain in place to support families completing these forms. Parent Partnerships link families and agencies set up to assist disabled children.*</p> <p>Supporting evidence needs to come from consultants, doctors, physiotherapists and key health professionals involved in a child's life.*</p> <p>Who are these healthcare professionals going to be? What are their qualifications? How do they get paid? Who are they answerable to? How do you assess a child? Who answers for a child? What if a claimant is non verbal?*</p> <p>Evidence should come from the medical teams looking after the claimant. My daughter has a Community Paediatrician and he regularly reviews my daughter, shouldn't he be involved. Evidence should be sought from other healthcare professionals. It should be possible to put a person's NHS number into a computer and be able to ascertain medical history. Most claimants often don't know what is needed or what important and what is not.*</p> <p>It think once a year a letter should be sent to all claimants asking for details of any changes to circumstances.*</p> <p>People should have clear and concise documents about what is expected of them and how long the process will take. What makes a person disabled? Is it mobility? Is it mental health issues? If you receive Personal Independence Payment can you claim for Carer's Allowance for a family member? Who do you contact locally to access what you need? Can you receive other benefits? How do you apply for Motability? Is this a passport to other services and if yes what are they? Who can support you at your local council – is it in my case Parent Partnership?*</p> <p>Simplicity and ease are what is needed. Respecting people's vulnerability. GPs need to take a bigger responsibility in supporting claimants applying.*</p> <p>What happens to children who are still growing and need to keep changing their equipment and wheelchairs as they become bigger?*</p> <p>Children grow up and their equipment and wheelchairs have to be replaced regularly. A large proportion of disabled children live with only one parent. It is three times more expensive to have a disabled child than an able bodied child. It is difficult for parents to work because they are caring for a child whose needs are constantly changing. Children need to regularly visit health</p> |

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|                   |               | <p>professionals as their needs change – my daughter who has cerebral palsy has had three operations in eight years. My daughter regularly visits the Encopretic Clinic, hospital and other health professionals. These visits cost me in time and petrol and child care for her twin brother and make working full time impossible. She attends both main stream and special needs schools and can only travel in wheelchair accessible vehicles. Her needs are complex and keep changing. As she becomes older our house will have to be further adapted to include hoists. She is very dependent on her Mother and needs one to one assistance all of the time.*</p> <p>I think it is more efficient not only for the claimant but also for the Government if DLA has a passport arrangement. This means that a person need only be assessed once which would save money. I think a person who receives disability living allowance should have their NHS number on a central computer and this should flag up every time they apply and this in turn be passed onto other relevant departments, for example Blue Badge Scheme. Every time there is a claim it has to be assessed and processed, so why not only do it once. You can then employ less people. It would free up carers time too and make life less stressful for claimants.*</p> <p>The implications would mean that there would be less efficiency and greater hardship for claimants*</p>  |
| EM288             | 31-Jan-11     | <p>hi I am emailing regarding the replacement of DLA. I hope you will consider all the discomfort you will be causing to all people in receive of dla that have to move on to the new benefit. *</p> <p>It is very difficult for people who are disabled to complete new forms and the hassle that will involve to move onto the new benefit. Surely this will cost the department a lot of money to print new leaflets, new rules and new forms. I thought the idea is to save money not spend more money to start up a new name for the same benefit. Don't forget the amount of hours of admin will be required just to achieve the process from DLA to the new benefit. WHAT A WASTE OF MONEY AND TIME!!!! Regards</p>   |
| EM289             | 31-Jan-11     | <p>Hi, I became disabled at 18 in [REDACTED] and completely lost the use of both legs through Polio. I have always received some form of mobility benefit and this has been instrumental in enabling me to work and lead an incredibly active life ( 5 Paralympics ). I still Chair a large organisation of and for disabled people in the Midlands and undertake a considerable amount of appeal and tribunal representation in connection with DWP benefits.*</p> <p>Ministerial forward - I have only read the Executive Summary but it is not helpful, where in the penultimate paragraph of her letter, Maria Miller appears to be confused between DLA and ESA where the government are encouraging people to return to work or take up employment. While DLA can assist people to be employed that is not its primary purpose.*</p> <p>Executive Summary - Paragraph 4 - At present DLA only covers daily living activities connected with personal care Will the Daily Living component include other things such as social activities, assistance with essential matters such as shopping, cleaning etc. where a disabled person has major additional expenses or is that wishful thinking ?*</p> <p>Paragraph 6 - Not permitting automatic entitlements other than for terminal illness is short sighted for such people as complete quadriplegic, etc. Surely this is costly and could be distressing for the most severely disabled person *</p> <p>Paragraph 7 - I am seriously worried about the last sentence where it is envisaged that a face to face meeting will be held. Experience has shown, that if this is anything like the ESA assessment, where a doctor fully assess a complete stranger in 30 to 40 minutes, serious errors can occur, especially in cases of neurological diseases where there is considerable variation and in cases of mental health. My organisation wins 95% of ESA appeals due to the inaccuracies of the assessment . There is no mention of an appeal process*</p> <p>Paragraph 8 - The fact that I use a wheel chair effectively should not be held against me. If someone chooses to purchase a piece of equipment to</p> |

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|                   |               | <p>improve their mobility or quality of life, surely they should not be penalised. This paragraph makes me question why should I bother to try and overcome the effects of my disability.*</p> <p>Paragraph 9 - appears to be quite sensible in cases where a condition varies or deteriorates.*</p> <p>In our experience there are only a very small minority who commit fraud, yet often completely genuine people are inappropriately accused of misusing the system.*</p> <p>Paragraph 10 - I feel that there are very few people who do not strive to find solutions to help them overcome their disabilities. Sadly many professionals are unable to think laterally and only offer set solutions which do not take into account the persons individual needs. Better training is required before this proposal will be effective .*</p> <p>I hope this helps</p>   |
| EM290             | 31-Jan-11     | <p>Dear Sir/Madam - Please find attached my own comments on the DLA consultation.*</p> <p>I am physically impaired but am a disability equality trainer who is totally committed the social model of disability. Having read this document I am absolutely horrified that so many of the points made in the document move us back 20 years to the medical model. I thought I had put my protest days behind me but having read some of the appalling proposals over the last 6 months I will be back on the streets protesting for civil rights. *</p> <p>We welcome the fact that DLA, or Personal Independence Payment (PIP) as it may soon be called, will remain a non-means-tested benefit.*</p> <p>Disabled people who are able to work have always wanted to work. It is the barriers in society that stop them.*</p> <p>What if people have impairments which are short term? They may need extra help and have no money for this.*</p> <p>We would rather not have health professionals involved at all in the assessment, as the majority of disabled people know what they need.*</p> <p>Aids and adaptations are helpful, but they do not take the place of PAs.*</p> <p>Why do you need a review for people whose impairments have not changed? This all costs money.*</p> <p>I feel that DLA is not a barrier to work as it is non-means tested.*</p> <p>Disabled people get involved in writing the assessment form and they are the people who know what needs to be asked.*</p> <p>How can disabled people be assured that the Government will take into account all the points that they have raised?*</p> <p>Some people will still require support when they are in hospital. Also, how many days will disabled people be able to have respite care before the benefit stops?*</p> <p>I believe the assessment should not take into account any equipment that disabled people might have, as equipment is always likely to break down, and this would lead to disabled people being more isolated in their own home and not being able to cope.*</p> <p>Once again many disabled people don't need health professionals involved in their assessment. They live with their impairments everyday and are the only ones who know what their needs are.</p> |
| EM291             | 31-Jan-11     | <p>I want to respond to your document regarding the reform of DLA. Firstly I believe it sets out from the wrong premise that anyone who is claiming DLA, doesn't really need it and must have lied to get it. It appears to me that everything I have read over the last few months regarding welfare reform is based around this view. *</p> <p>I am concerned about this because I have two adult sons with Asperger syndrome, so they are not ill but they are disabled (socially) and they will never recover. They will remain autistic for the rest of their lives. My youngest son receives DLA and Incapacity Benefit and he uses this to purchase outreach services so that he can get out of the house, to pay his keep for living in the family home, and to have his hair washed on a weekly basis and his prescriptions on a monthly basis. Having an assessment</p>   |

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|                   |               | <p>every six months means that he will be placed under a great deal of duress and may decide he cannot go in which case, I am quite sure, his benefit will stop. What is the purpose of the six monthly assessment for someone with a lifelong disability? He received DLA at lower order for mobility and middle order for care and does not, currently need to review until his 25<sup>th</sup> birthday (he is 20).*</p> <p>My eldest son is 30 and receives DLA at lower order of mobility and care. His has been awarded to him for the rest of his life. Whilst he works he only works part time and DLA tops up his salary to take account of his disability.*</p> <p>My real concerns are these:*</p> <p>Can you absolutely guarantee that the person carrying out the assessment of my sons will have enough knowledge and expertise of autism to make a valid and honest assessment?*</p> <p>Can you make a guarantee that those with a life long disability will not have to go through six monthly assessments?*</p> <p>Have you measured the impact of removing DLA from people who are unlikely to work?*</p> <p>Have you measured the impact that removing DLA will have on carers who receive carer's allowance? No DLA no CA.*</p> <p>I also want a guarantee that as my son has been awarded DLA for the rest of his life that this will not be taken from him*</p> <p>I have experience of my sons undergoing assessments conducted by so called experts that have led to wrong decisions being made and worst of all placing my children in difficult and uncomfortable situations. Bear in mind that for many adults with autism there are no services being offered by their local authority and benefits such as DLA are used to purchase these services. My son goes out for three hours a week (what he can afford). Is this what people should expect in a fair society.*</p> <p>I applaud you if you can make the application for DLA more straightforward but please don't disadvantage my children any more, they already deal with enough in terms of not being understood, they don't need to be labelled lazy and liars.*</p> <p>I urge you to impact assess what you are doing to ensure equality for all.</p> |
| EM292             | 31-Jan-11     | <p>Dear Sir/Madam, I have read the proposal for DLA reform and have some reservations. The proposal seems to be aimed at people of working age. My son who is 4 receives DLA as he has Autistic Spectrum Disorder. The paper only has a small section on children with disabilities and does not make it clear how children are going to be assessed. Clearly children cannot work and so will need different criteria? The paper needs to be specific how they are going to apply the criteria to children rather than introducing the new allowance and then thinking about disabled children later.*</p> <p>Another concern I have is who is going to make the decision whether a person will receive the new payment or not. It is impossible to expect people to understand all the disabilities out there and how that disability affects the individual. What if the person assessing my son has limited knowledge of an already complicated disability such as Autism?*</p> <p>The paper states that people don't like the DLA form as it is long and focuses on the negatives. I understand that a lot of information is needed in order to make a decision whether DLA should be given or not and so am happy to fill in the DLA form even though it does take several hours. The paper states that there is no system for re-assessment, I believe this to be untrue. My son's DLA states quite clearly that his benefit is to be paid for a limited amount of time then I will have to fill in another form to see if he is still entitled. If we have to do this, doesn't everybody who gets DLA? The new system will still have a lengthy form I assume plus the added cost of getting evidence from a professional. How much extra money will this cost? Will the professional be somebody who has knowledge of my son and how his disability affects him? How will you ensure this process is fair?*</p> <p>I am extremely anxious about the paper not taking into consideration the carers such as myself who look after disabled people. If DLA is replaced then you need to reassure people that the link to Carers Allowance will still</p>   |

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|                   |               | <p>be there. We rely on DLA/CA to get by and to provide the services that my son needs.*</p> <p>I believe the DLA reform as it stands is unequipped to deal with ALL disabled people and needs some extra work before it is rushed into force. Thank you for listening to my views.</p>   |
| EM293             | 01-Feb-11     | <p>I have sent some of this to my MP who may have passed it on but I have added to it. The DLA benefit which helps with mobility is one benefit that has allowed me to carry on with life. THE PROPOSAL TO REPLACE IT IS A TRAGEDY WAITING TO HAPPEN. It is hard to know where to start so I will refer to my own experience.*</p> <p>The first thing to note is that getting this benefit is not easy. There are pages and pages of forms to fill in. A medical history and a medical examination are required and there is no way any claimant can get benefit without entitlement. There are people who recover and lose the condition that entitled them to benefit and continue to receive benefit and an examination of each case where this is likely may be of benefit. But the chances of initially getting benefit you are not entitled to is so small that it probably does not happen. It is not economic to hunt them down.*</p> <p>There is more chance that people entitled to benefit will be turned down. My own experience over 30 years has provided proof that things could go wrong. My first claim for injury was that long ago. My injury was confirmed in writing by an experienced hospital consultant. It was accepted by county court. But when I had my medical examination for benefit one doctor gave the opinion that I did not have any problem. So benefit was turned down. It was a fraud to the extent that the doctor said I could do certain movements that I cannot do even now. I appealed but it was turned down. I lost considerable benefit and it made a significant change to my life quality.*</p> <p>Even later when my injury had been accepted to get a parking disc I had that taken away. For the medical examination I was called to the [REDACTED] surgery. The nearest point one could park was in the supermarket car park opposite. The first question was to ascertain where you parked. When told, the doctor said that there was no entitlement if one could walk that far. If you refused to go you lost entitlement so it was catch 22.*</p> <p>In these cases other doctors I knew told me that the government wanted to reduce the number of claimants. Whether the government was complicit in committing these wrongful exceptions or the doctors were trying to earn house points is unknown but the circumstances mirror the present day situation and the same type of thing will happen. If you want proof look at the recent record of those who have been taken off benefit recently. There are some disgusting cases. These will be repeated if personal assessments replace this benefit and in a big way never been seen before.*</p> <p>The government spokesman, with no proof at all indicates that there is a lot of fraud. It is setting the route for the withdrawal of vehicles from many people. One target is those in homes. I am a director of [REDACTED] Family Trust. If you are not aware of our group I can arrange for you to visit. You need to see the people who will be affected by this decision. Despite their apparent disabilities they really take in and have more awareness than is apparent. For most journeys out are an essential part of their lives and these are funded by DLA. The costs would transfer elsewhere. Perhaps to government as they would face increased fees as they pay the bills. If you are going to withdraw from those in homes the benefit that gets them out and about, IT IS TANTAMOUNT TO POLITICAL SUICIDE TO TAKE THIS AWAY AS THERE WOULD BE MILLIONS WHO ARE RELATED TO DISABLED IN SOME WAY AND THEY WOULD NEVER VOTE TORY OR LIBDEM AGAIN. IT IS REALLY HARD TO THINK OF ANYTHING SO HEARTLESS AS THIS IDEA AND DESPITE OTHER GOOD THINGS YOU</p> |

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|                   |               | <p>MAY DO THIS IS WHAT WILL BE REMEMBERED. IT IS ALLIED TO THATCHER MILK SNATCHER ONLY WORSE BY FAR.*</p> <p>At the end of the day your desire is to reduce benefits paid. The first step would be to write to all those receiving DLA stating your intent to ensure that claimants are still entitled. You may suggest that anyone now recovered should not now be receiving benefit and that you would be seeking them out. Then you can concentrate on those where the original certificate suggested that their disability would not be permanent. Then a paper sift would save costs. Those with progressive disabilities are unlikely to be frauds and can be eliminated from examination. Others could be written to asking for an update to their condition, with the option of a doctors certificate. to be drawn up.*</p> <p>Unfortunately my ME has now restricted me to the house and I am not fit enough to go to out patient appointments or the doctors. My only time out of the house since November was one visit to hospital to give blood and they refused to take me despite me arriving before their closing time. This is an ideal example of the problems that will come up. There are so many medical opinions on my condition but no cure despite taking powerful medicines. All it needs is a doctor amongst those who believe the condition does not exist to change my circumstances and entitlement. My ME can be treated the same way as my original injury which earned my DLA benefit in the first place. One doctor who does not believe me would be enough.*</p> <p>Locally many injustices are reaching the newspapers the worst of which was a man who lost his leg in a motorcycle accident a couple of years ago who was turned down and also had his appeal turned down and had his specially adapted car taken from him. If your are prepared to lose the trust and votes such decisions cost then do not turn back OTHERWISE DO A U-TURN AND LEAVE THINGS ALONE.</p> |
| EM294             | 01-Feb-11     | <p>My name is [REDACTED], i am very worried about this proposal, i have difficult typing this with my left hand because my right hand i cannot use at all i have considered killing myself because life is bloody awful enough full of pain then having to worry if your benefits are cut off because you cannot work because i cannot do anything much at all extremely reliant on my mum who is her late 60s, who cuts up food for me cooks all meals i would feel terrible guilty if i kill myself for her but frankly if i know it would work and i would die i would do it, i had to ring samaritans for support otherwise i would die, i donnot get out very much because i need taxis, i cannot walk very far, cannot sit for that long at all i had to buy something to lie down at home which was expensive, i am thinking of taking a pre payment funeral and a will because i donnot wantr my mom having that worry if i starve to death because i have no money.</p>  |
| EM295             | 01-Feb-11     | <p>Thank you for the opportunity to respond to the proposals for the reform of DLA. I am responding as a disabled person who relies heavily on both the care and mobility elements of this benefit. I consider myself to be very fortunate to live in an age when disabled people have benefited from a growing understanding of the problems of disabled living, and a determination by various governments to ameliorate those problems as far as possible. My difficulty with the current proposals for DLA is that the need for reform stems from the lack of affordability of the current system. This imperative automatically requires that costs rather than need will be the governing factor when considering help for the disabled. In addition, the proposals for frequent assessments will attach further costs to the bureaucracy of administration; which will presumably reduce the budget available for helping the disabled. *</p> <p>I know I speak for my disabled friends when I express our fear that we will return to a time when we will be denied the right to live a relatively normal life on the grounds of cost. We can already see that the drive to improve accessibility on the Tube has been halted, and in many less obvious ways the imperative to improve has ground to a halt. I cannot see that the government has any mandate from the electorate to target the most</p>  |

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|                   |               | vulnerable in society for cuts. Can I suggest that the whole country would endorse collection of tax from those who seek to avoid it, and the taxation of those whose income exceeds one hundred times the average salary.   |
| EM296             | 01-Feb-11     | <p>Question 1 What are the problems ...?*</p> <p>RESPONSE Much of this consultation document appears to focus on those disabilities that are obvious, e.g. use of wheel chairs, prosthetic limbs etc. There are a number of disabled, such as diffuse brain damage when awareness of the disability only becomes apparent when certain tasks are undertaken. Thus the problems and barriers affect different people in different ways and the new assessment procedures need to be carefully designed to ensure it captures the problems.*</p> <p>For instance in my daughter's case she suffered brain damage from a medical accident for which no compensation was payable. This has left her with emotional, mental and physical problems. Examples: Any conflict results in emotional breakdown.*</p> <p>Prolonged activity results in a sudden sharp deterioration in performance, which can cause safety problems, and thus her job is limited to 16 hours per week. The brain cannot properly process visual information that results in a form of dyslexia, and*</p> <p>an inability to locate objects spatially. So reading is difficult and in a crowd she sometimes cannot recognise her own parents from a distance of 6 feet. She cannot read a number plate at 25 yards because of this 'interference' effect. Assessment of the speed of vehicles is poor.*</p> <p>She cannot use open flame cooking as she cannot assess exactly where the flame is.*</p> <p>She will not use a sharp knife because of the danger of cutting herself as she is not sure*</p> <p>where the blade is in relation to her fingers.*</p> <p>Some of her movements are restricted so she cannot get a menial job such as a waitress*</p> <p>because she cannot manage collecting plates etc, and she cannot assess if a tray is horizontal. She is prone to falling over simple obstacles like some stairways because of the co-ordination problems. She cannot react quickly to a situation.*</p> <p>She needs help to plan and execute a journey that she is not familiar with, as it is difficult*</p> <p>for her to comprehend written instructions/information.*</p> <p>Question 2 Is there anything else about DLA that should stay the same?*</p> <p>RESPONSE It seems to me that the current criteria cover many aspects of disability requiring extra expenditure so those should not be changed, e.g. the inability to prepare meals requiring expenditure on more expensive pre-prepared foods.*</p> <p>Question 3 What are the main extra costs that disabled people face?*</p> <p>RESPONSE This surely depends on the disability, covering transport where public transport does not fulfil the requirements, expenditure on specialised equipment to enable a disabled person to live independently or to carry on employment.*</p> <p>Question 4 The new benefit will have two rates for each component: ....*</p> <p>RESPONSE That rather depends on the method of administration. Once the assessment is made it is just another rule for the computer system and as such two, three or four rates per component would seem to be equally simple to administer.*</p> <p>• What, if any, disadvantages or problems could having two rates per component cause?*</p> <p>RESPONSE This depends on the level of benefit being paid and the spread between the levels. If it is too wide there could be an element of unfairness.*</p> <p>Question 5 Should some health conditions or impairments ...individual applying?*</p> <p>RESPONSE I would expect that it would be possible to include some health conditions where the impairment is obvious, for instance dual amputees or</p> |

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|                   |               | <p>those whose impairment confines them to a wheel chair.*</p> <p>Question 6 How do we prioritise support ... lives? Which activities are most essential for everyday life?*</p> <p>RESPONSE By providing financial support to allow, wherever possible, those with impairments to be on a par with those without impairment.*</p> <p>Which activities are most essential for everyday life?*</p> <p>RESPONSE This seems a question that is rather like how long is a piece of string, however the needs of personal hygiene, the ability to feed oneself, to travel to work as appropriate, to engage in society generally so that they are not isolated and their spiritual needs can be met.*</p> <p>Question 7 How can we best ensure that the new assessment appropriately takes account of variable and fluctuating conditions?*</p> <p>RESPONSE By reminding claimants by post each year they are required to inform any changes of impairments.*</p> <p>Question 8 Should the assessment .... aids and adaptations they use?*</p> <p>RESPONSE - It should take into account any existing aids and the problems that might be associated with them and similarly for those for which they may be eligible.*</p> <p>Question 9: How could we improve the process ...easier to fill in?*</p> <p>RESPONSE A tick box system is used trying to cover all eventualities, it is difficult but I suggest a focus group of disabled persons be employed with the form designer to review the form.*</p> <ul style="list-style-type: none"> <li>• How can we improve information about the new benefit ... who is likely to qualify?*</li> </ul> <p>RESPONSE Define the requirements for the various levels of benefit as is currently done.*</p> <p>Question 10 What supporting evidence will help provide a clear assessment of ability and who is best placed to provide this?*</p> <p>RESPONSE A person's G.P. is best placed to make the assessment as they will be cognisant of all the difficulties. There has been much negative publicity of the assessments made by assessors who appear to be employed just to deny benefits to those who need them. What is really worrying is that the government has said that "we are looking at saving 20% of the Disability Living Allowance expenditure in line with the Chancellor's commitment in the Emergency Budget" This means that regardless of need, assessors will be under pressure to deny DLA claims to meet the target. Why a 20% target? It has obviously been derived without any scientific method and therefore should not be used. The only reductions in DLA payments should be when the recipient does not require them.*</p> <p>Question 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?*</p> <p>RESPONSE In the case of those who are easily suggestible they will be unable to state their case properly and might be easily swayed by suggestions from the health care professional who will be trying to meet the unscientific target of a 20% reduction in DLA payments.*</p> <ul style="list-style-type: none"> <li>• Are there any circumstances in which it may be inappropriate to require a face-to-face meeting... another location? *</li> </ul> <p>RESPONSE Yes, where the claimant may need physical help or psychological/carers support to answer the questions of the assessor, in my case this would be my daughter who would have trouble with the questioning.*</p> <p>Question 12 How should the reviews be carried out? *</p> <p>RESPONSE This must be based on the individual's condition and should be a minimum of 5 years to avoid the stigma of harassment. For instance if someone has had both legs amputated it would be inappropriate and demeaning for a regular review of that person's condition, as amputated limbs do not regrow.*</p> <ul style="list-style-type: none"> <li>• Should there be different types of review depending on the needs of the individual and their impairment/condition?*</li> </ul> <p>RESPONSE Yes, that most appropriate to the condition. Where the</p> |



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|                   |               | <p>condition is medically unlikely to improve, say like cerebral palsy, a simple self-report should be sufficient again the frequency of assessment should be such that the individual does not feel harassed.*</p> <p>Question 13 The system for PIP .... How can we encourage people to report changes in circumstances?*</p> <p>RESPONSE Send DLA recipients a yearly letter politely reminding them that they should report any changes in their condition.*</p> <p>Question 14 What types of advice and information are people applying ...the benefit claiming process?*</p> <p>RESPONSE Examples of common impairments and typical levels of payment.*</p> <p>Question 15 Could some form of requirement to access advice and support ... and what would need to be avoided?*</p> <p>RESPONSE Cannot understand this question, what is meant by "some form of requirement to access advice and support" All GPs should be made aware that any person with a disability can claim the new payment.*</p> <p>Question 16 How do disabled people currently fund.. and adaptations? Should there be an option to use ... one-off cost?*</p> <p>RESPONSE In our case no help was offered apart from a wheelchair. A local charity provided a computer which was invaluable. So yes one off payments should be offered.</p>   |
| EM297             | 01-Feb-11     | <p>Dear Sirs, I am registered blind with about 5% or residual vision (which is greatly impaired by cataract) but have been struggling to make sense of your on line questionnaire regarding DLA reform. In the first place it is reasonable to assume that the majority of disabled people will have some visual impairment and yet you issue this form in a tiny font squeezed into a small section of the screen leaving the bulk of the screen space black and completely wasted. Why???</p> <p>I am fairly computer competent but naturally assumed you expected the questionnaire to be completed and submitted on line. Yet this does not seem possible and I can find no guidance as to how you expect it to be completed.*</p> <p>I can only assume this is part of the plan to encourage as little response as possible. Another part of the plan is to give a only a few weeks consultation period which covers the Christmas and New Year holiday period. *</p> <p>From what I have managed to read of the proposed plan it seems change for change sake. Disabled people and their carers are the best and only people who have a true knowledge of what help is required and this is how the current DLA is assessed. *</p> <p>Why change one of the very best and most accurately targetted and awarded benefits that exist today? It works well and should be left alone. Your on line leaflet implies that a person supplied with an artificial leg is no longer considered disabled! This assumption is un believably crass. *</p> <p>This new system as outlined will not save the government money but merely redistribute it away from the disabled people who so desperately need it and give it to all those extra people who will need to be employed to assess and administer it. I am so angry I can hardly type! Regards,</p> |
| EM298             | 01-Feb-11     | <p>Please find attached my comments on the DLA consultation document. I am writing as an individual. I would like to know if any disabled individuals have been involved with the writing of this consultation document and how individuals can be involved in the drawing up of the criteria and implementation for the new system.*</p> <p>Comment on para 16. The fact that there are different levels of benefit for both mobility and care is actually a good thing. In my case I have had higher rate of mobility allowance for over 30 years but have only needed care component for two years due to a deterioration in my condition.*</p> <p>Para 17. I don't quite know why people think it is an out of work benefit. I don't know of anyone of working age who is disabled and receiving either benefit who thinks it is an out of work benefit.*</p> <p>Question 1- The main barriers that prevent me fully participating in society</p>   |

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|                   |               | <p>are inaccessible buildings (still!), attitudes, and cost. Many buildings have ramps but some have ramps that are too steep or are cambered. Although I am disabled I am not a permanent wheelchair user and find 2-3 steps easier than a ramp as I cannot bend my ankle. There is also an issue of cost. If I always have to have a carer with me, and have to pay for them, the cost of doing anything is doubled. Extra heating costs money. There is also an issue of choice eg shopping can be more expensive if you cannot go to different shops to compare prices. Also any aids often mean much more wear and tear on clothes, and they need laundering more frequently both of which mean additional cost. There seems to be a consistent problem that providers of services are inflexible and will often quote health and safety as a reason for not helping.*</p> <p>Question 2 I think having different rates in both mobility and care components is vital to allow for deteriorating disability, and the need for more help/care.*</p> <p>Question 3 – Some of the additional costs disabled people face are – (1) heating because the majority of physically disabled people suffer from cold intolerance and need to have heating on even in summer. (2) holidays and holidays insurance – if you need anything other standard accommodation and insurance, the price almost doubles. There seems to be nothing in the market between standard and fully wheelchair accessible holiday accommodation. (3) It is difficult to compare costs of everyday items if you cannot visit several shops (although this is getting easier because of the internet. (4) Clothing – often you have to pay more for clothing in order to get stuff that is hardwearing and which will be suitable for wheelchair users and/or those of us who use orthoses (appliances) (5) The cost of having to pay for a companion if you want to go eg to the theatre, cinema, museum, art gallery, etc.*</p> <p>Question 4 Although in principle I would agree with having 2 rates for each component, I think it needs to be clear what are the criteria for each rate and some consideration made about people who are borderline between the higher rate and the lower rate.*</p> <p>Question 5 – No - because two people can have exactly the same condition but have completely different mobility and care needs.*</p> <p>Para 21 I do not think people in a care home should have their benefit stopped because not all care homes provide transport and the resident of the care home would have no way of getting out on their own ie not with a group from the home.*</p> <p>Question 7 – I think the new assessment should make more use of those who know the claimant well – eg GP, district nurse, OT, physiotherapist. Especially for people with fluctuating and variable conditions, a one-off assessment may occur on a particularly good (or bad) day which would given an incomplete view of their condition to their assessor.*</p> <p>Question 8 - No. An unintended consequence of this would be that people will not request aids and adaptations they really need because they may think that if they do they will lose benefit. It can also go against common thinking. For example, some people in wheelchairs can do more than those using crutches, sticks, walking frames, etc. but the average person would regard the wheelchair user as being the more severely disabled and therefore deserving of more help although that may not actually be the case.*</p> <p>Question 9 The form needs to be in simple English and available in a variety of formats and ordinary disabled people need to be involved in the designing of the form.*</p> <p>Question 10 Useful supporting evidence could be GP assessment, OT assessment plus assessment from carers, family, employers, school, etc.*</p> <p>Question 11 It would be important for the health professional to have experience of dealing with people with communication difficulties and access to interpreters for those such as deaf people who do not have English as their first language. The claimant should be able to have a supporter with them to help with fear and anxiety*</p> |

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|                   |               | <p>Question 12 There needs to be regular reviews the frequency of which should be based on whether the condition is known to be stable, fluctuating, or deteriorating. The review may be different depending on the condition.*</p> <p>Question 13 – It should be made a condition of payment that for example once a year people will fill in a questionnaire which would highlight any changes in their condition.*</p> <p>Question 14 – As part of the claiming process people should definitely be able to access advice and information so that they know what the specific criteria are for each component and level. This should be done by personal interview either by phone or in person.*</p> <p>Question 15 Yes. Key features would include it being part of the diagnostic procedure but people need to know they have a choice of whether or not to apply for PIP and when.*</p> <p>Question 16 – How people fund their aids and adaptations is very variable. For those who know how to work the system they can mostly be obtained from NHS or Social Services. Otherwise people will buy them privately from mobility firms. I would be concerned about using Personal Independence Payments to pay for one-off costs if this means that NHS and councils will shirk their responsibility for providing aids and adaptations.*</p> <p>Question 18 Personally I am not sure that DLA has provided access to other services or entitlements except that if you receive higher rate mobility allowance you automatically get a blue disabled parking badge.*</p> <p>Question 19 – Probably, more bureaucracy, more time filling in forms, more people involved.*</p> <p>Question 22 – Although it is important to help those in most need, the criteria need to be much clearer and people need to know that if they have been turned down once, that as their condition deteriorates they can reply. There are many people, particularly those with fluctuating conditions, who would fit the criteria for those in most need on a bad day but on another not need much help. How would you deal with this?</p> |
| EM299             | 01-Feb-11     | <p>Dear Mr Pugh, <u>Disability Living Allowance Reform Public Consultation-Comments.*</u></p> <p>I have Huntington's Disease and I am registered Disabled and receive payments under the current system.*</p> <p>The Government considers the Disability Living Allowance (DLA) to be unfit for purpose, this is not correct; there are no problems with the DLA. Furthermore, there is no need for the new system or Personal Independence Payments.*</p> <p>If the Government is determined to introduce the new system of Personal Independence Payments, it would be unfair to make the new Legislation Retrospective from 2013/2014 basically, I cannot see any reason why the new legislation should be Retrospective, and it would be unfair on Disabled People like me. I can only hope that the Government does not make the new Legislation Retrospective as it would Disadvantage Disabled People like me. *</p> <p>Assuming that the Government does not make the new Legislation Retrospective, in the case of the new claimants after 2013/2014, why should new claimants wait 12 months for any payments after having qualified under the new Personal Independence Payments. It makes little sense to make new claimants wait 12 months before receiving any payment. *</p> <p>In view of the comments made in the email I can only hope that the current DLA system is left alone. The Government are to introduce new legislation in 2013/2014 I hope that it is not retrospective legislation and disabled people like me can be exempted from the new system if the new legislation is introduced why new claimants should wait 12 months before receiving any payments. I hope that the Government takes on board the comments of a disabled person. Yours Sincerely</p>  |
| EM300             | 01-Feb-11     | <p>One of my greatest concerns if the proposal to reduce/remove mobility payments for people who can use a wheelchair well. Just because someone can use a wheelchair it doesn't reduce the extra costs they experience as a</p>   |

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|                   |               | <p>result of being disabled. In rural areas (and even many suburban areas) there are no bus or train services and, even where they are, they are few and far between and certainly are not accessible to a wheelchair user. Chances are those services that run will not go to where a disabled person needs/wants to go.*</p> <p>Someone who can use a wheelchair well one day, may not be able to on another due to exhaustion or pain. So to reduce/remove DLA payments simply because someone can use a wheelchair seems incredibly cruel and might even lead to a situation where people choose not to use a wheelchair and hence become more socially isolated and most likely suffer further setbacks to their health, which would cost the NHS more in the long run.*</p> <p>I do think certain disabilities and conditions should be given automatic entitlement to the mobility component. I have been a paraplegic and full time wheelchair user for 20 years and can safely say that the cost of being disabled keeps on rising. These costs have no correlation with my ability to use a wheelchair. My condition is permanent, the only change being that as I get older day to day life gets more exhausting. So to have to reapply on a regular basis seems an unnecessary administrative burden, not to mention a time consuming and maybe stressful experience. *</p> <p>The majority of buildings in the UK are still inaccessible. Even now, many newly built homes are inaccessible as the building regulations are not enforced strictly enough. A classic example is where a house on a hill with an integral garage will have a smooth driveway to the garage, but steps to the front door. The majority of railway stations are inaccessible. The majority of railway stations are unmanned, so even if a wheelchair user could get on a platform, they couldn't get onto a train as there would be no staff and no portable ramp. Other countries have had the sense to make platforms the same height as the trains and so avoid such problems. The same is true for buses and coaches and bus stops and bus and coach stations. Even on mainline trains, it is still necessary to give two days prior notice before making a journey. So someone who can use a wheelchair well cannot just hop on a train at the drop of a hat or leap on a bus – nor run up and down stairs for that matter.*</p> <p>To drive a car, it is usually necessary to have some form of hand controls, which is an increased cost compared with someone able bodied. Often a larger car is needed to accommodate the wheelchair, which in turn usually means greater fuel cost.*</p> <p>Around the house, a wheelchair user would probably need a lowered work top in the kitchen, special adaptations to their bathroom, often a through-floor lift or a stair lift, wider doors, hard wearing floor surfaces. All of this is an additional cost of being disabled. It also makes it far harder and more expensive to move for work or family reasons.*</p> <p>Wheelchair users tend to need the central heating on more as they do not have the same circulation as an able bodied person and so get very cold legs and hence body.*</p> <p>If a wheelchair user wants to take up a sport to be fit and healthy and have some social inclusion, they can't just spend £100 on a pair of trainers for running, £100 on a pair of trainers for tennis, a few hundred pounds on a bike. Instead they need a specialist marathon chair, tennis chair or handbike. All of which cost thousands of pounds. Similarly most other sports would require some sort of adapted equipment which is all a greater cost compared than an able bodied person would incur to participate in the sports.*</p> <p>So, to conclude, just because someone can use a wheelchair well, it doesn't eliminate the extra costs incurred as a result of a disability and your proposed changes to DLA will cause real hardship to disabled people.</p> |

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| EM301             | 02-Feb-11     | <p>9. Whenever i want to go out anywhere it costs me double as i have to pay for my PA to do things with me. This restricts me from doing a lot of things that i would like to do, for cost reasons. It can be impossible at times to find the money to do social visits and meeting people. *</p> <p>No, i would be very happy for things to change with the DLA. I like the new way of working out the Allowances. *</p> <p>I still have to pay for the Trains and for my PA to travel with me. There are other ways to travel but i find that the train is the most comfortable for me as i have more room to move around if i need to.*</p> <p>No, i don't think that this will make the benefit easier to understand. I think there should be either a higher benefit or a lower benefit if this is possible, to try and keep things as uncomplicated as possible. *</p> <p>I don't think that people should have an automatic entitlement to the benefit, as not everyone needs the same amount, this could be taken advantage of. If each person is seen as an individual, more money will go to the right people; the people who need it most. It will be used to better their care. *</p> <p>People who are unable to wash, dress, feed, toilet, clean and shop with their own ability, should be a higher priority than people who can feed, toilet and wash without help. People who are unable to communicate as well as others should also be a higher priority as they need help in all areas of their lives including socialising and getting involved in the community.*</p> <p>People should be monitored. Every so often there could be some sort of informal meeting where there could be a conversation that goes through the individuals daily lives and not have someone intimidating a benefit user and make them worried that they may lose their benefit. *</p> <p>8. I think the aids and adaptations used should be taken into account. Aids and adaptations that should be included are wheelchairs, walking sticks, all aids for communication, hearing and up-keep of guide dogs as well as dogs that help individuals to do things around the house. *</p> <p>Make it clear on the letter that the benefit is only for people with a valid disability. It is not for people who, for example, have an injury That may only last for a few months. *</p> <p>The assessment would be made best by your own doctor who knows the individual and can clearly state whether their patient qualifies or not. If not the doctor a social worker who has known the individual for an acceptable amount of time. It is not as effective if the person who is making the decision has never met the person before makes a quick decision as they have only met the person a few minutes beforehand and they have no idea about the individuals medical history or know them personally. *</p> <p>It would be inappropriate if the healthcare assistant did not have enough experience to make a decision on a person's disability. They would not know the person well enough to make a decision. This is why they should keep in contact with the benefit users, so the user gets used to the people asking questions and will feel more comfortable. *</p> <p>If the person has an ongoing illness or disability they should not be checked every year as they may feel this is too much. They may feel as though they are not being trusted to decide if the amount that they are receiving is still the same or should be changed. They should only be seen every 5 or so years to check if their condition has deteriorated, otherwise they should contact you if they want the visit to be more frequent and not compulsory. *</p> <p>If the person is seen to be physically disabled or if they have obvious learning difficulties they should not have to give any more proof than this. If the individual does not physically appear to have anything wrong to show as evidence they should have a doctor or health professional to see people and they can make an honest decision on the persons needs. If the individual has a reason to receive the benefit they would not have any reason to have a problem with this. I think they should receive these visits every 6-12 months. *</p> <p>If the department want people to update them they should make it as easy as possible for the user to do so i.e. make the phone calls free and as quick as possible without having too many questions fired at them. They should</p> |

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|                   |               | <p>also allow the user's PA/Carer or anyone that they trust to contact you and speak on their behalf without this becoming a communication problem. A reward could be offered to people who choose to update the department of their current condition. Such as a small bonus of £10 or £20 could be enough to encourage people to get in touch with you. *</p> <p>Individuals contacting the department would usually be enquiring about whether they are eligible for the payment and if so how much they are entitled to. They may want to know about what could happen if their circumstances change and if they are allowed a higher amount for some reason. It would be better if the advice was offered as people will be updated correctly with the information and keep peoples mind at rest if they know they can contact someone if they have any questions/queries or just need a bit of advice. *</p> <p>Some individuals may not realise what they are entitled to and not notice how unwell they have become if it has happened slowly over time and not to their realisation. They may feel that they should not ask and feel uncomfortable in doing so. If it was easier for them to find out more information, this may encourage them to apply. *</p> <p>If the money for aids and adaptations was paid in a one-off payment it would be fine to cover the overall payment of the aid, but there would not be any money left for the maintenance of the aid or adaptation. Unless there was more money offered to cover these costs and if there was something to go wrong with the aid this would be covered too. It would be better for the individuals if there were a better choice of aids and adaptations offered. As there is not much choice for people, therefore they are opting to buy their own.*</p> <p>If a child has on ongoing illness or disability they should be checked the same as adults in the same health bracket. If the problem is not long lasting they should be checked more often as their situation and health will change more when they are young they are more likely to see an improvement in their health. *</p> <p>It would be better if the passporting information was on a website, sent in a letter and/or phone calls to the individuals to ensure they are receiving everything they are entitled to and are aware of what help is available to them, easily and within reach.*</p> <p>If this was the case people would not be aware of what is available to them and what advice they can get. Some people have to have peace of mind and have all of the information with them and know where they can get all of the relevant information from the right place.*</p> <p>It would be easier if there was one database and the people who need the information could see all of the information about the individual without sending people out within a few weeks of each other. There should be one contact number for all departments to save any confusion. People should not make too many copies of the individual's personal information as it can easily be seen by the wrong people.*</p> <p>Older people could benefit as they may receive payment for a longer amount of time. People of a minority race may also benefit from the changes as they may be looked into a bit more.*</p> <p>There is nothing else i would like to say.</p> |
| EM302             | 02-Feb-11     | <p>1. Means testing of disabled people*</p> <p>Discouraging them from taking well paid jobs which would enable them to accrue savings while still getting support*</p> <p>Relatives cannot leave or give money to disabled people since it just ends up going to the government*</p> <p>Inadequate access to buildings, public transport, etc*</p> <p>Inadequate working environments*</p> <p>Inadequate support from social care services*</p> <p>Prejudice by employers*</p> <p>End of Carers Allowance when in receipt of state pension*</p> <p>Inadequate benefits for disabled people and carers*</p> <p>Waiting time for disabled facilities grants*</p>  |

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|                   |               | <p>NHS postcode lottery*</p> <p>Social care postcode lottery*</p> <p>Lack of provision of social care independent of local budgeting policy/control*</p> <p>Lack of respect shown to patients/clients*</p> <p>Lack of continuity of social care workers*</p> <p>Priority given to social housing tenants*</p> <p>No joined-up thinking for disabled people and their carers*</p> <p>Problems faced by patients who cross boundaries and have to register as temporary patients and/or clients*</p> <p>Cross borough budgeting problems*</p> <p>Lack of services fitted to the individual rather than the other way around*</p> <p>Lack of integration of services for the individual, health, social care, education, etc*</p> <p>Reliance on the third sector*</p> <p>*</p> <p>2. General levels of payment*</p> <p>Mobility component so that Motability opportunities remain*</p> <p>*</p> <p>3. Increased transport cost, cannot use public transport, need specialised vehicles with modifications, etc*</p> <p>Taxi fares*</p> <p>Means testing of Disabled Facilities Grants*</p> <p>Having to pay for adaptations privately due to delay in processing Disabled facilities grants*</p> <p>Increased accommodation fees whether buying a house or renting due to special needs*</p> <p>Costs of extra heating*</p> <p>Cost of aids and adaptations*</p> <p>Cost of financing adequate care*</p> <p>Cost of special diets*</p> <p>Increased costs of holiday transport and accommodation (unable to use budget airlines)*</p> <p>*</p> <p>4. Do not believe reduction of number of rates will provide improvements to administrator or client in terms of understanding*</p> <p>*</p> <p>Disadvantage is that steps between levels could be large, giving threshold problems for those on the borderlines, meaning payment cannot be tailored to client needs*</p> <p>*</p> <p>5. Automatic entitlement for some conditions should remain Do not make life more complicated for these groups*</p> <p>*</p> <p>6. Am always concerned when asked to prioritise, since this can lead to specific groups with common disabilities and illnesses getting preferential treatment, despite people with less common disabilities or illnesses having equally pressing needs. Each individual needs to be assessed and treated equitably.*</p> <p>*</p> <p>Important activities are the same as those of everyone, being able to participate fully to the best of one's abilities in whatever one chooses to do, in comfort and safety.*</p> <p>*</p> <p>7. By appropriate training of assessors, perhaps taking advice from other professionals*</p> <p>*</p> <p>8. Am concerned about the implications of this question. An individual may have a wheelchair, but prefer not to be dependent on it. Indeed reliance on the wheelchair in all circumstances could lead to a deterioration in muscle tone and overall condition, to the extent that the individual becomes more</p> |

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|                   |               | <p>dependent on aids and adaptations. To be at least minimally mobile without a wheelchair is very important to the self-esteem and confidence of many disabled people. If PIP support level is to take into account aids and adaptations more than at present, then this must be done intelligently. *</p> <p>9. The sort of data that needs to be gathered has not changed. Some people are able to complete the form with no problems. Where they need help, this could be provided via a help-line, or a visit from a Welfare Rights Officer.*</p> <p>Publicity for the new benefit needs to be widespread*</p> <p>Easy read pamphlets*</p> <p>Websites*</p> <p>Adverts in local newspapers, particularly free papers*</p> <p>Notice-boards in GP surgeries, hospitals, community associations, neighbourhood offices etc*</p> <p>Targeting of specific groups forums, charities, and volunteer organisations.*</p> <p>10. This depends on the individual's circumstances and the nature of the disability or illness.*</p> <p>For well known conditions, the situation is usually clear.*</p> <p>For more uncommon conditions may need to take advice from other professionals, e.g., physiotherapists, GPs, consultants, etc*</p> <p>Often the individual's carer is best placed to comment on an individuals abilities and circumstances, and the assessment should take place when the carer is present and welcome his/her input.*</p> <p>11. The main difficulty may be getting to see the required level of professional. Trying to get appointments for clinical purposes with health care professionals is difficult. This is likely to be even more so for administrative assessment purposes.*</p> <p>12. Clearly these are a function of the individual's disability or illness. It will be difficult to have one size fits all. Again, a lot depends on the training given to the assessors.*</p> <p>13. Individuals need to be made aware at the assessment that they need to report changes in circumstances, and reminded at regular intervals, as in current documents from DWP.*</p> <p>Penalties need to be put in place that are effective, and deter the cheats from claiming dishonestly. However, there must be flexibility where the client is confused or unaware of their responsibilities, or unable to report changes in circumstances themselves, so that punitive measures are not taken against those who have no ill intent.*</p> <p>14. The topics raised in paragraphs 36 and 37 in respect of signposting and guidance are useful. Every step should be taken to make the individual aware of the various means and agencies that can be accessed to improve their quality of life.*</p> <p>15. Requirement implies retribution should advice and support not be sought, perhaps in terms of reducing or withholding PIP or other benefits. This seems inappropriate. Rather the emphasis must be on ensuring that people do take support and advice through encouragement and guidance.*</p> <p>16. There are clearly various ways, e.g. Disabled Facility Grants, free provision though Social Services or the NHS, from savings, through charities, etc. Does not seem appropriate to tag this onto PIPs.*</p> |



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|                   |               | <p>17. There are clear issues in terms of child protection and safe-guarding. Also of respecting the child's confidentiality. Very difficult to integrate support with current approach to special educational needs, particularly where needs are driven by a medical condition. Do not see the benefits system as the correct avenue through which to seek the much needed integration of support across all of the agencies.*</p> <p>* 18. Passporting is very important and is relatively straightforward. It opens many doors, and avoids obstacles.*</p> <p>* 19. Service providers would have to take on board decisions which they may not be best placed to make, leading to inconsistencies and delay. Individuals seeking support need that support as rapidly and easily as possible, and passporting aids this effectively.*</p> <p>* 20. It seems that every time one accesses another agency or provider, a new assessment is needed, and this is a major source of irritation to clients. There are proposals in Liberating the NHS documents about sharing of information. There is also much talk of a single assessment process. Sharing of information between agencies must be encouraged, but only provided the Data Protection and confidentiality issues can be sorted.*</p> <p>* 21. Do not foresee any significant impact on any of the protected groups provided the new benefit is rolled out adequately.*</p> <p>* 22. It is clearly essential that DLA or PIP be paid only to those with a real need, particularly in the current financial situation. Merely introducing the new benefit and different assessment processes will not necessarily make the required inroads in this area.*</p> <p>What is needed is adequate policing of the benefits. We must also be careful that in implementing the new benefit we do not throw out the best features of the old benefit.*</p>  |
| EM303             | 02-Feb-11     | <p>hello, 14yrs ago i was diagnosed to have M S, the condition affects my ability to walk comfortably any distance at all and my balance is also affected. As im sure you are aware as is typical with M S not all days are as affected as others. It has always been my intention to carry on my life like any other, i work, i have a [REDACTED] old daughter and am married. I applied for help in getting around and was awarded mobility allowance. As i live in a very rural area, having a reliable form of transport, with out the worry of having to go round garages etc to purchase a car, maintain it etc is an unbelievable help and reassurance to me especially as i was awarded this "for life" i felt that that was one thing i did not have to worry about and could reliegh on.*</p> <p>The thought of having to go through an assesment again is so worrying and stressfull, I feel when some one is awarded the help for life, has a condition like mine which is uncureable and is known not to get better but will in fact get worse, then how can this be questioned?*</p> <p>There is no public transport in my area, if i have no transport i will loose my job, i will be unable to get to Dr surgery, hospital is almost 90miles away this is the major factors that will affect me let alone basic things like shopping etc, doing these things is my main concerns, please consider the effect the reassessment will have on people like me, it is so scarey and stressfull.*</p> <p>I understand change is needed, but surley, those awarded the "for life" status should be left as is, if i was to be regularly to be travelling 90 miles for regular reassessment, this would affect my job, i am [REDACTED], i have worked all my life (since i was 17) this is some thing i do not want to change, my job is mentally a pillar in my life. Would it be better to start the new system on new applicants and more cost effective. Yours faithfully</p> |

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| EM304             | 02-Feb-11     | <p>Most of the document is the usual mix of lots of words saying very little! However, the following immediately come to mind.*</p> <p>I was awarded DLA 'for life' following a stroke. I can only assume that it was then felt that my condition and associated deficits were not likely to improve to the point where I was no longer disabled. What would be the purpose of reassessing me? Costly and futile! As I am now over 65, will I be reassessed anyway? The document is not clear.*</p> <p>'Signposting' is meaningless. There is no purpose e.g. signposting me to physiotherapy if there is no provision for its supply.*</p> <p>Current operation of mobility component just doesn't work adequately. It's no use uprating this by rise in RPI or CPI when motoring costs have risen by far more than that (petrol and insurance costs!). Please escalate the mobility allowance properly. Proposal to remove mobility component from those in long-term care homes is cruel. Are they never to go out?*</p> <p>Is there ANY evidence of the savings which could be made under the proposed new arrangements? Any evidence of people now in receipt of DLA who, under the new reassessment regime would no longer qualify? We are not told. It is highly probable that the amount of money lost to fraudulent incapacity benefit claims is much much larger than that which would be affected by these proposals.*</p> <p>IN SUMMARY*</p> <p>Document largely meaningless*</p> <p>Many reassessments will be costly and futile*</p> <p>Proposed withdrawal of mobility element from those in long-term residential care unjust and cruel.</p>  |
| EM305             | 02-Feb-11     | <p>I am a person with disabilities, who prior to becoming ill worked as a social worker, so have had a wide range of experience of DLA claims, from both personal experience and in helping others. Unfortunately due to my illness affecting my cognitive abilities, I am unable to respond as fully or as coherently as I would like. I have omitted some questions.*</p> <p><u>Q3.</u> Costs of getting around – cost of wheelchair (manual, electric), electric scooter, accessible transport, paying of a carer to either help by taking person out, or of doing and getting what is required instead if person unable to get out. Increased fuel bills – person often less able to go out so indoors for longer periods, plus as less mobile heating needs to be higher as not mobile. Needing to wash clothes, bedding etc more frequently. Care costs – to pay people to help with personal care and preparing meals. Prepared foods, even if can be used, are more expensive to buy. Cost of setting up home differently – I, for instance, also have a bed in the living room as well as the bedroom, and a fridge, kettle and microwave in the living room. Others may need a shower, special mattresses, spare room for carers to stay, recliner chairs, etc etc.*</p> <p>There are a myriad of costs that can be needed depending on the type of disability, often individually at relatively small cost but adding up when combined – such as wet wipes as unable to wash hands, paper plates, hands free telephone, remote controlled lights, curtains, etc etc Cost telephone and internet access – these are often the only or main tool for people to communicate, shop independently etc. For a well person this is a luxury, for a person with disabilities it is a lifeline but needs to be paid for regularly.*</p> <p><u>Q4</u> Two components won't make the benefit any more or less difficult to understand. However, the removal of the lower rate will mean hardship for the people currently assessed for this component. Paying someone to prepare food is expensive. *</p> <p><u>Q5</u> Has any research been done to ascertain whether those people currently on an indefinite award tend to deteriorate or improve over time? My anecdotal evidence would suggest that the conditions for which people are given an indefinite award tend to be those which deteriorate and result in greater care costs. If this is the case, reassessing everyone regularly will make the process much more expensive, both to administer and in increased payouts. It will also add much greater stress to people's lives. If</p> |

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|                   |               | <p>your care is dependant on receipt of DLA, it is incredibly stressful not knowing whether you are going to have the income for the six months or so in the lead up to a reassessment, and this takes away independence in planning care needs, employing carers, etc. It is even more so for people who rely on their DLA assessment for finance for care from the Independent Living Fund.*</p> <p>The removal of the mobility component from people in a care home is very worrying. It misinterprets and misunderstands independent living for people with disabilities. David Cameron – Prime Minister's Question Time 26th January – equated living in a care home as being in hospital. This is plainly wrong. A care home is a person's HOME, and they should be enabled to live as independently as possible, and this means receiving the mobility component of DLA or PIP.*</p> <p><u>Q7</u> The assessor needs to ask open ended questions about how the person's disability affects them over a long time period. There needs to be an understanding that how they were affected last week or last month is not necessarily an indicator of how they will be affected next week or next month.*</p> <p>Also needs to be an awareness of what can trigger a relapse in relapsing conditions (such as M.E., MS, arthritis). Someone may on the surface appear to be able to do more than they are currently doing, but it is very likely due to the fact that if they do more they are risking a severe relapse. This needs to be understood and accepted as part of the assessment and the lower level of ability needs to be the one that is their accepted level of what they are able to do. It is in no-one's interests if this is not accepted, the person does more, then becomes more ill. Also needs to be an awareness that feeling terribly ill and exhaustion are as debilitating as pain.*</p> <p><u>Q8</u> Assessing with aids and adaptations needs to bear in mind that people often use their DLA to pay for these. Needs to be taken into consideration, that most aids and adaptations don't remove the need for help – even someone very able at propelling themselves in a wheelchair or walking with a frame or crutches, is not able to carry a hot drink, for example. And although many public buildings are theoretically accessible, some parts (often the toilets) are not. Much public transport is not accessible. And most private homes are not accessible so visiting friends etc will often require help. It could get very complicated – is a motability car considered to be an aid? And what about internet access? (Which allows me to shop independently). Does the fact I can use this relatively successfully mean I don't need help to go out? *</p> <p>Could get into a ludicrous situation where someone can't afford the aid, so doesn't have it, becomes entitled to the mobility component, uses the aid, is assessed as therefore not being eligible for the mobility component, then the aid needs replacing/servicing, so they are unable to use it, so they then become eligible again.*</p> <p><u>Q9</u> Ensure that people with disabilities are involved in designing the claim form, and that they are in plain english and accessible, with open ended questions where people can explain their situation, not yes/no check boxes.*</p> <p><u>Q10</u> Assessors should "listen" to the claimant themselves, (or for those unable to express themselves, the person who knows them best) and respect them for the knowledge and information they have on their own condition. In the current system, it can feel like the claimant is the least important person in the process, and that the word of statutory agencies bears more weight in the decision than the claimant themselves, despite the fact that GPs, nurses etc may often not know how a condition affects daily life. I am usually granted my DLA on a time limited basis, and have therefore claimed 4 times. On all 4 occasions my GP has been asked for information, but the carers who give me my care have not been contacted. It should be those who provide the day to day care – or the care manager that assesses for this – whose views should be taken into consideration.*</p> <p><u>Q11</u> The assessors should not have centrally or locally imposed targets or agendas in how many people are granted PIP, or what the awards should</p> |

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|                   |               | <p>consist of. This is the only way that the assessments will be fair, assessed on each person's individual needs, and be seen to be fair.*</p> <p><u>Q12</u> The period of review should represent the person's circumstances. It is putting the claimant through stress and is not cost effective to review someone too frequently. For those with stable and/or deteriorating conditions, the period of review could be negotiated with the claimant at the time of assessment. There needs to be a process whereby the claimant can reapply if they think their condition now meets a higher rate of care of mobility, as there is now.*</p> <p><u>Q13.</u> This is difficult as improvement or deterioration can be very gradual, so the claimant may not notice. Even if they do notice, they may not know whether it is permanent, and the process of a reassessment is so stressful, may not wish to put themselves through it, only to discover shortly after that they become worse again, and have to reapply again. *</p> <p>Perhaps an annual letter – which would have an administrative cost – just reminding the claimant that if their condition has changed they need to let DWP know. Ideally it could state what level of change is required in someone's needs to require a change in the award. For instance, if someone is in the lower care rate band at present, it could say “if you do not need x hours of help per day” or “if you now need help at night”, to give an indication. I would reiterate though that I think its likely that most people's conditions deteriorate, and this is likely to therefore have a greater cost to the government.*</p> <p><u>Q14.</u> Signposting to other forms of support could be useful. Rather than just giving information saying “social services” for example, for the assessor to actually provide the appropriate contact local telephone number. *</p> <p><u>Q15.</u> No. People have the right to refuse to access support and treatment. If it is given under compulsion, it is unlikely to be effective. There are usually reasons why people don't accept help – they are frightened, don't understand, are confused etc etc. In my experience as a social worker, it was often people with memory loss who didn't have insight into their own difficulties and/or who felt that their relatives should be doing the caring. Removing the financial support of PIP would only make this much worse. Infact, DLA was often the first step in people accepting help. Once they saw the money coming in, they would then agree to help pay for someone to give their wife a break, for instance. They would not accept this in the abstract, only once they saw it happen.*</p> <p><u>Q16</u> Yes. The claimant themselves knows best as to how the money will best help them to live independently. It can also save other departments money in undertaking assessments etc. Also, a lot of costs that appear one off actually aren't, manual and electric wheelchairs and scooters need servicing, parts, batteries etc. If one off costs are not allowed, it takes away the whole purpose of having financial support that gives complete independence to the claimant, how you manage your own needs with your disability should not be prescribed by anyone else.*</p> <p><u>Q18</u> PIP should remain as a passport to other benefits such as the blue badge scheme. Much more cost effective to administer such schemes and much simpler for the claimant. *</p> <p><u>Q22</u> For claimants who need to pay for 24 hour care, the current benefit system does not seem to provide recompense for the additional costs of having another person living in the home – ie. additional food and fuel and water costs.</p> |

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| EM306             | 02-Feb-11     | <p>1. Mainly it is the ignorance of the general public leading to fear and lack of help and understanding. There is a huge lack of training in the education system in both mainstream and special schools leading to staff not being able to fully accept and educate the disabled children and the typically developing children around them. There is a huge lack of support for carers and families with disabled family members. *</p> <p>2. Anything else? I don't understand the question. It seems there is a missing question on this form. *</p> <p>3. Paying for assistance with travel, shopping, and all day to day activities including leisure. Also special enabling equipment and adaptations to the home. *</p> <p>4. Distrust of the adjudication system for the granting of the award – unless the parameters for each rate are set in stone – which, taking into account the variation of disabilities, may be difficult to achieve. *</p> <p>5. Some should be automatic. Making claims is very stressful, especially when trying to find the right words to describe the exact nature of the disability.*</p> <p>6. Loving, caring relationships are essential for everyday life. So we should prioritise support in that direction.*</p> <p>7. Provide clear wording for the applicant to use.*</p> <p>8. Should the assessment ... they use? What aids.... included? Should the assessment ....easily obtain?*</p> <p>Yes. Don't know. Don't know.*</p> <p>9. Publish the criteria, so we can work with you during the assessment. Presently we feel as though we are being questioned without being allowed to know why.*</p> <p>10. The people who spend the most time with the disabled person, provided there is clear guidelines/training for these people to give the appropriate evidence. For example Learning Support Assistants in schools could easily provide supporting evidence if they themselves were given clear guidance in how to provide it (as they do not currently have formal training).*</p> <p>11. Our son's behaviour would make this stressful – he has a fear of strangers and his behaviour would give a false impression. Others, through deference to professionals, may be intimidated and untruthful. *</p> <p>If the guidelines and criteria are watertight this may work well. However we would need to see the report and agree before submission as misunderstandings are already common.*</p> <p>12. Seems to be too variable to answer.*</p> <p>No, just have a simple form that allows you to amend the original application.*</p> <p>13. Ask them.*</p> <p>14. They are likely to need advice and information on what others in similar situations receive and why. Also information about other benefits and support that might help them. *</p> <p>Yes it would be helpful to provide it.*</p> <p>15. No, just give advice and information - if there are people not taking any action it is your fault if they don't have sufficient information to make an informed decision about the care that they would like to receive from the state. *</p> <p>16. We currently use DLA for aids and adaptations. *</p> <p>We should be able to use the money where needed surely?*</p> <p>17. Stressed, concerned and devastated parents. *</p> <p>That busy stressed, distracted, worried parents need extra support and information about their future path and the predictable changes in their child's development. And more support with filling out the enormous and very time consuming assessment forms.*</p> <p>18. It has been necessary in order to access some benefits, but it could be improved by automatically linking families to other entitlements.*</p> <p>19. Disabled people would continue to suffer from the lack of information and access to other benefits and services. Service providers would continue to suffer from lack of involvement from disabled people.*</p> |

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|                   |               | <p>20. It would be less stressful to think that one application led on to another, rather than one huge form which may, if incorrectly filled, lead to no benefits at all. *</p> <p>21. Don't know.*</p> <p>22. Essentially you need to absolutely reassure us that this is not merely a great cost cutting measure. And that the new system will be an improvement on the last.</p>   |
| EM307             | 02-Feb-11     | <p>1. The response to this has to be society as a whole. Whatever benefits or services are provided it is up to society as a whole to WANT to include disabled people in society and from my experience there are to many barriers. Physical Access, specialist services to meet very specific needs available locally, vehicular access that is accessible, money - these days you can not do very much without it. Willingness of those with the power to spend on disability needs AND attitudes of the general public need changing.*</p> <p>2. There are many things that should remain the same, but the main one has to be the ability to retain the mobility allowance in residential care, hospital, residential schools/colleges.. We as a family have experience of a residential school, hospitals and residential care. There are so many additional costs involved when the child is in hospital, not covered by anything else. When at a residential school my child was a weekly boarder and the mobility allowance was used to enable her to have community access at weekends and holidays, no one else covers these costs. When you add up the days my child was home, virtually as much as away. When my child entered residential care, the DLA mobility component was taken by the home to cover the cost of the homes minibus, the Local Authority funding did not cover this and I have checked with my local authority and they would expect the DLA to be used and have no extra money to cover these costs.*</p> <p>Also it is essential that the access to Carers Allowance should be available earlier. if there is a change to 6 months, before you can claim and Carers Allowance is dependent on this, then Carers will not get the meager allowance for 6 months. This is not acceptable. Carers need more help and support not less.*</p> <p>3. The main extra costs of someone with a chronic illness and a severe disability are extra heating, more use of utilities if at home a lot of time, extra wear and tear on the building and furniture and fittings, cost of adaptations and aids that help everyday living, adapted vehicles, visits to hospital often not in the area, loss of earnings of the carer.*</p> <p>The costs to the long term carer are physical problems caused by years of lifting etc and emotional problems from years of stress that continues even when they are in residential care.*</p> <p>4. It is not the number of rates that make it easier to understand , it is the clarity of the information and the application form. As for administering, I doubt it. *</p> <p>I think there should be more than 2 levels of each component, 2 levels is to restrictive. *</p> <p>5. I think there should be some conditions that have an automatic entitlement.They have been included overtime for a reason and why throw everything out. If you see it from the disabled persons perspective or their carer. To fill in a form when there is NO likelihood of any improvement and a real likelihood of a deterioration, it is a waste of every ones time. My child was born with a very severe disability, that is lifelong and will only get worse, whatever is provided in the way of aids / adaptations and any changes in my child's condition will be for the worse. But my child , I ,still has to complete the form that is not necessary. In a case like this there should be an automatic entitlement and a once the illness / disability is confirmed, by the</p> |

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|                   |               | <p>medical profession, the reviews should be only very small and not a full review. This is a waste of money on your part.*</p> <p>I agree with the social model of disability , but some conditions will not change.*</p> <p>6. This is impossible to answer. From a social model and from Choice it is what the person wants and needs. We are all different. No one should be discriminated against. For some it is the ability to work, but for others it is just getting up and not being in pain all day. From experience those with fluctuating conditions do not get a fair deal.*</p> <p>7. This is essential, I have personal experience of living with a person with such a condition and some days is so bad he cannot do very much at all , whilst on others he can do a little, BUT if he overdoes it , however small , be that physical or mental, that may be, he pays for it and has to rest etc. It is essential that whoever does the assessment accepts that how they see the person that day is not the full picture, it could be a good day. But the stress of it may cause problems for months.*</p> <p>8. I think that some aids and adaptations can be taken into account, BUT they can break down . My child has to use a wheel chair all day every day and is extremely restricted when it breaks down. Also using a wheelchair is not the be all , to use it outside the area has to be physically accessible , as has where you need to go and how you get there. Aids and adaptations help , but do not negate the disability caused by society. Using a wheelchair or other aids, is not an automatic aid to independence there are so many other factors. Therefore I feel if you need to use a wheelchair you should continue to get the higher rate mobility. *</p> <p>As for possible aids and adaptations, this is very difficult, if you have ever tried to get them , you will know how difficult it can be to get what you think you need. Unless you pay for it yourself , then it costs a lot of money. For some of the more basic I suppose it could be used ,BUT only if access to them is made easier and universal and not dependent on where you live.*</p> <p>9. You need to make the forms more user friendly, get people who have had to fill them in to tell you where they did not meet the needs and what would have been better, they need to be in plain English , but with prompts. To make it fair , ALL people should have the knowledge of how to fill them in and it not just be those who get help to fill it in. *</p> <p>Information should be in plain English and easy to read and understand. There should be people available to help complete the forms and give information in person, who are not those who will check for eligibility, someone you feel you can trust. *</p> <p>10. I believe it should be a health care person who knows you best, be that the GP, Consultant or other professional. But it should be someone who knows your whole condition , not just bits and has known you for a while and is able to give a clear picture of the reality of your condition. Someone who does not know you cannot assess you as well.*</p> <p>11. The face to face interview, as I have already stated, can have an adverse effect on the person, the stress of it can upset them for a long time afterwards. It can also only give an indicator of the problems, it may be a good day , for someone with a fluctuation condition, and not accurately show what they usually have to deal with.*</p> <p>I think that for someone with a lifelong condition that is not going to improve then there should not be a face to face interview, it is inappropriate and could cause both the person and their carer extra stress that will not change anything. It is also inappropriate when a person has a stable condition that will not improve even with help and also for those with a terminal illness. Why go to the expense of this if it is not necessary too.*</p> <p>12. Reviews should be dependent on the circumstances of the person. As I said previously a review should only be done when there is a likelihood of a change for the better. For some . like my child, this would be a miracle and to do a full review is inappropriate, by all means send a letter to be signed saying there is no change, but to do a full review can be very distressing.*</p> <p>It should not be disability specific , but it should be decided if the condition</p> |

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|                   |               | <p>etc is likely to change and the frequency of reviews set on that. The criteria should include length of time the person has already had the disability or illness and likely prognosis from the health care professional who knows them well.*</p> <p>13. In my experience the majority of people are honest and will report changes if they will make a difference to their needs. It is only a minority that do not report things. As I said above a letter to be completed with a few basic questions could be sent to all annually and the answers would decide if a fuller review is needed. Better clearer information and support would also help. Less of the them and us situation, more of a here to help you with your disability or illness.*</p> <p>14. I believe that information is essential, You cannot have too much information and a signposting service to give access to all the very good and often condition specific information available from Charities etc would help. Also to the correct local services available from statutory bodies. There could be a basic leaflet and an online resource.*</p> <p>15. I am not sure about this. All people who have a disability or long term illness are on a continuum and there are stages of this that people need to have, so it is difficult to say it is mandatory to do something when they may not be ready to do it.*</p> <p>16. From Experience we funded aids and adaptations for our child from a loan, from savings, from Charities and from one off payments from the local authority. I thought you could use the DLA /PIP on what you want and there is no necessity to spend it on anything. So to be able to use it on a one off item is a choice that should be available.*</p> <p>17. Children are growing and changing all the time and this should be taken into account, but as I said before there are some children, especially those with life threatening and life limiting conditions, with very little likelihood of improvements and stability being the goal rather than improvement. For these children and their families to review them can cause a lot of distress. However for a lot of children there will be changes and there should be reviews at a few year intervals.*</p> <p>I would have been happy for information from the Common Assessment to be shared, it makes a lot of sense. But it must be remembered that the needs of the child are outside of school as well as inside and that support offered is often restricted. For some Parent Carers they have to be on hand to deal with the child to enable them to attend things.*</p> <p>18. Passporting to other services etc is very useful. ie if you have DLA you do not have to fill in such a long form again and prove your entitlement. This should continue. However as I have said before it is essential the Carers have the entitlement to the meager Carers allowance ASAP and if changes are made waiting times for DLA/PIP then there MUST be some way Carers can get the Allowance earlier.*</p> <p>Sharing of information could be done and things happen automatically, that would be a pleasant change to having to apply individually all the time.*</p> <p>19. If there was no automatic passporting this would mean people and service providers would have to fill in extra forms that in the end would be very stressful and in some cases may lead to abnormalities if people do not understand what they should have put on the application form. Disabled people and there carers should be helped not hindered.*</p> <p>20. There is a need for a Common Assessment for Adults the same as there is now for children. I was always astounded that my child had to be reassessed so many times by so many people that in the end I did a summary of her needs and would ask what else do you need over this. In my innocence I assumed it would be shared and in this day of computers it should be easier, There need to be computer systems that can talk to one another , However it is essential that the people who do the assessing are very well trained to ensure that ALL the needs are covered , This may not be possible. I have problems with the idea that the financial assessment is done by the same person who assesses the needs. There is a possibility of not identifying all needs.*</p> |



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|                   |               | <p>21. Disabled people are on a continuum and this must be taken into account in all reforms. Those with the greatest needs will usually get , but those with lesser needs can achieve with a little , but will fail desperately if all help is withdrawn. Listen to the disability specific groups , they understand the different needs that none of us can understand unless we have lived it.*</p> <p>22. I know we live in tough times for all, but if we are a truly caring society we must provide for those that for whatever reason are vulnerable, sick or disabled . The big society will only work , if society wants it to and that is a very big problem. that people who are different know only to well. DLA/PIP whatever it is called is essential for people to live a life that is as independent and fulfilling as possible and the definition of that is as individual as we all are.*</p> <p>Thank you for the opportunity to be involved and share my years of experience*</p>   |
| EM308             | 02-Feb-11     | <p>I am a single mum of three young children and I have relapsing/remitting Multiple Sclerosis. I was diagnosed almost two years ago. My condition is such that it can vary by the hour. My biggest problem is fatigue. Sometimes I sleep for 18 hours a day. I suffer mobility problems, stomach and bowel problems. I also suffer with depression and mood swings. I rely on my dla payments to fund my Motability car. I have been looking to go back to work as my youngest child starts school in September, and I'm aware that as of next year, as my youngest child will be [REDACTED], I will have to look for work and come off income support.*</p> <p>*</p> <p>I am going to be in a tough situation - there are very few jobs out there at the moment. How many employers will offer a job to a disabled single mother, with the symptoms I have listed above?! I am prepared to work. But I would rely on my car to get my children to childminders/school and get myself to work. If I lost my dla and therefore my car, I would find it near impossible to work, from a logistical point of view. I receive no financial help from my childrens' father. He fraudulently claims several benefits, yet still does cash-in-hand work. I have reported this to the benefits fraud department, but he still is claiming! And yet you are cutting money from disabled people like myself. Myself and my childrens' quality of life will without doubt suffer if we lose my dla.</p> |
| EM309             | 02-Feb-11     | <p>Please find attached the collated responses from 20 Disabled People who attended a consultation exercise on 18 January 2011 at South Yorkshire Centre for Inclusive Living. One set of answers is from members of the deaf community. Please note that everyone felt the consultation period was especially short and covered the Christmas period which is not good practice. Best wishes*</p> <p>*</p> <p>QUESTIONS AND COMMENTS*</p> <p>What happens if you are over 64 and already on DLA? – We found the answer at the meeting and it says that you may continue to receive it if needs continue?*</p> <p>How much is it going to cost to implement and how are they going to afford to keep reviewing people who are obviously not getting better?*</p> <p>Reviews are going to be a waste of time and money – an impairment is a permanent thing.*</p> <p>What will happen to the people on the lower rate of care if care is going to two levels?*</p> <p>If a hearing impaired person is given an hearing aid or implant to aid their hearing and they can cope with it, does it mean they will lose money?*</p> <p>Access to work – is this staying?*</p> <p>How will it affect someone who works part time, they cannot survive on part time money?*</p> <p>[REDACTED] – commented that he had read on the internet that a Solicitor is saying the proposed PIP's are unlawful.*</p> <p>[REDACTED] asked if it was against Human Rights?*</p>                                   |

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|                   |               | <p>NOTES FROM EACH GROUPS DISCUSSION GROUPS*</p> <p>Problems/barriers to full participation Access – people’s preconceptions – hidden disabilities: pain fatigue, learning disabilities. - People’s prejudices – written off because your disabled. - Affordable, accessible transport - Access to information - Cost of adaptations/equipment - Accessibility of above – waiting lists - Limited access to therapies - Access to care services – carer needed to go out - Lack of adapted housing/workplaces - Lack of access to all community facilities – shops, leisure etc - Physical, financial, emotion and social (DET Training)*</p> <p>Is there anything about DLA that should stay the same Benefit should increase and be easier to access. - Access to motability scheme - Should compare a disabled person with a like person of the same age. - Motability side of DLA - Qualifying period of 3 months should stay the same.*</p> <p>What are the main extra costs that disabled people face? Special clothing; Heating ; Transport; Special diets; Continence products; Personal alarms; Paying for appropriate housing; Paying for care, extra costs of holidays and travelling ; Paying for carer, may need taxis*</p> <p>Paying for someone to help with normal domestic duties; Accessible/household appliances adapted e.g phones, special ovens, special equipment etc.; Care, heating, travel, leisure, water, dietary considerations, adaptations eg for home, mobility.*</p> <p>Will having two rates make.... ensuring appropriate levels of support? What disadvantages/problems could two rates component cause?; Not enough information about what the two rates are.; Condensing it to two rates – concern that only the most severe will benefit. Others who are still disabled but with needs will miss out (ie. Those already on lower rate).; Cannot fully answer until we know what the components are i.e which rate is going (Low/med/high); People on lower rate (if getting rid of lower rate) will miss out /lose it.*</p> <p>Should some health conditions ...on needs and circumstances of individuals? Any permanent impairment should entitle individual to some benefit.; Concern about who will pay for the regular checks – it would be an extra cost to the disabled person but other it would be an extra bureaucratic cost.; Needs to be individual.*</p> <p>How do we prioritise support ... Which activities are most essential for everyday life?All aspects of self care – most important ability to feed (including food provision and to physically feed).; Basic hygiene; Dress; Ability to get out and about ; Part a) Chuck money and people at it!Part b) Breathing!*</p> <p>How can we best ensure ... account of variable and fluctuating conditions?*</p> <p>Litsten to people, make it individual – show emphatic side – more understanding.Reviews should be as and when required – not set time scales.*</p> <p>Should the assessment ...into account any aids and adaptations they use? No it will discriminate against people.; Should take into account present and possible future adaptations.*</p> <p>How could we improve the process ... make it a more positive experience? Don’t ask the same question in several different ways. Different formats – short and to the point – easy to read – use straightforward English*</p> <p>What supporting evidence ... placed to provide this? Doctors/consultants notes; Social workers; Family/advocates; Some neutral – like SYCIL*</p> <p>An important part of the new process is likely ... with a healthcare professional. All individuals are to be consulted but some with a mental impairment/learning difficulty/behavioural problems or may be in denial of aspects of their disability may not give accurate information would need access to support from advocate/care who knows that person very well.*</p> <p>Will healthcare professionals understand social care needs of the individual, or understand the details of each individuals specific impairment.; Why might a face to face interview be appropriate?; It could cause stress to the individual. A person may not accept someone they don't know (eg. Someone on autistic spectrum).*</p> |

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|                   |               | <p>Difficulty – Ignorance ; Target led – i.e private companies etc; Affect – OT'S, GP'S, Physios ;Who's going to pay for it in different locations – inappropriate access.; Healthcare professionals don't always know the individuals needs/situations, meaning it can always be mislead. Everyone's needs are different and it's not always looked at in that way.*</p> <p>Be more knowledgeable and forthright useful with information to peoples with all needs.*</p> <p>How should reviews be carried out? – evidence, criteria and frequency Need right to insist on professional of same gender.; Need right to see and amend inaccuracies in reports.; The right to have an independent supporter there – advocate, carer etc. Someone they are comfortable with and who understands them.; Minimum standards of English from health professionals and understanding of individual's particular condition.; Why review individuals with non-changeable conditions?; Every individual is different on a personal nature and experience.*</p> <p>System for new payment will be easier to understand, so people will be expected to report changes in their needs. How can people be encouraged to report changes? People will only report changes that mean they will not lose money.; Need reassurance that if your condition grows worse and you report it, that your benefit will not be reduced, or even cut, as a result.; Too complicated, should be easier contact, not scaring people with rules etc.; Not making people go through the whole process again if situations and changes appear.*</p> <p>What types of advice and information are people applying for P.I.P likely to need? Would it be helpful to provide this as part of benefit claiming process?*</p> <p>Info should be in plain English (easy to understand) and widely available and well publicized.; Information available from all hospitals, GP practices, health visitors, social workers should also be more proactive in letting you know your entitlements.; Put more money into disabled people's organizations to help them support individuals through the process.; Advice should be made more understandable – and other formats i.e. easy read, Braille, different languages.; Criteria's – what's covered and what isn't without being penalised.*</p> <p>Could some form of requirement to access advice ... and what must be avoided?Peer support and independent advocacy – requirement for the system to accept the need and to promote it.; Requirement for the system to acknowledge need for different communication needs. I.e. Sight, hearing, language difficulties (including ethnicity).; Question is hard to understand and meaningless in some aspects but not in others. Force you to take all benefits available. No right to make people take things.*</p> <p>How do disabled people currently fund ...t to meet a one-off cost?Via NHS – OT's – pay themselves; Waiting lists, voucher schemes, half paid by NHS – and you pay other half.; One off payments may create shortfall off DLA/PIP – should be part of Personal Budget.; Adaptations need sometimes change and need modernizing as needs often change. ; The adaptations have to come out of the household budget meaning things need to be left out of needs in the household.; What qualifies as a one off case? ;Unless the adaptations need replacing or repairing.*</p> <p>What are the key differences ... assessing children?The fact that they will grow up and therefore their needs will change; Categorising children's needs.; All children's needs are different with growth rates, medical and sometimes mental needs been different.*</p> <p>How important or useful has DLA been ...? Are there things ... arrangements?Mobility wise – very important. Income support opens doors to other services.Making DLA/PIP more accessible/compatible to other benefits.No help has been acknowledged as it isn't sign posted.*</p> <p>What would be the ... to other benefits and services? Cancel any options Disabled people have - wider issues – jobs/retail etc; Would be absolutely diabolical. People would not be able to live normal lives.*</p> <p>What different assessments for ... and duplication?Medical records;</p> |

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|                   |               | <p>Assessments and information is not always correct. Causing problems and misunderstandings.*</p> <p>What impact could our proposals .... in developing the policy? The impact will effect everybodyNeed to consider the individual and not 'lumping' people together.It's going to lower equality to inequality. Don't do it – make it fair for people of all walks of life etc.*</p> <p>22. Concerns about consultation – quietly introduced before Christmas.. Short period of consultation.*</p> <p>People on DLA <u>NOT</u> notified of consultation!; VERY SNEAKY!!; This benefit – if there is a need for cuts – those who should lose benefit should be those who had a choice about their disability (i.e. Drug addicts/alcoholics etc) not someone whose disability was from birth/accident/illness etc.; DLA works well most of the time, but the criteria's need 'tightening up'.; Do not insult people's intelligence by trying to push things onto them. Where as you are not saving money but over spending it instead.; Social model is being removed into the medical model.</p>   |
| EM310             | 02-Feb-11     | <p>6. <i>How can we make sure that disabled people who most need..... to live an independent life?*</i></p> <p>The use of Interpreters, CSW's (Communication Support Workers) equipment for Deaf people (Minicom, etc.); Communication skills, interaction; Doctors, Sensory Team Social Services should identify a person's needs, review medical history before new assessments take place*</p> <p>7. <i>How can we make sure that the new benefit ....health condition can change?*</i></p> <p>By linking in with the Doctor ; Changes can be age related ; Make sure that the information provided by a Deaf person is correctly relayed to health professionals by using Deaf support workers/interpreters*</p> <p>8. <i>When a person makes a claim... should we take account of any aids and adaptation they use?*</i></p> <p>Aids and equipment should not be included in the assessment, the person is still disabled.*</p> <p>Respect for individuals ; People know what they can/cannot do – they know best themselves. ;They know what equipment is important to them so they can function normally; It is important that the people who assess those applying for a benefit should recognise the differences in people's needs even though on paper their disability looks the same e.g. 2 people with similar audiogram can have <u>very</u> different needs.*</p> <p>9. <i>How could we make the way a person asks for benefit better?*</i></p> <p>DVD in British Sign Language explaining information; Professional Interpreters; Translator; Experienced Deaf support workers who understands the information and can relay this to other Deaf people and Deaf people who have other needs (mental health issues) in their own language (BSL) ; Accessible information on the internet (BSL); Easy read information; Ensure those who are assessing are Deaf Aware and are able to communicate effectively and supportively*</p> <p>10. <i>Who are the best people to tell us ....what a person can and cannot do*</i></p> <p>Social Services Sensory Team; Doctor; Job Centre; DIAL; DDAG – Doncaster Deaf Action Group; SYCIL – South Yorkshire Centre for Inclusive Living; Family*</p> <p>*</p> <p>Information needed: Back ground medical history from health professionals, doctors etc.; The knowledge of a range of specific equipment needed to improve a person's quality of life; Cultural awareness*</p> <p>11. <i>An important part of the new process is likely .... difficulties? *</i></p> <p><i>Benefits*</i></p> <p>More personal; Can see clients difficulties or problems they are experiencing; Can see how they use their aids and equipment; Choice of assessor to one who is Deaf Aware is vital. *</p> <p><i>Difficulties*</i></p> <p>Ability to meet target interview time due to physical/mental problems; No appropriate support available for the person claiming benefit; Carrying out an</p> |

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|                   |               | <p>interview with an interpreter would be inappropriate in some circumstances like mental health you need a Deaf profession working 1:1.*</p> <p><i>12. How should the reviews be carried out, ... frequency of the reviews*</i></p> <p>In a supportive, understanding and calm manner ; With qualified, knowledgeable people; In a situation/place that is appropriate to the client's needs; Reviews should be a two way procedure and should be carried out depending on the health condition of the person applying overall, not just on the day of the interview. ; Constant reviewing can affect the confidence of a disabled person; Understand that aids/equipment don't remove the disability; Reviews should be guided by whether the person's condition is long/short term, chronic etc.; Availability of support worker/interpreters/Deaf Professionals*</p> <p><i>22. Is there anything else you would like to tell us about the proposals in This public consultation*</i></p> <p>Deaf people should be included in the review panel process; Deaf people should be included in any tribunal process; Deaf/Disabled people should be able to support/represent an individual with similar disabilities</p>  |
| EM311             | 02-Feb-11     | <p>After reading your plans for the changes for DLA I felt i had to answer the questions posted and to voice my concern over such changes! The following are my answers to them:- *</p> <p>*(1) The things that have stopped me leading an active and independent life has been my condition - I suffer with Stills Disease, have had it since birth and it has led to numerous operations sometimes as many as 3 in a year!!! My body causes me a great deal of pain and it is never ending, this means things are very difficult and the normal things that people take for granted can and sometimes are impossible for me. But there is the added complication that my condition is also variable which means on some days i can do certain things only to lose the ability when i have a flare up. My condition is progressive and so I have been getting worse and will continue to do so - never better!*</p> <p>Because of this i cannot socialize as much as i would like - lots of things have to go on hold until i am well enough and this can be for weeks at a time. Sometimes the only people I will see are my carers and doctors.*</p> <p>(2) I would like DLA to stay just as it is for me. The benefit and the amount has helped me to pay for my car which is relied on as my legs can't be - and for my carers who come in and out to help me - I have Direct payments which my care component is given to - without either of these things i would not be able to lead the life I do.*</p> <p>The flexibility that my DLA has given me has truly benefitted my life, I don't want someone to come in and change it all as in my eyes it will get worse and although you think it will lessen the amount spent on disabled people on this benefit - I believe it will triple the numbers!! However some changes do need to happen to prevent fraud in the future with this benefit, at this time I am aware that it happens with Incapacity Benefit and Income Support and not so much DLA.*</p> <p>(3) The extra costs that at the moment are not taken into consideration - this I do know about as my wheelchair, crutches and various other aids I use were all paid for by either myself or family/friends - this is because there is simply not enough money to pay for everything! My CPAP I am lucky enough to have through Family Practitioners and the masks that have to be renewed each year - this would otherwise been another expense that I have to find money for. At the moment I would say we are all struggling to pay the rising fuel costs as the mobility component can only go so far, and it stopped being sufficient years ago.*</p> <p>(4) I am really not sure how splitting the benefit into 2 parts for each component will make much difference or dividing it again either!*</p> <p>(5) I believe that certain health conditions should automatically receive the benefit especially if the condition is Progressive or Terminal, but the benefit should also cater for each persons specific need as far as I knew this is what is supposed to have been occurring already!!!!*</p> |

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|                   |               | <p>(6) I believe that if a person warrants a benefit their doctor, physio, OT, Consultants, Surgeons should already know about what benefits are available and whether their patients are eligible.*</p> <p>To me the most important actions that enable me to lead a reasonable life are my carers, without their help getting washed and dressed I would not be able to start the day, they help me with cooking, shopping, gardening, taking me to appointments when i can't drive - without them I would not be able to do this. This is just what affects me but it will be different to each person.*</p> <p>(7) Constant assessments would enable the benefit to change along with the patient, but I know these create a lot of stress to individuals asked to do this - however maybe the GP or specialists could be consulted so that there could be a network of people to support the various disabilities, which could liaise with the benefits people and the person themselves - as my consultants and GP do at the moment.*</p> <p>(8) When I have been assessed in the past all the aids and adaptations have always been noted, so am not sure why you would ask the question as though it was a new thing? Yes they should be taken into account but not dismissed if they are not using them as their condition can be variable and they may use them intermittently.*</p> <p>I like to walk but to do so causes me extreme pain on top of the constant pain I am always in, so I take to using crutches or my wheelchair when required but am not on them permanently!*</p> <p>(9) The claim forms are very black and white in the way they ask the questions they don't allow for those people in the grey areas - my condition is variable, however my disability is permanent - which means some of my answers would be "may be " answers and some have more than one answer -which the forms never allow for!!!!*</p> <p>I am not sure how to make it easier, but something does need to be done to make the forms easier and clearer, it certainly needs to be addressed. To get the message across the media can be useful, tv, radio, internet, doctors, health officials, posters in the relevant health centers everywhere.*</p> <p>(10) The person themselves are the best people to ask about their needs, with the back up of information from the relevant health authorities, as only the person will know what they need, others can only guess if they don't ask the patient - and that does not work.*</p> <p>Again the person themselves can say what they can and cannot do - however to ensure this is the case and stop fraud, the assessments and an independent doctor should also be used, exactly as they are at the moment.*</p> <p>(11) The bad things this can bring is that depending on the independent persons point of view or personal bias, you could end up with them influencing how the assessment takes place and even the answers given - as we all know depending on how a question is phrased can lead to many different interpretations of the question and in turn a lot of different answers being given. This could have a very detrimental impact on the person involved. Only one person does the assessment, I feel it should be a panel of doctors, physios, OT, and specialists.*</p> <p>The good things are that fraud would be picked up faster, the doctors who did the assessment in my case were very good, thoroughly checked all medical reports from all my consultants which meant they had heard from all who dealt with me, I have heard some very different stories from other people. There is no time when i would say there should not be face to face assessment.*</p> <p>(12) If a persons condition is temporary or can improve then the checks should be made more regularly, but if like myself my condition is progressive so will never improve - constant checks would gain nothing. Yes the way you check on the person should depend on their condition .*</p> <p>(13) I have always told the benefits people about changes because I am honest and it is what I agreed to do when I accepted the benefit, so people should not be allowed to keep their benefit if they don't declare the changes.*</p> <p>(14) They will need advice on the rules and regulations, and what will</p> |

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|                   |               | <p>happen if they do not keep yourselves informed of changes as well as Advice on how to appeal, what information they need to submit for their claim. *</p> <p>It would definitely help if you told people where they could get the information and the advice they need.*</p> <p>(15) With my adaptation within my home I had help from my council. With the aids for myself some have been bought with my money, some have been given by family, doctors, hospitals and various Occupational Therapists. I know that I could use my mobility component if need be for major adaptations to my car, or if I needed a large piece of machinery -ie electric wheelchair or scooter. *</p> <p>So if the person wishes to use all the money for a car, or machinery i don't see why they should not have that choice.*</p> <p>(16) The main differences when dealing with a claim for child, is that they are still developing, so any condition they have and needs they require will be very changeable.*</p> <p>There needs will be very different as they may need help with getting around in school, or special equipment to enable them to get to school, they won't have the same needs necessarily that an adult will have.*</p> <p>(17) In my case getting DLA has been really useful, I was eligible to apply for my blue badge at the age of 18 because of it, it has helped me get help with other benefits too, but i still had to apply it was not automatic each time.*</p> <p>I think that in order to be eligible for DLA you already have to be severely disabled, so I feel that you have already fulfilled most of the criteria for the Blue badge too, so it should remain automatic. It would be awful and a crime if they couldn't!*</p> <p>(18) A database of all the relevant information should in theory be a really good way to cross match the information requested - however I would be worried about documents going missing, or landing in the wrong hands, as other organizations have not managed to stop this from happening and valuable information ended up left on a train and people lost their benefits because of it!!*</p> <p>(19) Whether you are of a different sexual orientation, or race, or religion it should not make any difference to the main questions or the way they are being tackled as it is their medical condition that is in question, and that is not affected by any of those things. Unfortunately age will have some bearing because of the different needs required at different ages.*</p> <p>(20) As i have mentioned in some of the questions above, I feel DLA does not need to be changed for me as it works well the way it is, however it and other benefits are being abused and we do need to do something about that so that the people who genuinely need the benefit get it and those who don't are stopped from claiming. This will stop those with genuine disabling medical conditions from being subjected to many questions and assessments. I hope these answer the questions for you, although i do not like change sometimes changes can improve a situation - at the moment I have control of my help and finances and I would find it incredibly stressful to not have that control especially as i cannot control my condition! Kind Regards</p> |
| EM312             | 03-Feb-11     | <p>Hi There, I have Muscular Dystrophy FSH, and use a wheelchair, I am active within several local disability groups, and have filled in you questionnaire. Best regards,*</p> <p>*</p> <p>Question 1. Physical access to all things; the lack of aids, home adaptations, wheelchairs that are suited to the client needs, not the Social Services budget. Adequate finance to afford the right vehicle to transport oneself with their wheelchair and other paraphernalia required for the client's needs. There is a cash need for extra expenses occurred when doing or going on the simplest excursions and outings. *</p> <p><u>Question 2.</u> We must keep the same payments plus revise the need for extra payments for the severely impaired, with an open ended budget, as the</p>  |

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|                   |               | <p>cost is an X factor. Hopefully your revision of the DLA is to make it easier for clients to access, and to make sure the neediest will get the maximum entitlement. Additionally, disabled people incur higher costs in achieving the same standard of living as non-disabled people. *</p> <p><u>Question 3.</u> The extra cost of energy, as the person spends more time at home, and does not produce as much body heat through inactivity. The cost of a larger vehicle for clients with power chairs. The extra energy costs in the overnight charging of wheelchairs, bath hoists, through floor lifts, respirators and electric beds. There is an adaptation cost to the vehicle as in lifts for chair and person, higher expenses for food, clothing, utilities and recreation. *</p> <p><u>Question 4.</u> The higher rate of DLA needs to be open ended financially, to allow for the excessive needs of the more severely impaired. Understanding will depend on your presentation and flexibility of payment for the more severely impaired. The current structure should remain, by taking one out you will squeeze out the lower level and deprive the less impaired of valuable income. It is vital that the recent eligibility for the higher rate of mobility for people with sight loss is not abolished as part of these reforms it would be a crime. People living in rural areas with inadequate public transport would be subject to great hardship if they lost their mobility compound.*</p> <p><u>Question 5.</u> Yes, most certainly, especially conditions that are life long and progressive should have an automatic entitlement. All claims should be based on the needs of the claimant. *</p> <p><u>Question 6.</u> There must be no limit to activities and support there must be a right of access and social inclusion. The freedom of mobility, the freedom to choose when you yourself want to do something, get up in the morning, have a shower or not have one, eat, go out, have a cup of tea or even go down the pub; these are the actions that are important to live an independent life. All in all the activities that are available to every one else, must be available to all. *</p> <p><u>Question 7.</u> By regular consultation with the clients GP's, Specialist and care team, also keeping the benefit open ended financially to enable cost cover, especially for progressive conditions. Allow the client to self assess and be believed and understood.*</p> <p><u>Question 8.</u> Yes most certainly, for the more severely impaired there will be a need for a more sophisticated power chair (Like a Balder) having all singing all dancing facilities; in the long run it will bring the cost of caring down, as the user being better facilitated will be more independent. We should always pitch ahead when assessing a person's needs as by doing so it will be there in place ready to alleviate hardship and suffering; and costing less in the long run by eliminating crisis management. The bottom line is one size does not fit all, every adaptation will be different, as the person is. *</p> <p><u>Question 9.</u> That is an exercise in common sense for your selves; perhaps when designing the form bring in a panel of users to advise. Anyone eligible for DLA will have a certain criteria to qualify; these criteria should be clearly written. There needs to be help available from your selves as the forms are so big and complex. *</p> <p><u>Question 10.</u> Firstly you're GP, then your occupational therapist, your consultant, social worker and your caring team. Obviously the evidence in pecking order will be consultant, occupational therapist, GP, carers and social worker. The person themselves are the best at assessing themselves, and then all the support info from the pro's above. *</p> <p><u>Question 11.</u> The only problem for a genuine claimant with severe impairments that needs your service will be the ability of the health care professional within the client's field of service requirement. (One size does not fit all) The advantages of face to face are a direct response to your claim, as opposed to mail order diagnosis. Not everybody will be able to have face to face e.g. autism, social phobia's, cerebral palsy etc. The person's carer should always be accompanying the client, as they will know the situation even better. The interviewer must have disability awareness and equality</p> |



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|                   |               | <p>training; a consideration could be to employ disabled people to give the interviews. *</p> <p><u>Question 12.</u> As I have said anyone receiving DLA will have a severe impairment, therefore will be or at least should be having regular consultations with their specialist. The lesser the impairment / condition, the less reviews required.*</p> <p>Question 13. People who are likely to recover or have minor impairments should be under closer scrutiny and not go more than twelve weeks between checkups. The client should not have total responsibility over their medical status. The frequency of the check up's would become cost effective by the lack of system misuse. *</p> <p><u>Question 14.</u> There must be a consultant with an open book approach to the client, the client should have their credentials in place before the consultation and the consultant must give as much assistance possible. Advice and advocacy should be available at all times and there should be disabled interviewers.*</p> <p><u>Question 15.</u> You should be carrying enough information on the person to enable you to offer services and adaptations, equipment etc, as required.*</p> <p><u>Question 16.</u> You should surely know the answer to this question, as your various departments do the paying out, if you do not; try linking up to each other and saving us all a headache and even money? To pay for an essential piece of equipment on a one off should be allowed, and there still must be sufficient funds for day to day needs.*</p> <p>Question 17. The fact that the child is growing and will need size changes regularly, this goes from shoes to wheelchairs. The DLA mobility payment for children must stay in place for those attending residential schools.*</p> <p><u>Question 18.</u> It is a stepping stone in the right direction; it cuts out a lot of the paper work, and need to have more specialist analysis and consultation. *</p> <p><u>Question 19.</u> It would entail more effort and form filling in other directions, more work for your department; basically a chaotic situation would arise for both parties. It could lead to a person's isolation within their own home.*</p> <p><u>Question 20.</u> Government departments should have a central information pool of client files and history to hand, to be able to share between departments.*</p> <p>Question 21. There should be no impact in any proposals for anybody; the word equality means "for all" there must be no exception. The new benefit must be Universal for all.*</p> <p><u>Question 22.</u> You have not given enough, if any of your proposed changes to DLA when it becomes Personal Independence Payment. The questions are fudged and repetitive. You have not given enough if any of your proposed changes to DLA when it becomes Personal Independence Payment, it has took me four days to read and understand this form and try to answer the questions, I still do not feel this has been a positive exercise._ You have not used any Welsh Disability group to ask advice and assist in the setting up of this complex exercise. I also believe that DLA works and the introduction of a new benefit is going to cause chaos and hardship, to people who are already battling for comfort and ease of life.</p> |
| EM313             | 03-Feb-11     | <p>QUESTION 1. The cost – I used to go to some classes during the week which were very beneficial to me meeting people and also the exercise they provided. I initially got them free but then if you received incapacity benefit you had to pay. If you were unemployed they remained free. I had to stop. *</p> <p>The nature of the disability – I have Parkinson's Disease – very unpredictable and debilitating. I try and lead an independent life but when bad, it is not possible. The manifestations of the illness could also reduce confidence in going out and meeting people. It can also leave you vulnerable.*</p> <p>Isolation – a vicious circle – can't get out – don't meet people – feel out of society – isolated.*</p>  |

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|                   |               | <p>Frightened of benefits system – “what if someone see’s me doing this”<br/>There is a great feeling of fear that benefits will be stopped if you are seen doing something that you might not normally do. If you have a fluctuating illness like PD this fear is quite strong – although entitlement is there to live a full life as much as possible - it’s the big brother syndrome that rules.*</p> <p>QUESTION 2. DLA should never be means tested. I am of this opinion because the assumption is made that if you are married, you are given financial assistance from your spouse. This is not always the case. Also the current cut off point for benefits re income/savings has not altered in line with inflation. *</p> <p>QUESTION 3. Medication costs; Transport Costs – use of taxis, use of a car and all costs attached.; Additional therapies – such as physio, back massages, swimming – activities to keep mobile.; Homecare – cleaners, ironing, personal care, shopping assistance; Heating – as home all day*</p> <p>QUESTION 4. The fairest system would be perhaps to have a rating of 1 – 10 so it would be possible to target needs specifically although I acknowledge the administration of this might be cost prohibitive.*</p> <p>QUESTION 5. Automatic entitlement should be given to those with any chronic, incurable, deteriorating illness. Illness that have been diagnosed by a consultant. Such illness that are only going to get worse such as Parkinson’s Disease or ME or MS. Their illnesses can only get worse and they should be left alone.*</p> <p>Other disabilities for automatic entitlement would be total loss of sight, or paraplegic. *</p> <p>QUESTION 6. Prioritising support must surely be based on personal care, keeping warm and help with everyday duties including shopping, housework and company. I don’t really understand this question.*</p> <p>QUESTION 7. I would suggest that a simple diary sheet is sent with the appointment letter. Maybe allowing the person to keep a diary of their condition over a two week period, so the assessor can read first hand what it has been like.*</p> <p>QUESTION 8. If the aids and adaptations enabled a person to totally overcome a disability ie bad eyesight corrected by glasses – then they should be taken into account. If the aids just made life easier, then they shouldn’t be taken into account. *</p> <p>QUESTION 9. Re claim form - Keep form simple. No ambiguous questions. If you need to have yes and no answers, always allow a space for situations to be described that are not that clear cut. *</p> <p>Re information on benefits – Provide a leaflet at Doctor’s surgeries – keeping it very simple, in plain english. For example:-*</p> <table><tr><th>The Benefit</th><th>Who can apply</th><th>How to apply</th><th>What happens next*</th></tr><tr><td>Description</td><td>Bullet points</td><td>Bullet points</td><td>Bullet points*</td></tr></table> <p>Re interview - As to making it a positive experience – very difficult I would have thought given the nature of the meeting. Make the person at ease – don’t treat just as a number, offer them a cup of coffee – take away the fear factor – private room.*</p> <p>QUESTION 10 Supporting evidence should come from: A description of the disability from the patient.; A description of the disability from medical care team - all aspects of medical condition.; Any organisation that is currently providing support.*</p> <p>QUESTION 11. Face to face interviews – The care professional would have to have a knowledge of the illness or disability and the difficulty might be, getting that level of skill at all times. For the patient – face to face could be very stressful which could bring on forgetfulness, getting tongue tied, mind going blank etc. If loaded questions are being fired at you, it would be quite easy to answer incorrectly. Enabling the patient to bring someone with them might alleviate this. For patients such as I quoted for exemption – no face to face formal interviews should be needed. Perhaps an informal visit at home at a later stage, just to get a grounding knowledge would be appropriate.*</p> <p>QUESTION 12. Reviews should be established with the nature of the disability and illness. For example a bad back should be reviewed on a</p> | The Benefit        | Who can apply | How to apply | What happens next* | Description | Bullet points | Bullet points | Bullet points* |
| The Benefit       | Who can apply | How to apply  | What happens next* |               |              |                    |             |               |               |                |
| Description       | Bullet points | Bullet points   | Bullet points*     |               |              |                    |             |               |               |                |

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|                   |               | <p>monthly basis perhaps. Something that will mend or ease should be reviewed frequently.*</p> <p>Illnesses such as Parkinson's should only be reviewed annually on an update basis only.*</p> <p>QUESTION 13. Send a letter out asking for any changes to be described. Exceptions to the benefit could be asked for only significant changes as you are likely to be hit with lots of paper if you ask for all changes to be described. Also write to GP's asking for a general update. Then keep a good diary system.*</p> <p>QUESTION 14 – linked to q18*</p> <p>QUESTION 15 – If the disability can be reversed by use of advice and support, it is a good idea to make it a requirement.*</p> <p>QUESTION 16 – If the one off payment was available in addition to normal weekly payment – to assist in adaptation or an aid – this would clearly be beneficial.*</p> <p>QUESTION 17 – No answer*</p> <p>QUESTION 18 – Upon the granting of the benefit – once again a leaflet simply listing groups/benefits along with what they provide and contact details would be enough. Too many leaflets can be overwhelming and likely not to be looked at.*</p> <p>QUESTION 19 – serious implications. Being able to use the DLA on a mobility car is essential for many people.*</p> <p>QUESTION 20 In an ideal world, sharing information between various organisations is a good idea. However, I believe the disabled person would have to see sight of what information was being held before allowing it to be shared. Sometimes appointments with the medical profession can have unhappy outcomes and these could be detrimental to the claimant.*</p> <p>QUESTION 21 The impact of the policy will depend on the government getting its facts right about illnesses and disabilities. *</p> <p>QUESTION 22 Quote "This is our opportunity to improve the support for disabled people and better enable them to lead full, active and independent lives. Personal Independence Payment will maintain the key principles of DLA, providing cash support to help overcome the barriers which prevent disabled people from participating fully in everyday life, but it will be delivered in a fairer, more consistent and sustainable manner. *</p> <p>Please get it right! Remove the fear that lies in many genuine ill people that benefits are going to be removed – that you truly are going to support us to lead active lives – as much as possible.</p> |
| EM314             | 03-Feb-11     | <p>I am responding as an individual. I work part time. I am an adult in the most vulnerable group. My disability which is Cerebral Palsy will not get better and will probably get worse due to a lack of mobility, problems with my circulation and the natural effects of the aging process. I am 38 years old. I have an indefinite award for the high rate care and mobility component. I am a full time wheelchair user who requires full time personal care. My monetary needs due to my disability have not changed and have indeed increased due to a substantial rise in the cost of living. So how can the change in benefit possibly benefit me – as in reality I need more financial support. - Not the same and certainly not less.</p>   |
| EM315             | 03-Feb-11     | <p>My responses are not to specific questions that the Minister of state requires as they are not relevant to all who receive DLA. Once again, Government is ignoring those with long term, incurable neurological conditions in its endeavours. The same applied in DWP documentation recently in the reassessment for incapacity benefit.*</p> <p>Whereas it is fully understood that there are many who receive DLA for a period but their conditions improve, there is a significant community within the UK who are not "terminally" ill but who have conditions from which they will never recover and will, indeed, deteriorate over time.*</p> <p>There are several neurological conditions to which this applies but I write specifically about Multiple Sclerosis.*</p> <p>The National Health Service has improved its means of diagnosis over the</p>  |

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|                   |               | <p>last few decades but there has been limited success in inhibiting the symptoms of the disease and in slowing its progress over time. There is no known cure. Equally, no-one ever has Multiple Sclerosis as cause of death on the Death Certificate because we die of other causes or complications.* We are diagnosed at any point in our lives from our twenties onwards. There are an unlucky few diagnosed in their early years and before they turn twenty but the vast majority are diagnosed in their late twenties or thirties. These are facts already clearly known and understood by the Neurological community and you will have been informed of this by the MS Society. No two people have the same MS due to the complexity of the central nervous system. All we have in common are the lesions in our brains, optic nerves and spinal cords. Symptoms range from fatigue, a condition not understood outside of the Neurological community, impaired vision, neuropathic pain, cognitive issues, numbness and loss of normal use of limbs. Anyone with MS can have one, some or all of these symptoms. Because the disease starts in most people as a relapse-remitting disease there are periods of incapacity followed by periods of recovery. The intervals between these episodes and their severity is unpredictable but the effects of a relapse are often debilitating, depressing and incapacitating. With aging, the recovery becomes a slower process and disability often increases slowly over time and becomes irreversible. There are those who start with the progressive form of the disease and their decline is tragic to watch. But none of us die from MS. Thus by your definition it is not a terminal illness. It is, however, a life sentence.*</p> <p>We have been diagnosed by highly trained and skilled Neurologists. We are cared for by MS Nurses in areas where we have won the postcode lottery and they have been appointed. Our GPs usually do the research necessary and manage us on the advice of our neurologists. and they fully understand our condition and how it affects our daily lives. These are all services that have been paid for by the National Health Service. The current plans for the replacement of DLA now presumes that these people need “checking up on”. This makes different interpretations concerning the integrity of this community possible. They are incompetent. They are corrupt. They are in collusion with their patients to make their condition appear worse than it actually is. Whereas in truth, none of these are likely.*</p> <p>There is not one person with MS who leaves work before they have to. There is not one person with MS who would not return to work if they could. We make bad employees after a certain point because we cannot guarantee from day to day or week to week or month to month when we will be fit for work. We can only fight our symptoms for so long and then we have to stop for our own safety, the safety of those around us and the integrity of the organisations in which we worked. *</p> <p>I was diagnosed in 1982 and ceased working in 2005 at the age of 57. I did not apply for DLA until my circumstance demanded that I needed additional support to exercise my right to as equal a life as possible as compared to fit and able people. If my DLA or its replacement are taken away I will not be able to lead any life at all. DLA pays for my cleaner as I am physically unable to clean my home. My Motability car is my lifeline to shops, friends and family. Without this I would be housebound as I my nearest bus stop is too far away for me to walk –yes, I can still walk short distances – getting taxis would be too expensive and train journeys are too tiring. I am one of in excess of 100,000 people in the UK with MS.*</p> <p>Your proposals are causing fear and despair within this community as we are incurable and live a life of uncertainty as the neurologists cannot predict with any certainty the progress of our disease and nor can they predict which symptoms it will cause. It is not their fault. The science is not sophisticated enough yet and, not being a headline grabber like cancer, research is underfunded as is support for us to live in the community. A madness is spending tens of thousands of pounds on a cancer patient to prolong life by up to 24 months but not paying a few thousand pounds to adapt someone's home to the level of disability they are most likely to suffer rather than the</p> |

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|                   |               | <p>level of disability they are suffering now. We can live for decades with this disease. It is for you to decide which gives the better value for money. Our families have the burden of worrying about us far longer than the family of someone with terminal cancer. The waste of money is palpable in this area because the care system is not "joined up".*</p> <p>My point is this that once we are diagnosed and once our neurologists have identified that we have gone beyond the tipping point, it is a waste of time and money to reassess us. To be fair to us you would have to assess us in the middle of a relapse and not during remission. I would be most unhappy to be assessed by anyone other than a consultant neurologist as I would not have any respect for the opinion of someone "medically qualified" whatever that may mean. I would rather the neurologists were involved in treating the diagnosed rather than checking up on each other.*</p> <p>The decision that needs to be taken concerning all with incurable long term neurological conditions is that we do not require reassessment as our conditions will never improve. Focus on the true abusers of the system. Retrain GPs and practice nurses to advise patients that they are no longer entitled to benefit and get them to inform DWP and local councils so that benefits are correctly reassessed according to the revised circumstances. Please stop attacking those of us truly in need. We are the most vulnerable in society that the Government has repeatedly promised to protect.</p>  |
| EM316             | 03-Feb-11     | <p>To whom it may concern I have read through the proposed DLA reform to abolish this and replace it with Personal Independence Payment.*</p> <p>I have a 17 year old son who is Autistic with severe learning difficulties and challenging behaviour. He has a lifelong learning disability and has been receiving DLA middle rate for care and lower rate for mobility since the age of 3 years old. *</p> <p>At first I had to complete the forms for re- assessment every 3 years ie 3, 6 and 9 years. After that I wrote to the DLA saying that this re-assessment was very distressing as it highlighted how severely disabled my child was compared with an able bodied child of the same age and that there was no significant improvement in my son. Fortunately, I was always able to get my Consultant Paediatrician to complete the section in the DLA forms when I attended the outpatients clinic. The DLA kindly wrote back to inform me that I did not need to fill out the forms every 3 years until he reached 16 years old. Obviously if there were any changes I had to inform them immediately. I have also completed the re-assessment at age 16 and my son still receives the same care and mobility rate.*</p> <p>I am extremely grateful for this payment as this pays for his respite and holiday play scheme which allows the rest of the family some valuable time to do other activities.*</p> <p>With the new PIP you say that when someone goes into residential care all payments will stop. Under the present DLA if my son attends residential college equivalent to residential care then the care component payment will cease but they will still be paid the mobility component. Also during the college holidays eg Easter, Christmas and Summer holidays the care component will be also paid for whole weeks during the holidays.*</p> <p>With the new scheme my son would lose out on these payments as we are hoping that he will attend a residential college from September 2012 for a duration of 3 years.*</p> <p>Under the new PIP scheme my son does not have the mental capacity to identity and report changes in his needs he would have to rely on care workers or parents to do this for him, he can not be liable if changes are not reported.*</p> <p>Reviewing awards under the new PIP scheme - this needs to be carried out by a health care professional which is very costly and time consuming. This should not be carried out over the telephone as the reviewer will not be able to physically see how a person's disability affects them on a daily basis when carrying out day to day tasks and personal care resulting in incorrect re-assessment and incorrect payment.*</p> <p>I agree with your criteria of long term disability - over 12 months as I have</p> |

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|                   |               | <p>been angered by recent articles concerning people falsely claiming DLA - they are physically able to run marathons and work on building sites when they are suppose to unable to walk very far.*</p> <p>This new scheme must protect the true disabled person. Unfortunately, my son's needs are substantial he will never be able to work or live independently and he will be reliant on money from the state to help him lead a fulfilling and happy life, please protect these vulnerable people. My son will outlive me and I will not be there to make sure his needs are being met.</p>   |
| EM317             | 04-Feb-11     | <p>Dear Sir/Madam, My son is severely Autistic. I have read the full consultation with interest and like so many government changes the 'devil is always in the detail'. Having fought long and hard for my son I can say with total truth than I have never found any one in the Scottish Government, Permanent Civil Servants, Council (Education, Social Services, Housing, etc), NHS (Fife), MP's( Gordon Brown is my son's MP), MSP (numerous), Councillors, etc who understand Autism let alone understand their complex needs. Indeed just 2 weeks ago the Scottish Parliament blocked new laws for People With Autism.*</p> <p>So forgive me if I express some basic fears and required safety net guarantees that need to be confirmed for People With Autism and certainly those with severe Autism in the case of my son.*</p> <p>I have pasted in below from Annex 1 of the consultation document those conditions that will be subject to automatic award. *</p> <p>=====*</p> <p>Table 3 Conditions and impairments which currently lead to an automatic award of DLA*</p> <p>Condition/Impairment: Severely mentally impaired*</p> <p>Description: Severe behavioural problems which require help day and night*</p> <p>Award: DLA higher rate mobility component*</p> <p>=*</p> <p>Comments*</p> <p>Autism is a developmental disorder. It is neither a mental health nor learning difficulty impairment but carries with it many of the problems associated with these 2 conditions. So will Autism have a new/separate category under your changes?*</p> <p>My son has always been on higher rate DLA with full mobility component. In the beginning it took me many hundreds of hours of communication with DWP Blackpool to get them to accept that my son had severe impairment with all of his senses. In that he 'did not see with meaning', 'he did not walk with meaning', 'he did not smell with meaning', 'he did not hear with meaning', 'he did not touch with meaning', for the very little speech he has 'he didn't speak with meaning'. In reality to the incompetents I have listed above and as far as they were concerned he, from a distance, done all of them ok. But to the expert he was effectively blind, deaf, dumb, physically walked and run (but due to incompetent care in Gordon Brown's Constituency a person with Autism ran straight on to the Dundee to Kirkcaldy railway line and straight into the path of a fast moving train and was killed. Note that the local papers, procurator fiscal and other bodies covered up the unnecessary killing of this young man) and suffers from severe behaviour and lashing out if in the presence of a members of the public for what seems no reason. So because of the total incompetence and access to competent assessors in Autism what guarantees will you give that People With Autism will not continue to be mistreated, abused and now killed under your new system as they presently are under the Education , Health and Social Care System?*</p> <p>Presently my son loses 50% of his higher rate DLA Care component</p> |

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|                   |               | <p>because it is clawed back as he gets 'Independent Living Fund (ILF)'. Will the new system give him his much needed 50% back*</p> <p>Presently a bankrupt Fife Council (Gordon Brown's) expects close relatives of my son to provide an average of 15 hours free support (Council and ILF together only fund up to 9 hours every day, note my son's behaviours means he requires 2 to 1 care) to look after my son in his own accommodation. In addition my son is on Income Support but the bankrupt Fife Council also refuse to pay him Housing Benefit. This means we either have to put him into one of the Processing Homes (which we will never do, we will never let our son be systematically abused due to the incompetence as referenced above) or fund raise for him to allow him to stay in his own home. So will your new system start to provide for him. *</p> <p>I conclude by stating that I do understand the need for reform as within Gordon Brown's constituency we all know of hundreds of people that are healthy enough to do some work and who every week can be seen on all day and sometimes all night pub crawls. So let's hope your new system , as a minimum focuses on People With Autism.*</p> <p>I have copied in a small number of those on my distribution list (includes Gordon Brown, Alex Salmond, Nick Clegg, David Cameron , etc)</p>   |
| EM318             | 04-Feb-11     | <p>My response to the consultation on DLA reform is as follows - I am responding to the questions at Chapter 5 of the Consultation booklet as per the number order of the questions raised.*</p> <p>This response is separate from the group comments which are being submitted jointly by other HCDP welfare rights staff, but that in no way questions, or casts doubt, on the opinions of my colleagues there. It has simply been more convenient for me to prepare my response from home.*</p> <p>Q1 Transport difficulties, access to support agencies, knowledge of help available, care costs, heating costs, loss of self-esteem, inability to use aids and adaptations, adverse responses from potential employers.*</p> <p>Q2 The 3 levels of Care Component.*</p> <p>Q3 Transport, heating, special dietary needs, personal and domestic help/care, alternative therapies, cost of items not provided by the NHS.*</p> <p>Q4 I don't believe that having 2 rates of Care Component will ease either administration of DLA or claimants understanding of it. Nor would it be likely to provide adequate support for claimants whose main problem is preparing a meal suited to their needs.*</p> <p>Q5 Yes some conditions should continue to give automatic entitlement to DLA.*</p> <p>Q6 Prioritising the level of help and support needed can logically only be done in 2 ways. In the case of automatic entitlement claimants on the basis of medical knowledge and advice from the medical professionals involved. In other cases by expert assessment in the home by professionals - for example occupational therapists, doctors, social workers and counsellors.*</p> <p>Q7 By frequent review/assessments plus professional input as at Q6.*</p> <p>Q8 No. Existing users of aids and adaptations can still have difficulty using them, and this can vary day to day. Potential users have a human right to decline such help, or may feel that by using aids and adaptations they are admitting to their level of disability and losing their dignity.*</p> <p>Q9 The claim form has already been simplified with no apparent impact on it's ease of completion. The requirement to complete any form is difficult - often impossible - for some claimants. Given the level and type of individual assessment proposed for PIP is a claim form appropriate at all?*</p> <p>Promoting the benefit clearly to potential claimants can only be done by a very clear and ongoing/repeated high profile advertising campaign, plus ensuring that GPs and other health care professionals are fully conversant with PIP criteria.*</p> <p>Q10 Evidence will vary according to individual need. In many cases evidence from health care professionals. In a few cases evidence from employers may be helpful. But a large number of claimants have already exhausted the extent of medical and other care available to them. Evidence from carers may help when - and if - care is provided. Otherwise individual</p> |

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|                   |               | <p>assessments will be needed by DWP appointed professionals.*</p> <p>Q11 Any health care professional who is unknown to the claimant may be treated with suspicion and/or mistrust. People with disabilities are often unwilling - or find it very difficult - to discuss the full extent of their problems and need time to build trust with someone new to them.*</p> <p>Q12 Evidence and criteria used for setting the frequency of reviews can only be based on the level of claimant need and the nature of their disability. Clearly those with most needs should need only a cursory review, while claimants with less - or less apparent needs - will require more time.*</p> <p>Q13 Clarification of the requirement to notify changes in circumstances is essential, whether by ongoing advertising and/or a complete overhaul of the award notification so as to make it much more clearly understood. One obvious change would be to print the requirement in bold capitals on the award letter and place it before the actual detail of the award. Claimants cannot be assumed to have read beyond the most important part of any award letter.*</p> <p>Q14 Claimants need impartial advice from specialists who are independent of the DWP.*</p> <p>Q15 Yes - access to independent advice could go a long way towards reassuring potential claimants that they have an entitlement to make a claim, and that they are not seen as 'using' the system, which is a common misconception. Any such advice would need to be seen as completely independent of - and separate from - the DWP.*</p> <p>Q16 Currently only essential aids and adaptations are provided free by the NHS and Local Authorities. Grant aid is limited and claimants are often not aware of it anyway. Local Authority grants for adaptations are often subject to budgetary restraints, or do not cover costs in full. PIP could help to 'top up' any shortfalls or delays. Most importantly many people with disabilities are unaware of the range of aids available and require information. When they are aware they buy small items themselves, or take out high interest loans for expensive items such as stair lifts or mobility scooters. The current provision for funding mobility scooters through the Motability scheme does not seem to be widely known. The option to meet one off costs via PIP may help in many cases, but should always be an option - because any resulting reduction or cessation of PIP payments for a period of time could cause financial hardship.*</p> <p>Q17 As at present. The level of personal care and mobility needs as compared with a child without disabilities of the same age.*</p> <p>Q18 The main impact of DLA in accessing other help has been the Motability scheme, which is widely known. Also the 'Blue Badge' scheme along with bus passes and rail concessions.*</p> <p>Claimants seem generally less aware of the criteria and rules involving Carers and claims for Carers Allowance, and even less aware of passporting to Disability Premiums with IS and PC.*</p> <p>DWP staff should be best placed to advise fully on these entitlements and to ensure that they are put into place. Preferably automatically and without delays when appropriate.*</p> <p>Q19 Transport concessions, free prescriptions, parking concessions, provision of carers, access to dental/orthoptic/podiatry services, housing and council tax benefits, Income Support and Pension Credit, access to public amenities, swimming pools etc could all be affected and reduce the quality of life for people with disabilities.*</p> <p>Q20 I assume this question is aimed at the possible use of ATOS medical information, which is already sometimes used in establishing DLA criteria. I believe the current criteria for DLA and ESA are too diverse for them to be used in this way. It would of course be possible for ATOS to be used to assess DLA under appropriate criteria, but preferably in the home environment.*</p> <p>IIDB criteria are more closely linked to DLA but it is a low takeup benefit. The IIDB assessments however would seem to be more appropriate as a model.*</p> <p>Q21 Non native English speakers continue to have particular difficulty in</p> |



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|                   |               | <p>accessing DLA due to a lack of suitably qualified interpreters. Attention could also be given to any cultural reluctance to make claims, and to other cultural needs - for example the need to bathe before prayers and to kneel to pray etc.*</p> <p>Q22 Personally I believe that to implement PIP fully and fairly as per the proposals is likely to involve a great deal more cost than the existing system. There is also going to be a huge demand for help with the new PIP claim forms, and existing DLA claimants will need to see plenty of advance information and guidance. Also that any necessary involvement by NHS and Local Authorities in the assessment process, and in the provision of care needs identified, may be limited by their own budgetary restraints.</p>   |
| EM319             | 04-Feb-11     | <p>Dear Sir/Madam, I read with interest the public consultation for Disability Living allowance reform. I would like to respond to a number of the questions and points raised in the document. I realise that for the most efficient provision of the new benefit assessments will be have to take place, but I am concerned about the sensitivity of it and the appropriateness in cases of long-term disability. I think that the best person to do an assessment is someone familiar with the person such as a long term GP with an independent professional then checking this assessment. I am concerned that re-defining 'mobility' may give an inaccurate view of a person's abilities to get around as even if they have an electric wheelchair this does not necessarily mean they are mobile or able to get around.*</p> <p>What are the proposed provisions for those disabled or otherwise impaired for less than twelve months if the new requirement is to have long-term health condition for twelve months?*</p> <p>I am concerned about the possibility of the services provided by social services and care being passed on to public agencies, the private sector or taking advantage of the voluntary sector. Many thanks,</p>   |
| EM320             | 04-Feb-11     | <p>I have been in receipt of DLA since I was 65 and, at the time, found the assessment process, rejection, appeal, tribunal, appeal altogether an extraordinarily stressful experience despite my appeal finally being upheld. I am very dismayed to read that the Department of Work and Pensions is considering further assessment using new eligibility criteria for people like myself who had been awarded DLA indefinitely and are now past 'working' age.*</p> <p>I have, amongst other conditions, a progressive neurological condition which has been difficult to come to terms with but, greatly helped by the DLA benefit which I was awarded, I now have achieved a measure of independence which I cherish. As I said, it is with dismay, or perhaps trepidation, that I have learned that the DWP is 'considering' the situation of people like me who may have to face the whole stressful process for a second time and under different criteria. *</p> <p>I am quite sure that very many people, in similar circumstances, will feel aggrieved and disappointed or worse, resentful and suspicious, for there seems to be a sense of goalposts being shifted to accommodate targets. I do hope that it is possible to find a more appropriate response to this issue than that which many older and vulnerable people dread. Yours faithfully</p> |
| EM321             | 04-Feb-11     | <p>Hi I would like to respond to your consultation regarding dla I receive both components of dla and without them I would house bound I was born with cerebral palsy and Severe deformities to both my legs and complete urinary incontinence but I managed to work as a qualified nurse for people with learning difficulties until 2004 when I had 1 leg amputated and iam now suffering major problems with the other leg during the last 50 years I have had approximately 30 operations. My condition is now deteriorating so I am reliant on my car which I get from motability paid for my mobility component of my dla for without it I would be house bound and the care component helps with my personal needs ie my wife has to assist me in all my care needs which are severe ie bathing changing incontinence pads ect I am under the care of 4 hospitals and I have been told that my condition will only deteriorate I hope you will take my comments on board . Ps I am registered</p>  |

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|                   |               | physically disabled with the nhs and local authority and they have adapted my house and I have been assessed by a dr for my benefits Thank you for your time  |
| EM322             | 04-Feb-11     | <i>I have been looking at the proposed changes to the D.L.A to the new P.I.P and I am very concerned about the proposed changes. I agree that D.L.A was and is an abused benefit, however this abuse is both at public and government levels. I firmly believe that many people were encouraged to claim incapacity benefit to help massage the unemployment figures. This in turn then opened the door to claim D.L.A. I strongly object to this abuse, yet I am now going to find myself having to jump through hoops yet again to prove that I am a disabled person, how humiliating and embarrassing. As a disabled person with a lifelong and chronic condition that is not going to improve I have to prove on a regular basis that I am a disabled person which I find humiliating to say the least. Disabled people are just that, we are still people with feelings we don't want to be the way we are in constant pain etc. It appears to me that disabled people are being labelled as a huge drain and burden on the country's resources etc. There is such a thing as a genuine disabled person, and I object to being labelled as a scrounger when I have paid thousands in tax and N.I throughout my working my life. Some of the proposed changes and the way in which people are to assessed are just plain wrong. It's very easy to say "You are fit to work", but where is the work and who will employ you when you disclose that you have a disability? Whether you like it or not I will always be a disabled person.</i> |
| EM323             | 04-Feb-11     | Dear Sir/Madam. In my submission it would be wrong to require everyone in receipt of Disability Living Allowance [DLA] to apply for the new Personal Independence Payment. If anyone is receiving DLA for a condition such as Motor Neurone Disease, Multiple Sclerosis or Poliomyelitis for example it will waste money to put them through the assessment process again. If, however, any such person's condition deteriorated so as to qualify for more help a re-application could then be a reasonable requirement. Yours faithfully;  |
| EM324             | 04-Feb-11     | <p>I suffer with mental ill health and it varies from day to day how much or what I am able to do. I volunteer as I want to try to be as active in society as I can but there are often days I have to phone in and say that I am unable to go in. When I feel unsafe and have the voices telling me to self harm, I have to lie on my kitchen floor until my husband comes home in order to keep myself safe. I have tried to work but the stress causes me to self harm. *</p> <p>People with mental ill health are stigmatized and discriminated against in society and it makes it almost impossible to get a job that is flexible enough, and has sympathetic employers, that would allow me to work on the days that I feel well enough to go out. Voluntary work allows me to do what I can, when I can.*</p> <p>My DLA allows me to get the support I need most of the time and to put petrol in my car. It also allows me to have an independent income that I do not have to justify to my husband.*</p> <p>Please do not make the assessments so difficult for people like me to pass that we end up being socially isolated. Please ensure that the doctors and nurses who will be carrying out the assessments are fully trained in mental health difficulties so that we stand a fair chance of having a fair assessment that can take into account that mental ill health can vary dramatically from day to day.*</p>  |

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|                   |               | <p>Please do not discriminate against this vulnerable group of people of which I am one of many. We are not shirking or hiding behind our illnesses, if we could go out to work, we would.</p>  |
| EM325             | 04-Feb-11     | <p>Dear Sir/madam, I hope you will take my views into account during your consultation period which I understand ends on 14th of this month. I have been in receipt of Higher Rate Mobility since 2005 and of Middle Rate Care since 2009. This following an assault that left me crippled and eventually caused all manner of other issues as operations failed me and my condition worsened over the years. As with the ESA reforms I have viewed with no little trepidation the proposals to amend DLA. *</p> <p>DLA has been a lifeline for me these last few years, especially regards my mobility payments, indeed I couldn't have survived without it as my issues have deteriorated as regards my knees, hip and back - all stemming from a serious leg injury seven years ago I use my payments to get around and to pay friends and family etc to assist me on a daily basis, especially as I have issues with my bathing, toilet needs, dressing and getting to and from a sitting position. I also have to visit hospital on a regular basis and the payments help cover for this. The payments have been my only lifeline.*</p> <p>My particular concern is the area of the paper where it is hinted that some areas of the new WCA for ESA may overlap with the new PIP assesment.*</p> <p>Many of us feel, with good reason that this will simply be a measure to force thousands of obviously disabled people off the mobility component altogether under the guise of being able to use "reasonable" adaptations.*</p> <p>Whilst it is reasonable to take adaptations into account in the 21st century, merely having an adaptation does not always mean a disabled person doesn't still face substantial barriers to attain normal everyday living, even when using said adaptations. In short, the adaptation doesn't truly make them able bodied.*</p> <p>This is true of wheelchairs as well as users of crutches, sticks, zimmer frames etc, as these adaptations cannot always be utilised with ease or without difficulty or extreme discomfort, often due to multiple conditions. In the same way a person can use crutches or a stick or zimmer frame but may only be able to make little headway the same is often true of a wheelchair user. Does being able to use an adaptation in a limited way make that person truly able?*</p> <p>Even then, there are some days when that person may not even be able to venture out or cope with his/her daily needs at all - even with such adaptations so severe and fluctuating are some of their conditions. Many people I have spoken to are convinced the wheelchair is possibly being added merely to disbar large sections of the disabled population from eligibility. ( This is true whether you use one or you can be deemed able to use one).*</p> <p>.Taking account of a wheelchair as well as taking account of a walking stick or such aid could pose difficulties for many very disabled people in quite different ways. The stigma attached with being in a wheelchair is still a fearful thing. Though I don't use one myself I have witnessed the disabled hate crimes on buses and trains in the past, especially against wheelchair users and the abuse they have to face.*</p> <p>I think many people are worried that using a wheelchair ( or being deemed able to use one) would, under the new proposals render them able bodied in</p> |

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|                   |               | <p>the eyes of the law,( in essence if you are perceived as able to use a wheelchair then you aren't really disabled enough to be eligible to claim PIP - or indeed to be labelled disabled).In truth I feel most people believe that's where all this is heading.*</p> <p>That would have grave consequences for people who lose their mobility cars and even the free passes for public transport that go with them for those who are able to use buses and trains etc. I would like to see some protection for the people caught up in this and perhaps classed as "borderline".*</p> <p>For those wheelchair users, (real or imaginary) forced onto the unreliable and scary world of public transport, which in this country is frankly, third world in many areas outside of London I really do have concerns. Imagine if people in wheelchairs were not "officially" classed as disabled under the social model of disability? It is a world of hatred and simmering resentment as it is - I dread to think how drivers and public alike would react to wheelchair users then.*</p> <p>Another area I have had difficulty with is social care provision. For example I have been waiting for going on for three years now to have a disabled shower fitted,( though some of that period was disrupted as I moved from Cheshire to Lancashire and had to have the process swapped over). My care payments have helped me fund trips with a person to assist me with showering at the local leisure centre. If I didnt have these payments I wouldn't have been able to maintain even the basic hygiene whilst I wait for the local council to grant me some largesse for a shower. That's the reality for people ( and it was the reality even before the cuts and the recession).*</p> <p>Tampering with people's care payments by taking various adaptation even more into account will further endanger disabled people's ability to live normal lives as again, I reiterate the thrust of these reforms will be to exclude as many claimants as possible, rather than to truly modernise the system.*</p> <p>I could support some of these reforms if I thought they were compassionately thought out and had a modernisation ethos behind them. Instead, i fear they have at their heart the motive of pushing more and more disabled people onto the margins of the benefit or even off the benefit altogether.*</p> <p>As ever, I have to acknowledge that DLA is abused by many people and I have seen proof of this over the years as I have become involved with it. Whilst I applaud the weeding out of people who are simply swinging the lead, and perhaps the idea of more regular assesments and penalties for not reporting changes in condition ( though the latter already exists) are a good thing - my fear is that as usual, too many genuine cases will be caught up in this as the bar will simply be set too high. Infact ridiculously so, as it has been with ESA*</p> <p>I hope you will take my views into consideration and foge a modern but fair assesment for disabled people as this is an awful country to have to live in as it is without having what little support one has withdrawn..</p> |
| EM326             | 04-Feb-11     | <p>Dear Sir/Madam, Having read the consultation document I am concerned about the impact this may have on people with mental health conditions.*</p> <p>My 20 year old daughter suffers from depression and a diagnosed personality disorder. She is currently receiving Low Rate Mobility and High Rate Care. I also work in the community with people with a physical and sensory impairment, so I feel I have quite a good grasp on some of the issues people with all kinds of disabilities have.*</p> <p>Whilst I understand that some difficulties are "measurable", often with mental health issues that is more difficult. *</p> <p>My daughter has managed to work part time for the past year, but to do this, it takes huge amounts of support from me, both during the day and at night. She has periods when she can not work and days when I literally have to "take her to work". Here we are not talking about "aids and equipment"; we are talking about issues far more complex.*</p> <p>My daughter does not see this benefit as an "out of work" benefit, in fact her DLA and also her working tax credit (which she is entitled to as she has high rate care) enables her TO work and have some independence. She could</p>  |

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|                   |               | <p>not work full time (she has most of her difficulties at night and therefore gets very tired and anxious). If my daughter was not on HR Care and therefore not on working tax credit, I fear she would be more likely NOT to work as Income Support would provide her with money to merely stay at home.*</p> <p>So I urge the professionals working on this review to take into consideration, people with issues other than those which are physical. Yours faithfully</p>   |
| EM327             | 05-Feb-11     | <p>Hello, I am responding to the reform questionnaire as an individual multi-disabled person.*</p> <ol style="list-style-type: none"> <li>1. I am visually impaired, wear digital hearing aids and am a wheelchair user. Barriers: communication, transport, inaccessibility, lack of training, inequality, affordable specialist housing/buildings.*</li> <li>2. People with multiple disabilities should automatically receive a DLA.*</li> <li>3. telephone and other communications, electricity, transport, cleaning (ie dirt/damage), clothing, specialist equipment.*</li> <li>4. Having a higher and lower rate in each section won't necessarily mean things are easier to understand and could make things even more complex. Having a higher and lower variant rather than higher, middle and lower rates mean that it's possible some people that under the present tests might get benefit under the new system almost certainly would miss out and not get benefit at all!*</li> <li>5. If there were a two tier allowance with a higher and lower section, some illnesses and disabilities should automatically receive the lower rate in each section but an individual's needs and circumstances would be needed to see if they should be put on the higher rates.*</li> <li>6. Those that can do the least you assess * only once* and give them the full amount of the highest rates of both elements of PIP.*</li> </ol> <p>Being able to communicate effectively: ie verbally, written, by telephone, electronically. Mobility: walking (inside and out), using modes of public and private transport, going to a bank, building society, post office, shop, theatre, cinema, pub. finance: being able to count, use basic money. cooking and living household skills: making tea, coffee, warming up food, making a simple meal, making a bed, washing, ironing. hygiene: being able to get out of bed, go to the toilet, dress, fasten shoelaces, put on maycup. A set of marks would have to be devised for each element of the test/assessment and lowest marks would get the highest benefits.*</p> <ol style="list-style-type: none"> <li>7. Unless a person notices a difference in illness such as a qualified doctor or a person can be trusted and reports it, this is going to be very difficult if not impossible to police.*</li> <li>8. Again it could be very difficult here: for example, a blind person who uses a guide dog may be construed to have a perfect aid but other blind people who have guide dogs may not be competent and need additional help; another example, I, myself need to use a wheelchair but because I'm totally blind and have no perception of light nor darkness and also have hearing problems cannot use the wheelchair without someone's help so that aid shouldn't be a bar for me getting benefit but those who can see without any visual difficulty and can propel either a manual or electronic wheelchair should receive less benefit because they use that type of wheelchair. You say that people who can use a computer should receive less benefit but a deafblind person will need an expensive specialised computer costing thousands of pounds which would be their communications lifeline and this ought to be paid for by special benefit and the costs of repair. A specific amount of benefit ought to be put aside for essential upgrades. *</li> <li>9. The form should use short sharp succinct simple sentences with smaller</li> </ol> |

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|                   |               | <p>wording that everyone can understand - at present the sentences are long and wordy, words of twelve or more characters are used for jargon which the layman has never heard of so doesn't understand. Any explanation should be the next sentence, not at the end or beginning of a long form.*</p> <p>10. A GP or Consultant will know more about a person's condition or illness than anyone who *<br/>may be*<br/>a qualified healthcare person who is employed by The Government to test/assess and little if any importance should be put on that person's inability to have knowledge of any disabled person's ability or illness, especially in a person who has complex or rare illness/disability for example, I have Alstrom Syndrome and Forestier's Disease which have many complexes and illnesses and, after 10 minutes of typing/braille reading, my hands are so sore and painful it is impossible to do much for a long length of time.*</p> <p>11. Most people would never want an assessment in their own homes even if that meant a guide/assistant having to accompany them! People who are profoundly deaf, have a mental handicap, have language/speech problems or little intelligence should be spared an interview as then wouldn't understand any questions and it would be a waste of time and money as will be the case with assessments which the Government wants repeated time and again. *</p> <p>12. If a person's needs are greater than 40% then unless a qualified Consultant specialising in their condition/disability says they are less than 40% ill/disabled, only assessment/test should be conducted. All others should have a six monthly assessment/test by someone specifically qualified ie their GP supported by a Consultant.*</p> <p>13. Draconian punishments will deter people all the more from telling you their health/disability has improved especially when they are poor, in debt and the Government's time limits mean they will be put on lower benefits because for reasons not their own fault they can't get work in the too short one year time limit the Government has set to find work.*</p> <p>14. Most disabled people are helped and advised by specialists health advisors and disability charities who have the expertise and knowledge to know what advice and services are available and how to get them, but whatever these people advise, it should be Government in additional payments that should pay as an extra, not as a social service and not part of a benefit or a restriction put on a disabled/person with ill health!*</p> <p>15. No, this would only work if the benefit was means tested and those with say over 40,00 pounds of paid or saved income, regardless of their disability (unless then were ill), this could be discriminatory, unworkable and may be against Human Rights.*</p> <p>16. Affordable items are bought out of a person's own pocket as part of their benefit or savings, and more expensive items are given on the NHS such as wheelchairs and hearing aids or where charities have been able to raise enough money by fundraising which they find difficult or impossible especially with Government cutbacks. Disabled/ill people should *<br/>never*<br/>have to pay for aids/equipment and it is a blatant disgrace that Government seems to want to place disabled/ill people at the bottom of society and make them pay/suffer for their illness/condition - no other country in the world does anything as draconian as what this Government proposes and the quicker they are got rid of the better - we were and will always be better off with Labour!*</p> <p>17. The Carers Allowance shouldn't be altered in any way and if children are assessed for Special Educational Needs that should put them straight on to PEP without having to have another assessment other than checks if they were less than 40% ill/disabled.*</p> <p>18. Without my DLA I wouldn't get Housing Benefit, Council Tax Benefit, Income Support, and support from the utilities because I am disabled and in receipt of other benefits. *</p> |

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|                   |               | <p>19. Without all these benefits and the extra money they give me, I wouldn't be able to afford to manage or to have an independent life and this new PEP as I see it will take us back to the dark ages of 30 years ago when disabled people couldn't afford to go out of their own homes, afford to eat or afford to have essential heating, electricity and water and may not be able to afford leisure or activities either.*</p> <p>20. Totally different benefits mean totally different situations and duplicating information could lead to corrupting data, data illegally altered by someone and a living allowance being totally different to a support allowance and in no way should such information be used elsewhere!*</p> <p>21. Don't know and don't feel qualified to answer such a question as this.*</p> <p>22. No.</p>   |
| EM328             | 05-Feb-11     | <p>This is my response to the request for consultation re the Govt, proposed reforms to the DLA . I speak as a Person with Multiple Sclerosis ( PWMS ) Copied here is Specialist MS Nurse [REDACTED] and Branch Chair of the MS Society in [REDACTED] *</p> <p>I have taken a look at the Govt Doc " A Public Consultation DLA reform " issued Dec 2010 they are looking for feedback by 14th Feb.2011*</p> <p>Reads nicely, is warm and caring re ensuring people with Disabilities lead a full and active life. *</p> <p>Reiterates that the proposed Personal Independence Payment ( PIP ) to replace DLA remains a NOT means tested cash benefit which is independent of work . *</p> <p>Timescale for introduction of reassessing those currently claiming DLA is 2013/14*</p> <p>Reassessment will require that claimants are medically reassessed to ensure they are receiving the correct level of financial support ; there is a passing reference to awareness of fluctuating conditions . *</p> <p>The few MS friends I have asked how they feel about being medically examined are OK about it but see it as wasteful of resources . *</p> <p>Annex 1, Table 3, page 37 has a table showing those Impairments for which an automatic award of DLA is given as of April 2011. This is a fast-track to award of DLA and does not require further medical examination . *</p> <p>Further on in the consultation document at Page 39 in the glossary of terms there is the following definition :*</p> <p>Impairment Impairment is an injury, illness or a physical, sensory or cognitive condition for example being blind, having a learning difficulty, having restricted mobility or having multiple sclerosis*</p> <p>So while MS is defined as an Impairment its Diagnosis does not automatically lead to the award of DLA and presumably neither automatically to the award of PIP.*</p> <p>A Way of Streamlining this for the Govt and reducing the money spent on medical examination of PWMS who do have a fluctuating medical condition is for MS to appear at table 3 giving it as a Diagnosis which is automatically awarded DLA/PIP . Sincerely</p> |
| EM329             | 05-Feb-11     | <p>I wish to respond to one of the questions on this consultation and that is the question about aids and adaptations. I have quantitative information which you might find informative. Please feel free to contact me if you require further explanation.*</p> <p>Situation: My wife developed a severe form of MS just over 10 years ago. She became unable to walk and unable to dress/undress herself etc.*</p> <p>Adaptations &amp; Aids - One of the questions in the consultation is should the assessment take account of adaptations and aids. If the benefits of such item are taken into account in the assessment, then it is only fair that the costs are taken into account as well. Over the last 10 years, since my wife was first taken ill and started receiving DLA we have received a total of £60k, for which we are very grateful. However we have spent £120k on adaptations to house and garden and special equipment, including transport.</p>  |

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|                   |               | <p>We have had no government assistance towards the cost of these adaptations, other than the DLA.*</p> <p>Some of these items were capital expenditure which may not occur again in our lifetimes, e.g. adaptations to kitchen (£20k), some e.g. purchase of an adapted vehicle (£30k) will have to be repeated within 10 years but some are annual maintenance costs e.g. maintenance costs for hoist &amp; lift (£600).*</p> <p>So, by all means take account of the fact that my wife, who can't walk, could certainly not prepare a meal for us without aids and adaptations, can now prepare a meal for us. But note that she would not have been able to do so without the £20,000 we spent on a new kitchen, designed for a wheelchair user and the £5,000 we spent on an electric wheelchair. *</p> <p>With Best Wishes from</p>   |
| EM330             | 05-Feb-11     | <p>We have a daughter, [REDACTED], who is [REDACTED], and has a learning disability, Down's Syndrome. She is living in a residential care home in Devon, which is run by a charity. She has lived there since 2001, and is happy among the good friends she has made with the other residents. Down's Syndrome is a condition which does not improve, and [REDACTED] will unfortunately never be able to live independently. While we understand the need to simplify and clarify the existing benefits system, there are some areas in the proposed reform of Disability Living Allowance (DLA) and its replacement by the Personal Independence Payment (PIP) which have caused us, as [REDACTED] parents, concern.*</p> <p>The proposed face to face interviews with an "approved healthcare professional" may well not be appropriate for someone with Down's Syndrome, and could be counter productive. However well intentioned the interviewer, people with Down's Syndrome can easily become overawed, and will tend to give answers they think will please the interviewer rather than considered and accurate answers. They can also find it very difficult, sometimes impossible, to communicate with strangers, may not understand questions, and may become monosyllabic, avoiding eye contact, giving only yes or no answers. *</p> <p>There is it seems no guarantee that the person conducting the interview will be experienced in dealing with learning disabilities, or be aware of the need to consider evidence from sources such as carers and family members in order to understand fully the individual's needs. The impression is that this has been designed more with physical or medical disabilities in mind, and that learning disabilities, where the views from many different sources can be critical in assessing individual needs, have not been fully considered.*</p> <p>What support will be given to those with learning disabilities during the interview? As already stated above, people with Down's Syndrome can and often do become overawed in the presence of strangers, withdraw into themselves, and do not communicate intelligibly. They can all too easily feel threatened, putting their head down, ceasing to make eye contact, and if any answers are forthcoming they are likely to be monosyllabic. The support of someone familiar during the interview can help to create a more relaxed atmosphere, leading to a more constructive result. *</p> <p>Evidence to support applications for Personal Independence Payment will have to be produced. This can be difficult, time consuming, and costly. What advice will be available on the evidence which should be included, and what help in obtaining this evidence will be available to adults with learning disabilities?*</p> <p>It is proposed that benefits are reviewed regularly. While this might be desirable in the case of medical or physical disabilities, which might improve (or of course worsen), is it really appropriate or cost effective for adults with</p> |



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|                   |               | <p>permanent learning disabilities, whose abilities are unlikely to change for the better, and may decrease as they grow older? *</p> <p>It is proposed that the mobility element should be removed from those in residential care. This is in fact an extremely valuable component to those living in a rural residential care home, who need it to pay for transport to day services, which are not provided on site, and medical appointments, as well as for shopping and visits to recreational facilities. Public transport (which also has to be paid for) is not always available or appropriate.*</p> <p>At present those diagnosed with Down's Syndrome are automatically eligible for DLA. Down's Syndrome is a congenital condition which does not improve. Will it be cost effective to put those with this or similar conditions through what will inevitably be a time consuming and expensive interview and assessment process for PIP, which will simply confirm what is already known? *</p> <p>It seems invidious that babies with Down's Syndrome, a congenital condition, should have to go through a six-month qualifying period before they become eligible for PIP. *</p> <p>We would be grateful if you would consider the points above, and will take steps to ensure that the transition to PIP is achieved without stress or financial loss for those with a learning disability such as Down's Syndrome.*</p>   |
| EM331             | 05-Feb-11     | <p>I am a parent of a disabled child (autistic girl aged [REDACTED]) and have received DLA since my daughter was [REDACTED]. *</p> <p>I am also a trustee of [REDACTED] and have run [REDACTED] Forum for Parents of Children and Young People with Disabilities or Special Needs for the last 5 years. I also conduct regular market research for the London Borough of [REDACTED] on the needs of families with disabled children and adults. *</p> <p>The parent forum, has a membership of 250 families and we also work with around 50 carers of adults. I work on a day to day basis with parents and carers and meet well over 100 each year. I have been asked on many occasions to help families with their DLA forms and I occasionally discuss it with them, but we generally signpost parents to another charity for one to one support work including DLA applications (Local Authorities support this work because it is deemed to be bring money into the Borough and having a preventative effect).*</p> <p>I am responding to the consultation as an individual and not on behalf of [REDACTED] parent/carer members as a whole. My views are likely to differ from many other recipients of DLA. *</p> <p>The DLA form is long and complex. This complexity opens up the system to manipulation because the form can be filled in in a specific way to maximise benefit once a parent has expert help. On the other hand, people who cannot obtain this kind of advice will potentially lose out. I support the proposal that the application process should be simplified and standardised. The risk associated with a more standardised approach is that a small number of individual circumstances may not fit the criteria and some families will be at a disadvantage. I suggest that you allow some kind of appeal or special circumstances panel (or perhaps a discretionary element to be exercised by medical practitioners) to allow some flexibility if there is an unusual case. Care should be taken to avoid every case going to a special panel, of course.*</p> <p>The "passport" element means that people can be very determined to obtain the higher rate of mobility allowance, especially to access motability cars and blue badges. There is an incentive for people to manipulate the facts in order to cross this threshold. As above, a more objective test would be sensible</p> |

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|                   |               | <p>with particularly clear rules applied to the higher rate of mobility. This may also potentially alleviate the problem of disabled parking spaces being clogged up. *</p> <p>There are many occasions when a severely disabled person has to be driven home because there are no disabled parking spaces available at a large venue, but we see very able people getting into the cars parked there. Perhaps there is someone with arthritis (which comes and goes and limits them to a certain distance, or an autistic child who occasionally can sit down and refuse to move). There would seem some justification in having 2 tiers of blue badge or 2 tiers of disabled space. One could be spaces allocated to people so they don't have to look for a space but it could be at the edge of a car park, and the other could be specifically located to minimise travelling distance for severe mobility problems which cannot be overcome with aids and equipment.*</p> <p>Many parents have motability cars but still have their children picked up every day by taxi to be taken to a school outside the statutory walking distance. I suggest that once someone has a benefit which is for the transport needs of the disabled person, a duplicate benefit such as a home to school transport is removed – sort of a reverse passport (although there could be exceptional circumstances e.g. 2 disabled children, a disabled child and adult in the same household etc). The combination of loose regulation with regard to what higher rate mobility DLA may be used for and tight regulation with regard to eligibility for home to school transport results in an enormous cost to Local Authorities and therefore the taxpayer. *</p> <p>It is important and an excellent principle that this benefit is not an unemployment benefit and not means tested. I agree that this needs to be made clear so that people who are at a real disadvantage by having a disabled child/person are not afraid to make a claim.*</p> <p>There is no incentive at the moment to inform the benefits system of changes in a person's condition. However, they will reapply quickly if they feel there is additional benefit to be claimed. Your proposal that there are regular reviews is a good one. The only alternative would be that there are severe penalties for not reporting changes along with regular spot checks, and I expect people would prefer the review system.*</p> <p>I strongly suggest that there are categories of people for whom regular reviews and medical examinations are not necessary after it has been done once. These include children with PMLD (profound and multiple learning disabilities) and some severe learning disabilities. Where a child is born with a severe disability which means that they will definitely never walk, talk or be continent and sleep is always likely to be disrupted because of oxygen, medication or personal care needs, then I think sending this person for a regular medical review is unnecessary and unreasonable. A similar case may be made for certain types of adult onset conditions. Doctors should be able to identify these cases.*</p> <p>On the issue of residential care/schools you may wish to look at a number of specific cases which will be cited by people responding to this consultation. In many cases, this would indeed be duplicate benefit, but in others it may be critical to quality of life. For children, a 52 week placement should not include a mobility element as long as LAs are making sure that the placement is organising the appropriate number of outings and trips. For term time residential placements or weekly boarding, I suggest that if a parent is willing to organise their own child's transport to and from a residential placement, then the DLA mobility component may be used as a cheap way of incentivising this. If parents fall back on LA funded transport it would be much more costly. As in 3 above, some kind of link between these 2 things would be beneficial.*</p> <p>Automatic qualification for DLA is not appropriate. I agree with your proposal. For example, MS patients now have an almost normal life expectancy whereas it would have been considered a terminal condition 20 years ago. Many people diagnosed with MS do not experience any debilitating symptoms for 10 years or more. Once their condition does start to affect</p> |

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|                   |               | <p>them, the benefit should kick in. I know a number of MS sufferers who agree with this principle.*</p> <p>Reducing the levels of benefit to 2 instead of 3 is causing concern amongst claimants because they expect you to just remove the lowest level of benefit and cut these people off from claiming DLA. It would be sensible to have 2 levels but not to do it this way. It would be helpful if you could reassure families who genuinely qualify now, that they are likely to continue to qualify in the future and that the change will be gradual e.g. after a medical review has taken place.*</p> <p>Aiming the benefit to those who genuinely experience challenges due to their disability is sensible. Aids and equipment should be taken into account but this has to be done carefully. Someone may have a wheelchair as well as sticks at home, but not have a car adapted for a wheelchair because they tend to be OK on sticks outside the home as long as they have blue badge parking. If this person were to lose the higher rate of mobility AND their blue badge, it could potentially keep them in their home permanently (eventually resulting in deterioration, depressed and possibly a residential placement). Instead, they would need a one off grant for a wheelchair suitable for use outside, a ramp, a car adaptation plus a hoist in the car. This would indeed maximise their independence. It is a reasonable expectation that they use aids but not reasonable for them to pay for expensive adaptations.*</p> <p>How far will you take the logic in terms of aids and independence? For example, will you remove the mobility component from a child who has poor behaviour due to ADHD but who is not on Ritalin types of drugs which may reduce their challenging behaviours (perhaps through parental choice)?</p> <p>Might parents need to prove that they have attended training on nutrition, sleep and behaviour in order to show that challenging behaviour is a genuine condition and not triggered by life style? I do not have a good answer for this but do feel that the behaviour element is an area of potential exploitation of the benefit. Even if someone has no awareness of road safety, should this qualify them for a high level of benefit which will not be spent on any form of alleviation equipment or treatment, in effect just a gift? I would need to give this some more thought. *</p> <p>Where a person normally pays their DLA to a provider in order to get out and about e.g. outings from a care home, or the family rely on the DLA be able to go and visit someone in a residential setting, it must be handled carefully. There is some danger of reducing quality of life if these 2 situations are no longer possible. This could potentially be tragic. Again, an exceptional circumstances panel may be useful and perhaps some negotiation with care homes or family railcards instead of DLA being withdrawn per se. *</p> <p>On balance, I feel that this review of DLA is long overdue. The focus on impact rather than the medical model of disability is welcome. Simplification is welcome. Making sure it goes to those who need it is welcome.</p> <p>Exploitation of a benefit is sad to witness because money could be spent so much more usefully at the front line on people who require significant support. Please consider the home to school transport double benefit as a priority in this regard. I hope this has been helpful and please do not hesitate to contact me for further clarification.</p> |
| EM332             | 06-Feb-11     | <p>I am writing this as an individual who has a very severe health condition:- namely Asthma.*</p> <p>This debilitating illness has a severe impact on your daily routine from the minute you get up in the morning to the time you go to bed. When you get up in the morning you are suffering from a severe shortage of breath, having a shave, a shower and getting dressed can be a very tiring and exhausting daily routine. I have to get my wife to assist me with the above tasks as I get severely out of breath even attempting these daily tasks.*</p> <p>I am on daily medication ranging from inhalers, nebuliser, steroid inhalers, steroid tablets all of which attempt to bring my breathing to a standard that makes my daily living of a standard that at best can be described as only giving me temporary respite between each batch of medication. I am prone to many chest infections which will result in me having to take an antibiotic</p>  |

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|                   |               | <p>daily for long periods. Getting around daily and walking slowly can be a very tiring, and nerve wracking experience as you are constantly aware that an Asthma attack can come on rapidly leaving you struggling for breath.*</p> <p>I attend a Respiratory Clinic at my local hospital to see my consultant from times ranging from every month to every four months depending on my condition on the day of my appointment at the clinic, I have various tests including, measuring my sats level (blood oxygen) levels, my weight and a computerised lung capacity test, x ray when required. I then see the consultant at which time he discusses my condition, reviews my results and agrees any fine tuning of my medication.*</p> <p>What is common with this condition is that it does undermine your confidence seriously and has a major adverse effect on your confidence levels.*</p> <p>This alone makes me think that any sufferer with this condition would be very prone to having an Asthma Attack at the thought of having a medical by an independent doctor as the worry of having to not only go and see some new doctor to get assessed but the trauma of the travel. the parking and walking to such a meeting would have a very disturbing effect on the Asthma sufferers condition, is it not a more sensible approach to have a report sent to the decision maker by that persons Consultant especially if the condition will NOT IMPROVE AND INDEED BE ADVISED THAT IT WILL GET WORSE. The consultant has all the necessary medical evidence to support any medical evidence, more so than an independent doctor can provide and indeed the consultant would have a more accurate picture of the patients condition as the consultant is seeing the patient on a very regular basis. *</p> <p>This independent medical I feel could infringe in to a persons Human Rights and infringe into the Disability Discrimination Act. especially as the patient themselves know they have a condition that will never improve and indeed been told by their consultant it will get worse.*</p> <p>Surely there is strong evidence that Asthma is one condition that should be added to Annex 1 of this report. (Automatic Award of DLA), as this condition already does have under DLA rules an indefinite award status allocated to this condition if the papers seen by the decision makers from that patients consultant indicates that the condition is serious.*</p> <p>I thank you for allowing me to pass on my comments on this reform and look forward with interest at how this will be taken forward in the future reform of DLA.</p> |
| EM333             | 03-Feb-11     | <p>I live in constant pain, have great difficulty walking, cannot get a diagnosis to assist help improve my poor quality of life, receive minimum DLA which goes nowhere helping me access facilities that would * improve my health. I receive contribution based benefit so denied the financial assistance non contributing benefit receivers get. As a victim of a violent assault, government policy and procedures deny me * equal rights and assistance in many areas of my miserable existance and leaves me to suffer physically, financially and emotionally whilst attending their own needs and that of immigrants and criminals. Reform * is needed in house first!</p>  |
| EM334             | 06-Feb-11     | <p>Dear Sirs, I am an Occupational Therapist/Driver Assessor with over 26 years of experience and have frequently recommended this benefit to many of my clients who are eligible under the current criteria. The major problem I still feel with the current scheme is the cut off age limit which in the current scheme of things seems to be ageist. I appreciate the fact to raise the upper age limit would increase costs, but surely the eligibility criteria as the paper suggests could encompass some of this to allow people above the age of 65 with long term conditions to be able to claim PIP.*</p> <p>I welcome a review of this benefit but it must not lose sight of the tremendous benefit it gives to disabled people who would otherwise remain housebound or not be able to play a role within their family life or locality or work. Stricter criteria I do not feel is the way forward especially by only restricting it to long term conditions as other conditions have a massive</p>  |

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|                   |               | <p>impact on Mobility especially, this area needs to be considered carefully with any proposed change. Organisations such as Motability should certainly be consulted with regard to provision of vehicles and vehicle adaptations. It is important in an age where people are reliant upon motor vehicles that every opportunity should be offered to maximise their independence.*</p> <p>I hope these views are considered in the due process.</p>   |
| EM335             | 07-Feb-11     | <p>I would like to respond to the questions in review document, however I feel that it might be appropriate to include a short personal profile so that you might appreciate how I have responded.*</p> <p>I am aged [REDACTED] and receive the higher mobility allowance and the middle rate care component. I have lived with the effects of polio having contracted the disease at 20 months and although disabled I have worked continually until the age of [REDACTED] and did not claim until faced with increased health problems and being advised to retire from work in 2005. My award was made on an indefinite basis and it was on the strength of this award that I felt that I could proceed. I am therefore concerned that if the rules are changed and that I am reassessed that I could be financially disadvantaged.*</p> <p>It seems likely that there are other people that were made awards similarly on an indefinite basis and therefore there should be transitional arrangements for such claimants. A solution might be that claimants aged over 60 having been made awards on an indefinite basis should either continue on the old system and continue to receive the annual cost of living increases or change over automatically to the nearest point of the new scale provided that it is not less than the previous award. Please see attachment DLA Review which responds to the 22 set questions. Yours Sincerely</p>   |
| EM336             | 07-Feb-11     | <p>I found this document very interesting and hope it will go some way to providing the type of help and support needed by disabled people. My main concern is the cut-off age for this benefit and its successor, Personal Independence Payment. Presumably there has to be one but people do not stop socialising or working for that matter at age 65, with or without disabilities.*</p> <p>Twice I applied for DLA during the 21 years I have suffered from ME/Chronic Fatigue Syndrome and, irrespective of the severe pain, weakness and lack of stamina I have suffered ever since, I have had no help with this disabling condition. I have spent in excess of £15K over the years on various treatments and support for this illness without any government or health service support. Fortunately, when I left the Civil Service aged [REDACTED], I was able to obtain a part-time, supported employment which I enjoyed for 9 years until aged [REDACTED]. But apart from the usual appliances to assist in the workplace, there was no aid with transport. My car was paramount for working, not only because I could not use public transport, but because the office was a bit off the beaten track. Nevertheless I enjoyed the work scenario, giving me some independence and also a promotion to Office Manager and Company Secretary. There was little or no socialising done during this period outside the workplace because of the severity of the illness. But working gave me a great sense of worth and self esteem and my colleagues were both helpful and understanding of my situation.*</p> <p>Now in retirement, although awarded Incapacity for life, I am on State Retirement Pension. Presumably there is no record of my disability because of this so doubtless I do not appear in any statistics on that front. To date, my condition has not improved, regardless of the money spent, and I am much poorer financially than I would have been without the illness. This brings me to the point that I want to make and that is to be in receipt of a benefit to enhance my life but there are none available and that it would appear that all my contributions in my working life to the system have bypassed me. I have been very disadvantaged financially because of my illness.*</p> <p>I hope the government would consider this point. I understand with the</p> |

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|                   |               | <p>rising State Pension age this might be a consideration for the future. I hope these comments will give the government another slant on things. They are intended to be constructive and not destructive. I enjoyed a very fulfilling and productive working life in the Civil Service (Scottish Office) and look back with pride at my achievements there and maintain a very positive outlook on life.</p>   |
| EM337             | 07-Feb-11     | <p>I think that something should be done about some people who should not really get it, but then there is the genuine people who really need DLA. For example people who have cancer, walking difficulties and other types of illnesses.*</p> <p>Some people are worried that the genuine people who need DLA will have it taken of them and these people will struggle. Some people may have good days and then they may have bad days. It seems that the government just want to get people off DLA. Why is it always the disabled people seem to be made to pay for everything. Something should be done about immigration and not disabled people.</p>  |
| EM338             | 07-Feb-11     | <p>Q 1 Having a level playing field - ie adaption in classroom or workplace to allow disabled people the same access to as many facilities and education as possible.*</p> <p>Q2 For children, for terminally ill and people between 16-65 who are disabled - ie everyone who is eligible.*</p> <p>Q3 In my family we have had to buy special telephones which are significantly higher priced than normal phones in order that my son can talk to his family on the phone. We have had to buy adaptors and leads to allow him to plug in to watch movies on a plane like everyone else. We have had to buy special vibrating alarm clock to wake him up. Light fire alarms. My son is deaf. Money also goes to paying for transport and parking to frequent hospital appointments.*</p> <p>Q4 In theory sounds simpler but what if you fall between the 2 parts?*</p> <p>Q5 In current economic climate it should be based on the needs of person asking for the benefit.*</p> <p>Q6 Disabled people should have independence in the classroom and workplace. Adaptions should be made to allow them to be independent as much as possible. This may be technology, this may be physical changes e.g. carpeting, ramps etc*</p> <p>Q7 Have clear sign posts of how long benefit lasts and when you need to reapply but think permanent conditions should not need to reply time and time again. Only if a temporary disability should it be reassessed. e.g. if you are blind - you will always be blind until science finds a solution. but if you are wheelchair bound due to road accident for example but after months maybe years of physio etc you can walk again then you should not be getting benefit forever.*</p> <p>Q8 Absolutely need to consider aids and adaptions they use.e.g. radio aid, hearing aids, glasses, positioning in a classroom, sound proofing a room, ramps, a personal guide, interpreter etc. Need to also take future aids and adaptions - for example one a child is adult may require different aids and adaptions will change over time for their needs and also what is available.*</p> <p>Q9 Good case study type examples. Make it available to complete online with saving option so dont need to do it all in one sitting.*</p> <p>• How could we tell people about the new benefit so that they know what the benefit is for and who is likely to get the benefit? *</p> <p>By email, telephone, text, or letter - whatever the person requests*</p> <p>Q 10 Dependent on age and disability either the carer or the person them self.*</p> <p>Q 11 Added stress to person or carer - have to prove to they are disabled. If terminal illness no need for face to face contact or if child.*</p> <p>Q 12 Level of information provided - type of disability and its permanency or not. Absolutely needs of person and condition should be taken into account.*</p> <p>Q 13 Make it easy for them to provide with updates in same way do with tax</p> |

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|                   |               | <p>credits system at moment.*</p> <p>Q 14 Yes pointing people to other that can help would be useful and safe time and worry for many.*</p> <p>Q 15 Depends on age and disability - not one size fits all. If children then some devices provided free of charge by health service or education service. Others are paid by parents or funding bodies. As I say not one size fits all.*</p> <p>Q 16 It would seem obvious that things will change more for a child into adulthood and what they require as they leave home etc, in ways of adaption and aids.*</p> <p>Q 17 Think in some cases this is ok - not everyone needs a blue badge but they do need DLA to help with extra adaption or aids etc. Again back to there is not one size fits all.*</p> <p>Q 18 Medical details -the facts. So people dont have to tell this over and over again. Contact details etc.*</p> <p>Q 19 At present without details on new benefit can not comment on how it would affect things.*</p> <p>Q20 It should work for those who genuinely need it and not the scammers and scroungers who drain the system from the rest of us.</p>   |
| EM339             | 07-Feb-11     | <p>I'm [REDACTED], have multiple sclerosis, type 1 diabetes, ulcerative colitis and depression. However, that's not important and I do not wish to dwell on these facts.*</p> <p>However it is important as a result of the disability living allowance (DLA) review. I hope that this review will seek to distinguish between those with genuine disabilities and those with more suspect claims. However the review is being portrayed as coalition cuts that plan to clamp down on disabled people.*</p> <p>When faced with losing the benefits that enable me to function in a way that any other Britain takes for granted it is important. Not having financial security is scary, but not having financial security while not having the physical or mental capacity to meet my own basic needs is terrifying. *</p> <p>The guarantee of assistance to live and move leads to a sense of ability. It enables me to focus on the positive aspects of myself that are entirely separate from my disability. But when faced with having such assistance removed, I become increasingly focused on my own disability and weaknesses.*</p> <p>Disability benefits are an entitlement, and it remains as simple as that. I rarely use the word "disabled", because it's use is like admitting defeat to my condition. Perhaps this is strange, but to me, this is how it should be. I do not wish or need to be constantly reminded of my own vulnerability.*</p> <p>DLA assists me in feeling less disabled, allowing me to put myself back in that neutral position of having a near-to-everyday existence that rarely focuses on disability. When the state threatens my welfare, it makes me feel vulnerable. It forces me to list and dwell upon my weaknesses.*</p> <p>Faced with looming cuts, there are many people, myself included, who fear exclusion and isolation. It is horrific, and it needs to be voiced. There is something quite horrific in having to cling on to my sense of ability by focusing on my lack of it.*</p> <p>Nobody wants to be "disabled", we simply want to get on and live as a part of society. There is no irony lost that it is the DLA benefit that allows the disabled to do just that. Yours sincerely,</p> |
| EM340             | 07-Feb-11     | <p>Dear Sir/Madam, I wish to express my concerns about the proposed reform of the DLA system. My child has multiple and complex disabilities including 1) Autism Spectrum disorder affecting social, indepedence, communication, and organisational diffiucties, 2) Marfan Syndrome which results in severe eye problems and partial sight, structural heart problems which carry risk or aortal rupture (fatal), excesssive skeletal growth leading to physical and occupational therapy problems, 3) Speech and Language needs. *</p> <p>He currently receives DLA at the mid-rate for Care and the lower rate for Mobility. This support is invaluable to us and is used in the ways outlined below with estimated annual costs. *</p>  |

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|                   |               | <p>a) Transport Costs to and from medical appointments in London and Chertsey*</p> <ul style="list-style-type: none"> <li>- Moorfields Eye Hospital, London, 3 x per year by train and taxi/tube*</li> <li>- Royal Brompton Hospital, London, 1-2 x per year by train and taxi/tube*</li> <li>- St Peters Hospital, Chertsey, 2-3 x per year for Ophthalmology and Paediatric Cardiology by car*</li> </ul> <p>b) Nutrition and Supplementation*</p> <ul style="list-style-type: none"> <li>- Professionally advised nutritional supplement program essential to improving health and function*</li> <li>- High quality nutrition which is significantly more costly than standard food items*</li> </ul> <p>c) Recreational Activities Financing (many sports and pastimes are unsuitable so we focus on those he can do)*</p> <ul style="list-style-type: none"> <li>- Piano tuition, 30min lessons weekly during term time*</li> <li>- Physical activity training, weekly year round*</li> <li>- Bicycle, lightweight design and materials so more easily handled than most*</li> </ul> <p>d) Therapy Support from independent sources*</p> <ul style="list-style-type: none"> <li>- Relationship Development Intervention (RDI) program, ongoing by parents with biweekly consultant support*</li> <li>- HANDLE program, ongoing by parents with 6-weekly consultant support*</li> <li>- Homeopathic advice and provision*</li> </ul> <p>e) Educational Support from independent sources*</p> <ul style="list-style-type: none"> <li>- Kumon maths program, ongoing by parents with weekly consultant support*</li> </ul> <p>In addition to these costs we undertake a range of home-based support systems to help with progress at school and to help with independence, mobility, organisation and social skills development. These are a huge drain on time within the family and on the emotional health of everyone involved. Activities include:*</p> <p>i) Additional homework and support from parents to develop skills and confidence needed at school *</p> <ul style="list-style-type: none"> <li>- Touch typing practise to support visual impairment needs*</li> <li>- additional numeracy and literacy work to support progress at school*</li> </ul> <p>ii) Non-academic work and support*</p> <ul style="list-style-type: none"> <li>- RDI and HANDLE program activities daily to work on the many deficits of autism*</li> <li>- ongoing independence and behaviour development*</li> </ul> <p>iii) Secondary education preferences*</p> <ul style="list-style-type: none"> <li>- with such a complex case it will be a huge task to research and select an appropriate secondary education placement for my child, one which will be able to cope with his needs and will enable him to succeed educationally and socially. I have already visited 12 possible schools incurring considerable travel cost and time, and am likely to add to this greatly in the coming months.*</li> </ul> <p>The costs incurred in respect of these activities greatly exceeds the value of the DLA received (by two and a half times). Even with the addition of the Child Benefit for both my children it is still more than the costs we bear resulting from the disabilities and difficulties (by one and two-thirds times).*</p> <p>Proposed changes to both these systems (DLA and Child Benefit) put at risk the ability of families like ours to do the best for our children. I am fortunate in being articulate enough and emotionally strong enough to cope with most things. Many others are less fortunate than ourselves and will suffer much more as a result. The end result of inadequate provision in childhood and especially through the critical and much neglected transition to adult life will be a vastly increased cost to the public sector in later years which is a worse outcome for individuals with disability, their families and society as a whole.*</p> <p>I urge you to reconsider the proposed changes to both systems, and to consider the real impact on families who are so dependent on this support and the financial stability that comes with it to cope with the needs of their children and their disabilities.</p> |



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| EM341             | 07-Feb-11     | <p>I am writing in a private capacity as a registered carer (also in full-time work) for a close relative who is registered as a disabled person. I will take each of your questions in turn.*</p> <p>*</p> <p>1. This is a complex question. At one level there is a lack of accessibility to all sorts of buildings and venues (in spite of legislation). Then there is the issue of parking spaces for disabled people – and their regular abuse — and unsuitable meter machines located up inaccessible kerbs and car-park barriers that are hard to use if, e.g., you have arthritic arms and fingers. * Or it can be at a personal level: homes of relatives are not always disabled friendly and are not equipped with stair lifts, beds at the correct height, grab rails in toilets, walk-in showers, etc. *</p> <p>There is a wider issue that some disabled facilities do not meet the needs of all. *</p> <p>A further barrier appears to be the lack of willingness of the government to continue to fund DLA and Incapacity Benefit (IB) where appropriate.*</p> <p>2. Pretty much everything except the complexity of the form.*</p> <p>3. a. Aids around the house, e.g. kettle tippers, adapted cutlery, shower stools, orthopaedic chair, grab rails, raised toilet seats, jar openers, special clothing (Velcro).*</p> <p>b. Stair lift. This needs an annual service (with cover for breakdown) (currently £160). Parts are extra; in 2010 a battery needed replacing at a cost of over £100.*</p> <p>c. Podiatry felt. This needs to be purchased on a private basis and is surprisingly expensive.*</p> <p>d. Accommodation. Not all accommodation is disabled friendly (in spite of legislation). This often means having to stay at more expensive locations to get the disabled facilities.*</p> <p>e. Holidays. Accommodation for disabled visitors tends to be more expensive and not so much choice. (This relates to holidays in UK.)*</p> <p>4. I am not sure that a two rate system will address the range of disability. How severe a disability or impairment would you need to have to fall into the higher category? What about those with fluctuating (e.g. degenerative inflammatory) conditions?*</p> <p>5. There are some disabilities that are chronic, inflammatory and / or progressive, and affecting a number of joints (polyarthritic) and it seems to me that there would be a strong advantage in providing an automatic entitlement. In an ideal world a claim should be based on the needs of the individual, but a two tier proposal hardly allows for much tailoring to the individual.*</p> <p>6. The criteria of a long-term (or terminal etc.) disability appear to be appropriate. *</p> <p>There is more to life than getting up, washing, eating, and going back to bed. There is a need for disabled people to meet with others, socialise, have access to places of worship, and other suitable social activities whether or not they are 'fit to work'. *</p> <p>7. There can be better or worse phases for some disabilities. In other words there may not be a linear development. Can a two-tier system as proposed be flexible for a fluctuating medical condition? Would you require a certificate from a medical practitioner, GP or specialist?*</p> <p>8. Many aids have to be purchased and provided by the disabled person. Stairlifts, for example, cannot be transported to the home of a relative in order to stay the night and many do not receive council grants for these at home. Call-out contracts and maintenance are essential and costly.*</p> <p>9. Your forms assume that all disabilities are the same. They cause great anxiety and heartache in many who agonise over 'accurate' wording, especially in those whose conditions vary. The forms need to be more carefully nuanced. The present form does not take account of good days and bad days or spells. You also need to look at staff training so that they treat disabled people and their carers with a little more sensitivity and respect. *</p> |

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|                   |               | <p>10. A consultant or GP should be in a position to support an application but they do not always know their patients as in previous years. Carers are best placed to make a non-professional assessment of needs, perhaps backed up by a written note or signature from a health professional.*</p> <p>11. A 'healthcare professional' is very open-ended. Does it mean a doctor or nurse? Healthcare administrator? Would the HCP be appraised of a range of disabilities? Would this face-to-face discussion include a medical examination? Could the meeting be in the disabled person's home, please?*</p> <p>12. There needs to be recognition in the system that some chronic, progressive inflammatory and degenerative disabilities do not improve even if symptoms fluctuate. Reviews are stressful for disabled people (and their families) who already live very stressed lives. If a consultant only sees a patient once a year (due to NHS backlogs rather than patient needs which is our personal experience at a specialist national NHS hospital), it would be unhelpful to have a benefit review on a more regular basis.*</p> <p>13. You could use secure Web 2.0 facilities to improve information on the status of the individual. But of course disabled people (or their nominated representatives, e.g. carer, social worker, etc.) would need to have easy access to the internet in their own homes – and this assumes that they can afford usable equipment as well as have access to affordable highspeed broadband. (And changes to the benefit system may start to exclude disabled people on grounds of cost and accessibility.) Could disabled people or their registered carers be invited to complete a web-based questionnaire every three years?*</p> <p>14. It is quite difficult to know what support is available for disabled people especially at a time when the government is tightening reins. Government websites need to be better designed to provide access to information in an accessible format. E.g. about benefits, rights to social worker, advocacy, welfare rights, hospital choices, day centres, railcard, blue badge scheme. Welfare rights officers are only available via a social worker for those who have an 'open' file at time of need. *</p> <p>15. Disabled people are already trying to juggle the health system (trying to order medication, collect scripts, and obtain prescription often on weekly (plus) basis) that is time-consuming. This could add another layer of bureaucracy on people whose lives are already dominated by illness and disability. *</p> <p>16. a. Most aids and adaptations are normally self-funded these days. There is a reliance on benefits to pay for these (and what will happen when the proposed changes to incapacity benefit take effect?), or on family members to provide often expensive pieces of equipment.*</p> <p>b. Motability. This scheme makes a massive contribution to those disabled people who qualify giving them a level of independence whether they drive or are driven, especially as public transport and taxis are often so hard to access. *</p> <p>17. No strong view.*</p> <p>18. The following areas could be subject to 'passporting' arrangements:*</p> <p>a. Motability is a key support for living with a disability. *</p> <p>b. The Blue Badge scheme is also in part accessed through eligibility to DLA. *</p> <p>c. It would be far better if all registered disabled people were under a social worker all the time not only for what can be short 'open file' periods.*</p> <p>d. Disabled Person's Railcard.*</p> <p>19. The renewal (not initial application!) of the Blue Badge is now an 8 page form. A passport system would be extremely helpful. The Motability system is a key integrated package.*</p> <p>20. There is an issue here about the Freedom of Information Act.*</p> <p>21. *</p> <p>22. a. Executive summary (9): 'We know that some people's needs may change over time, and sometimes so gradually that the customer themselves won't notice'. We feel strongly that disabled people are not <i>customers</i> choosing products and services. They are an integral part of society. Such</p> |

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|                   |               | <p>wording is insulting and I suspect reflects a lack of sensitivity to disabled people. *</p> <p>b. Consultation period: a 12 week consultation period is recommended (6.3), yet 6 December 2010 to 14 February 2011 is only 10 weeks. This also spans the Christmas holiday period. The timing is therefore suspect.*</p> <p>c. Carers (38): carers who work full-time are often juggling home needs against those of work. Caring is a 24 hour-a-day, 7-day-a-week, 365 day-a-year responsibility. The proposed changes to the benefit system will only place further pressure on family (and unpaid) carers. Paid carers are not always an option. In our experience paid carers do not come until after 10 am to get the disabled person showered and ready for the day. This is very demoralizing for the disabled person.</p>   |
| EM342             | 07-Feb-11     | <p>My name is [REDACTED] and I'm [REDACTED] years of age and a disabled person for the past 7 years due to a spinal injury. Below I've answered the questions which related to myself.*</p> <ol style="list-style-type: none"> <li>1. Problems are first of all being Independent in the first place I.e as a wheelchair user being able to be Independent isn't easy due to levels off access to your destination such as local towns and toilets as access is always limited. The disability itself prevents a disabled person from living an Independent life as help from carers is required and help and support to get around.*</li> <li>2. I feel as a spinal injury disabled person sadly my condition will never change therefore my requirements for help with mobility and care will reason the same for the foreseeable future therefore I cannot understand the need to keep assessing individuals whose condition will remain the same such as mine.*</li> <li>3. Extra costs are in my case as a disabled person in a wheelchair I have a car supplied to me by the Motability therefore allowing me to get to a to b safely and also providing me with a lifeline to independence without the mobility car the independence would cease - costs involved would be if you have continence issues such as myself the costs can be dramatic in the care component . *</li> <li>4. The new levels of benefit makes sense . *</li> <li>5. I feel as a spinal injury disabled person sadly my condition will never change therefore my requirements for help with mobility and care will reason the same for the foreseeable future therefore I cannot understand the need to keep assessing individuals whose condition will remain the same such as mine.*</li> <li>6. Being able to remain Independent which you cannot put a price on and is invaluable In my case being able to get around which means I use my Motability car for this as I cannot use a bus or train as a wheelchair user therefore the Motability car is invaluable to my everyday needs and is a lifeline to provide me with the independence and to remain part of society . *</li> <li>7. Keep in touch with gp's Keep in touch with claimants GP's after all they know the claimants better than anyone else.*</li> <li>8. I am a wheelchair user I only go out to the real world with the use of my Motability car as mentioned before as a wheelchair user I'm unable to use a bus or a train now when I do go outside I always have a minimum of one person with me to help me to get in and out of the car and into my wheelchair safely which has to be dismantled and then reassembled so an able bodied individual is required yes it's the 21st century but attempting to go out and about in a wheelchair is difficult and can be dangerous if your on your own . *</li> <li>9. Help could be offered by the dwp to assist with firm filling.*</li> <li>10. GP or consultant at hospital as they will know the individual really well *</li> <li>11. It will be difficult to discuss the problems you face on a daily basis which can be embarrassing and demoralising *</li> <li>12. As mentioned before if your a spinal injury disabled person then there would no need for reviews or reassessments as the disability would always remain the same.*</li> </ol> |

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|                   |               | <p>13. By advising of the penalties involved . *</p> <p>14. N/a*</p> <p>15. N/a*</p> <p>16. In my case I use adaptations hand controls to drive my car which are funded by the Motability scheme.*</p> <p>17. N/a*</p> <p>18. I'm my case I use my mobility payment to lease a Motability which is my access and lufelibe to the outside world and keeping me Independant and part of society without this I would be confined to my home and distanced from the outside world . *</p> <p>19. Again lack of independence and lack of communication with the outside world . *</p> <p>20. Sharing info with all government bodies . *</p> <p>21. N/a*</p> <p>22 Since being told in 2004 that I would never walk again I kinda understandably gave up hope for life past being in a wheelchair I then was told about the Motability scheme which provided disabled people with vehicles to enable them to get out and about safely. I did not give up hope and learnt to drive whilst in a wheelchair and passed my test enabling me to obtain a vehicle through the Motability scheme which had enabled me to have independence and be part of society I have secured part time employment which I can only achieve through the use of the Motability car - therefore pay my taxes and way in the world - take the car away from me I will lose my job have zero independence and be confined to my home and excluded from the outside world this is a FACT!!</p>  |
| EM343             | 08-Feb-11     | <p>Question 1 Money, lack of good careers, access to buildings, access to information*</p> <p>Question 2 All of it. I need mobility to get about, if not then i dont go out, then I cant work and cant be part of a functioning society. I then put nothing back into it. Care suplements the amount I get in direct payments which arent enough to cover the actual care I need*</p> <p>Question 3 Cost of car as automatics are more expensive than manual. Medication, washing, mobility aids, clothes, more fuel as others walk, printer costs, transport to and from medical appointments, more expensive public transport due to only being able to access certain types of transport, cost of PA transport and tickets to things. *</p> <p>Question 4 If i am getting the same amount and the forms are more transparent then I have no issues. *</p> <p>Question 5 I think that some conditions should automatically qualify, for example if you have a completely severed spinal cord it isnt going to get better. Some other conditions like MS or MND only get worse with time and not better*</p> <p>Question 6 The ability to get about, my car and my chair, The ability to choose when i want to do things and what i want to do.*</p> <p>Question 7 For most people it takes so long to get DLA that if they were going to get better they would have done so by the time DLA comes through. For a majority of people their condition is only likely to get worse. For some conditions this questions isnt viable unless you want an hour by hour update on how my CFS/ME is doing that hour as it changes hourly*</p> <p>Question 8 No. This is a disincentive to anyone to better their lives, for example it has taken me 2 years to learn how to use my wheelchair so I am now able to get about there for you wouldnt help me at all, If i hacnt bothered I would get help. and just because I can get about in my wheelchair = no help which then means no motability car, so then I cant get about more than 200m from my house so then I cant work so there is no point in getting about. Also the fact that I can use a wheelchair without help is due to the fact that I brought myself a lightweight active chair, if i hadnt and was still in my NHS chair then I couldnt get about in it.*</p> <p>What aids and adaptations should we take into account? maybe things like braille labels on jars if they mean someone can do something without any help or maybe a long handled bath brush so you can wash without help, but</p> |

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|                   |               | <p>only minor aids*</p> <p>Should we only take aids and adaptations into account if the person already uses them? Or should we take aids and adaptations into account that a person could use and get hold of easily? Are you going to supply the aids someone might need. For example if you funded my £4500 wheelchair then I wouldnt need as many hours PA care*</p> <p>Question 9 • How could ... easier to fill in? Dont ask the same question more than once to catch people out*</p> <p>• How could we tell people about the new benefit ... to get the benefit? I assume you are going to send us all paperwork*</p> <p>Question 10 This depends on your parameters for assessing the benefit*</p> <p>Question 11 Who are you going to ask? My GP only sees me when I am really ill and has no idea what I do the 360 other days of the year. PA / careers come and go weekly, you could ask my mum but she would have read the form and say what is on it etc. So either you talk to someone who knows nothing about you or someone who is bias Is there any time when it would not be right to say that a person had to meet an independent person face to face, either in the person's own home or somewhere else? Yes, if the form has enough info to make a decision why waste time and money asking the same questions again*</p> <p>Question 12 If the person has a permanent condition then award it indefinitely like DLA is. *</p> <p>Should the way we look at a claim again depend on the needs of the person and their health condition or disability? I dont understand this question ....*</p> <p>Question 13 Send out a form once a year to sign stating any changes, or tick the no change box*</p> <p>What types of help and advice are people who will ask for the new benefit likely to need? A clear explanation about how this complete review is going to save money without cutting benefit money*</p> <p>Would it help if we told people to get help and advice and where to get it from? No*</p> <p>Question 15 with difficulty. I save up for a long time until i am able to afford things.*</p> <p>Should disabled people be allowed to use the new benefit to pay for a one-off cost? no*</p> <p>Question 16 Children are still developing so you would expect changes therefore you should ask more often*</p> <p>Question 17 It is vital, DLA allows you to access blue badges, motability, direct payments, disabled rail cards, various other cards that let your PA in for free etc*</p> <p>What can we do to make things better? Not change how motability works*</p> <p>At the moment people who get Disability Living Allowance automatically get help from other benefits and services, like the Blue Badge scheme and the Warm Front scheme. The warm front scheme is news to me!*</p> <p>What would it mean to disabled people if they did not automatically get help from these other benefits or services? More paperwork for the admin, therefore more costs for government, more stress for applicants, therefore worsening condition, more need to claim. Harder to track for the government if someone becomes better and then doesnt get one of the benefits it would be easy for them the carry on collecting others.*</p> <p>Question 18 Nothing, I have data protection, for example I might tell the DLA people about incontinence as it is relevant. I wont put this on other forms like my blue badge application as its not relevant. Also one wrong piece of data then gets replicated to other agencies</p> |

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| EM344             | 08-Feb-11     | <p>I am answering the questions in relation to my personal situation. After leading a very active full life in work and hobbies, Pallindromic Rheumatism, Osteoarthritis and Cervical Spondylosis changed my life drastically. I receive full rate DLA.*</p> <p>What are the problems ....., full and active lives? *</p> <p>Logistics of getting there and being there *</p> <p>The cost*</p> <p>Getting help when they need it*</p> <p>Lack of understanding and being treated with respect*</p> <p>Lack of affordable amenities locally*</p> <p>Is there anything else .... stay the same? *</p> <p>Yes most of it, why rebrand a perfectly good scheme which will take quite a lot of money to do? *</p> <p>All that needs changing is the ATOS part. *</p> <p>I agree everyone should have a medical interview but there must be consideration given to reports/notes from the claimant's consultant, GP, physiotherapist and others.*</p> <p>What are the main extra costs ... face? *</p> <p>Fuel as I cannot walk very far, cannot stand at bus stops or go up steps to local train station; *</p> <p>heating costs as need to be kept warm all the time (£126 last month)*</p> <p>gardener as cannot cut own grass &amp; hedges or get down to weed; *</p> <p>odd-jobs as can no longer do much DIY; cleaning windows, washing the car; cleaning the house*</p> <p>physiotherapy as NHS say have had "my quota" for 3 years (£37 per session sometimes once or twice a week to keep in employment); *</p> <p>prescription charges (on restricted drugs so cannot have more than 1 months supply);*</p> <p>specialist gym membership (£300 per year)*</p> <p>equipment e.g. mobility scooter, ramps (need stair chair but cannot afford) *</p> <p>grocery and other deliveries (when too much pain to go to shops)*</p> <p>dog walking or swimming (when weather bad I don't go out but my dog should)*</p> <p>The new benefit .....</p> <ul style="list-style-type: none"> <li>• Will having two rates per component make the benefit easier to understand and administer, *</li> </ul> <p>while ensuring appropriate levels of support? No*</p> <ul style="list-style-type: none"> <li>• What, if any, disadvantages or problems could having two rates per component cause? *</li> </ul> <p>What about people on the middle rate now – will you downgrade or upgrade them? *</p> <p>There are many levels of disability.*</p> <p>The 11 possible combinations as they are should remain*</p> <p>Should some health ... of the individual applying? Leave as is.*</p> <p>How do we prioritise support .... active lives? By having cross agency references – why can't all the different departments "speak" to each other?*</p> <p>Which activities are most essential for everyday life?*</p> <p>To lead as normal a life as possible *</p> <p>To be able to get out of house and socialise*</p> <p>Personal hygiene*</p> <p>To have good quality food and drink*</p> <p>Access to any medical care necessary and treatment available no matter what*</p> <p>How can we best ensure that the new assessment .... conditions?*</p> <p>Difficult question but I consider this is where medical consultants reports should be considered*</p> <p>Is the condition getting better permanently or is it likely to be progressively worse at each flare up?*</p> <p>If it is going to get progressively worse then I think the worst scenario should be accepted*</p> <p>Should the assessment ... aids and adaptations they use?*</p> |

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|                   |               | <p>No aids and adaptations should be included*</p> <p>Neither. Aids and adaptations do not make a person less disabled.*</p> <p>Take for example my mobility scooter. This allows me to go to events, take the dog out, go shopping but do you understand the logistics involved? I can't get it into the house; need a vehicle to transport it, ramps to get it in and out. Pavements have not been dropped so I have to turn around without falling into the road. You try and get one out in a supermarket or street car park.*</p> <p>I have trained my dog to retrieve things that I drop, pick up his bowl – would dogs be considered an aid? Can't get him to peel the veg, do the washing up or ironing etc. so there are still problems to overcome even though we might have an aid*</p> <p>I should walk using two sticks but my wrists and hands can be very painful. Would you say just because I could be provided with sticks that my benefits would be reduced? If so forget the sticks.*</p> <p>How could we improve the process of applying ... more positive experience? *</p> <p>Although the DLA form is long it does cover most things. There should be more people available to assist in form completion.*</p> <p>Keeping the diary of a week and writing everything down was quite an eye opener for me – I didn't realise how much my life was really affected until I filled it in. My friends were right.*</p> <p>Write information in plain English and list everything as bullet points. Keep it short though as most people usually only absorb the first page, glance at the second page and ignore the third.*</p> <p>What supporting evidence will help ... provide this?*</p> <p>Claimant*</p> <p>GP and/or Consultant *</p> <p>Therapists – physio, occupational*</p> <p>Social Worker*</p> <p>An important part of the new process ... a healthcare professional.*</p> <p>I personally have no problem with this as long as the healthcare professional is not on a bonus scheme for the number they refuse.*</p> <p>The healthcare professional must be knowledgeable, independent and impartial. It is important that the professional has specialist knowledge of the medical condition suffered by the applicant.*</p> <p>It would be easier for some people at home particularly if there is no easy parking close by.*</p> <p>How should the reviews be carried out? *</p> <p>Surely this will depend on the individual's medical condition. *</p> <p>Yes, there could be different types of review e.g. telephone or form to fill in*</p> <p>The system for .... to report changes in circumstances?*</p> <p>Have a graduated reduction – do not just stop it.*</p> <p>Mention that other benefits/agencies could help them.*</p> <p>What types of advice and information ... benefit claiming process?*</p> <p>I have done a lot of research myself and through my GP. Doing this gave me access to the Expert Patient Programme, [REDACTED] Health Trainers. It was important to me to continue working as best I could and to continue going to the events I love. I also needed some adventure, something to look forward to.*</p> <p>Claimants need full information of what is available to them in their district to help them overcome some obstacles. *</p> <p>I have never understood why everything has its own department and never shall two departments speak nor have information about each other.*</p> <p>Could some form of requirement ... not take action? If so, what would be the key features .... to be avoided?*</p> <p>I think everyone should have access to the Expert Patient Programme, physiotherapy and health trainers.*</p> <p>Everyone eligible for DLA should be able to access aids and adaptations advice – I was not eligible for anything as I was working.*</p> <p>Physiotherapy should be more available. There were so many people who</p> |

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|                   |               | <p>just did not turn up - there should be a charge for non attendance unless have a really good reason. Then people like me could go when necessary. It was physiotherapy that kept me able to work until I was made redundant in October.*</p> <p>How do disabled people currently ... to meet a one-off cost?*</p> <p>I have had to pay for everything myself *</p> <p>I would happily have used my DLA to pay for aids and adaptations if this option had been open to me – except the scooter as the motability ones were too expensive and not the kind I wanted.*</p> <p>What are the key differences that we should take into account when assessing children? *</p> <p>How important or useful ...or entitlements? Are there things we can do ... arrangements?*</p> <p>Firstly apart from getting information about Blue Badge and car tax I had to research everything else myself*</p> <p>The Blue Badge Scheme has saved my life (second to the scooter). It meant I could continue working. Being able to park close to work in an all day disabled bay was brilliant. It also really helps when I go shopping and go to events. I can also go on M6 Toll Road free.*</p> <p>The free car tax has also helped financially and meant I could keep my existing vehicle.*</p> <p>Motability is very useful although I decided to keep my existing automatic vehicle which could house the scooter.*</p> <p>My house has been insulated free of charge which has made a tremendous difference.*</p> <p>Information on bus passes, Ring &amp; Ride, train passes would have been useful*</p> <p>What would be the implications ... other benefits and services?*</p> <p>Disaster*</p> <p>Going back to the dark ages*</p> <p>What different assessments ... bureaucracy and duplication?*</p> <p>I cannot understand why the different departments do not work together. *</p> <p>Why do I have to go for an ESA medical and then a DLA medical?*</p> <p>What impact could ... considered in developing the policy? *</p> <p><i>“Proposals to replace DLA with a new benefit that is better focused on helping disabled people to lead independent lives provide an opportunity to promote equality of opportunity to those least likely to live full and active lives. It is likely that some disabled people with lesser barriers to leading independent lives will receive reduced support, but this has been justified by the policy aim to focus support on those with greatest needs.”*</i></p> <p>How are non disabled people going to know that this is going to work? DLA has given me help to lead a more normal life. How will the new benefit alter this? How can it be justified reducing support to those “who have lesser barriers”. Any barrier is just that. One day your body can be normal and the next it can create such barriers either physically or mentally no matter how lesser it might be in the eyes of someone who has never experienced long term disability. Please do not go down the road of “it works in theory (but ends up) not work in practise”.*</p> <p>Is there anything else ... public consultation? I repeat what I previously said – I cannot understand why there is a proposal to radically change the DLA system. As I understand it, it works well and has a low percentage fraud rate. Whatever is decided PLEASE GET IT RIGHT FIRST TIME. *</p> <p>I have no problem with my personal information being used for the purpose of this consultation.</p> |



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| EM345             | 08-Feb-11     | <p>I have been reading the proposals and I am very unhappy about the provisions. I do not get DLA so this is not personal.*</p> <p>1 This seems to me to be a money saving effort aimed at the most needy people in England. I know there are cheats, but surely the needy should not suffer because of liars. Put more money into the inspectorate so that the cheats are weeded out without affecting genuine people.*</p> <p>2. The assessment worries me. I have heard and I believe that the doctors who perform the assessments are paid for every person they get off the benefit. My daughter has ME and I KNOW when she is in a really bad phase. She is able to walk 100 yards, but she gets overstimulated by noise and light. This is certainly not all in the mind and she certainly could not work in a normal work environment. Instead of doctors who do not know the patient, why not get an assessment from their own doctor who has seen them at their best and at their worst? That would be a much fairer option than getting someone who is paid to say people are not disabled. My daughter had a very responsible job as an occupational health nurse until this dreaded thing hit her, and gets very frustrated at her inability to do things she used to find easy. If you live in close proximity to a person who is ill, you see the reality of it in a way that someone who walks in and out with the express purpose of getting that person off benefit can't comprehend. I also know that this threat is affecting her adversely as it is many others. The worry and stress are very detrimental.</p>   |
| EM346             | 08-Feb-11     | <p>Hello, I am Age Concern Gwent's Information Service Manager and regularly deal with applications to both Attendance Allowance and Disability Living Allowance. I have a few comments to make on the future of DLA.*</p> <p>Any genuine attempt to reform a system open to abuse has to be welcomed. However, in these tough financial times, it would be all too easy to see DLA reform as a cost cutting exercise – indeed there does seem to be something of a hostile attitude being taken to people “on benefits” nowadays – perhaps whipped up by some in the media, and this negative attitude is certainly not being countered by the Government to any great extent. *</p> <p>Any reforms to DLA must be fair and be seen to be fair. Of course, everyone seems to know “someone” who is on high rate mobility yet appears perfectly able to walk. I feel this aspect of DLA – the High Mobility award, in particular, does merit attention and should be subject to regular periodic review. *</p> <p>At Age Concern we regularly help people with completion of application forms for DLA and it is often evident that the only reason someone wants to claim is to boost their finances – they see DLA as a possible extra income source – not as money they can use to make their life easier (buying disability equipment etc). That said, I would not want DLA to become means tested, or not be available to those in employment.*</p> <p>I think that a closer check with the applicant's medical practitioners would be an obvious and desirable thing to include in the revised DLA (or P.I.P as I understand it will be called). Actually requiring a medical examination/interview in every case would, I suppose, be costly, but would serve to deter spurious applications. Similarly, reviews every five or ten years would be desirable, again involving some medical input and not just completion of a new form.*</p> <p>If resources allowed, I also think home visits by DCS staff would make the review process fairer. Deciding review applications simply on completion of new DLA forms does not give a true picture. As one of my colleagues said to me, <i>“We all know some people tell a better story than others”</i>. Also of course, advisers are often asked to help completing forms – and while we at Age Concern strive to be honest and accurate, I am sure some other advisers could view the form completion process as something of a challenge and might feel a failure if a claim was unsuccessful.*</p> <p>Whatever system is decided upon, I hope it will be clear and fair, with each application dealt with in the same way. That said, it is also important not to make the whole thing so daunting that it puts off genuine people from applying. I hope these comments are helpful.</p> |

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| EM347             | 08-Feb-11     | <p>Dear Sir, I am writing concerning the proposed reform there is to be made to the DLA which I receive at the highest level because I suffer with Primary Progressive MS, which was diagnosed in 1991 and has seen me reduced from a very active, sportsminded individual, to someone who now relies solely on a wheelchair for transport and a dedicated wife for care and support.*</p> <p>I managed to 'hold down' a part time job until April 09, but fatigue and inability to move, saw me retire to now be limited to getting around the house and local area in the wheelchair. Having the full amount DLA paid to me has been a tremendous help as of course I am now not earning and my wife has had to reduce her days at work to three, as she found that looking after me and doing a five day week, too much. With this reduction in income and the inherent cost's that come with being disabled, both regular and lump sum, having DLA has become a necessary component of our regular income.*</p> <p>When I was first offered DLA and subsequently as it was increased to the full amount, it stated that this would be a payment that would be there 'indefinitely'. How now do I stand with regard the proposed changes, are they likely to reduce the amount paid and is this legally possible? As you can see I am very much against any reduction or change in the current system, as the amount paid in DLA, forms an integral part of our overall income.</p>  |
| EM348             | 08-Feb-11     | <p>I submit these comments on your consultation document with long experience in two areas - the first as a Tribunal Judge of some 30 years's standing who has been dealing with DLA appeals since the introduction of the benefit and the second as a person with disabilities who has been in receipt of DLA since inception and before that Mobility Allowance. I would emphasise that these are my personal comments and not official "judicial" comments.*</p> <p><u>The background*</u></p> <p>The old Mobility Allowance was introduced to help people with disabilities get to and therefore be able to work. - *</p> <p>With the introduction of DLA the scope widened to include care - both components defined by statute, regulation and clarified/complicated by case law. *</p> <p>The higher rate mobility component is still for those who cannot walk or are virtually unable to do so. The lower rate is for someone who cannot walk in unfamiliar places without guidance or supervision from another. *</p> <p>The three care components concern the ability to make a main meal for the claimant him/herself, required attention from another in connection with bodily functions, supervision and watching over. *</p> <p>There are limited disabilities which lead to automatic awards*</p> <p><u>General provisions and applications*</u></p> <p>The current qualifying period is 3 months and consideration is to be given to extending it to 6 months. *</p> <p>The current minimum period of expected disability is 6 months. There is no logical reason to extend this and it would be illogical to reduce it. *</p> <p>At present a claimant can apply and be granted DLA for life or a limited period without any medical evidence whatsoever. This can result in a justifiable award or a completely unwarranted award. In the latter case this could be in respect of a completely honest claimant or a dishonest one. The system should be changed. Many incorrect awards could be avoided if medical evidence is a prerequisite. Many a time I have been completely bemused as to why an award has been granted without medical evidence or refused on renewal or supersession application without such evidence. I submit that:*</p> <p>there should be an automatic referral of claimants for a medical - preferably at their home. This is obviously going to cost more but should save in the long run on by eliminating both incorrect awards and possible appeals. *</p> <p>I caution on reliance on medical evidence from a claimant's GP. GPs can provide useful information on diagnosis and treatment but are notoriously unreliable on the practical effect of a claimant's illness or disability. Many just repeat what they have been told by the claimant rather than give an</p> |

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|                   |               | <p>objective view. *</p> <p>there is no reason why there should not be automatic awards as long as these are absolutely clear and backed by medical evidence provided by the claimant. It may not be necessary for a medical for automatic awards eg in the cases of the terminally ill or of the new provisions for the visually impaired *</p> <p>life awards should not be automatic but considered in cases in which it is patently medically obvious that there is unlikely to be any improvement - perhaps the medical examiner could be asked to express an opinion as to whether a claimant has a permanent illness or one where recovery/improvement is possible eg for a claimant waiting for a hip replacement or a claimant with chronic fatigue syndrome *</p> <p>time limited awards can be sensible but I caution against automatic limited awards - this would lead to increased and unnecessary expense and possible distress to the more seriously disabled. However, it is eminently sensible to limit awards to those claimants for whom recovery/improvement is possible and indeed for those who are far too young age to be "written off". Awards for children should always be limited. *</p> <p>The consultation refers to periodical reviews which appears to be the same as the current limited awards ie renewals. The only current "reviews" which are undertaken are those chosen at random or instigated by reports of false claims - both these should be retained.*</p> <p>I strongly recommend that in the majority of cases there should be an automatic referral of a claimant for a medical and that life awards should not be abolished but only made with caution*</p> <p>*</p> <p><u>The mobility component - higher rate*</u></p> <p>*</p> <p>"Unable to walk" is easy to check. "Virtually unable to walk" is more of a minefield BUT would not be such a minefield if there were an initial sifting by a medical. There is legislation, regulation and case law. It may be more of a minefield BUT it is hard to envisage any other way of coming to a sensible conclusion than continuing under the existing system. If a claimant is turned down at a medical then, as now, it is open to that claimant to appeal.</p> <p>Appeals do not relate to whether or not a claimant can work - work has nothing to do with it. Tribunals with legal, medical and disability members decide whether or not that initial opinion was right - this system works now and there is no reason why it should not continue to work.*</p> <p>*</p> <p>In the Detailed proposals for a new benefit at Paragraph 14 reference is made to definitions reflecting the views of disability in the 1990s not the modern day. Surely the words "unable to walk" and "virtually unable to walk" are as perfectly clear in the year 2011 as they were in the 1990s.</p> <p>There is no indication of what may be intended by a person's "ability to get around more generally" and a broader definition of mobility "in connection with everyday life". That concept is so vague that it is likely to give rise to far far more complications than exist under the current legislation.*</p> <p>At paragraph 27 in the same section there is reference to taking into account aids and adaptations in particular the fact that prosthetic limbs are taken into account but not wheelchairs. A prosthetic limb helps a person to walk but a wheelchair does not. Even if a claimant is able to walk with a prosthetic limb he/she may still be in the category of "virtually unable to walk". That would depend on the facts in each particular case. *</p> <p>If a person genuinely cannot walk or is virtually unable to walk then the fact that such a person uses a wheelchair outside [remember the walking test is outside not in the home] that should not exclude them from the mobility component. It is impossible to "wheel" ad infinitum. It would be ridiculous to suggest that if a claimant can "wheel" 50 metres to get to a car and then drive off to work or to Blackpool or wherever this excluded him from the mobility component. The expense of the necessity of a car or taxis is still there. The expense occurs because that claimant cannot walk to wherever</p> |

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|                   |               | <p>he or she wants to go or to catch a bus.*</p> <p>Should you try to change the current provisions for the higher rate of the mobility component to exclude claimants who are able to use a wheelchair this would be a disaster. You would be excluding the more positive claimants who do not sit back and do nothing but, with the help of DLA, get on with their lives. You would encourage the least positive claimants to sit at home and vegetate.*</p> <p>I recommend that you leave the higher rate of the mobility component alone. If you introduce medicals at the point of claim then this will sift out the unjustified awards which are made on paper.*</p> <p><i>[In this case I am not impartial. I can (just) get to my car walking with two sticks or holding onto my husband's arm and using one stick. The car is about 10 metres away from the back door. I am not in pain. My legs just do not work properly having had polio at the age of 15. I drive to court. I cannot walk into the court building and I cannot walk inside the court building. I use a wheelchair which the court clerks help me to get out of my car as I cannot get it out myself even although there is a hoist in the car. I cannot walk to shop - I drive to a local Shopmobility and a scooter is brought to the car for me. My car is my legs - with it I can get to work, with it I can get to shops, restaurants or whatever. It is my independence. My mobility allowance then DLA has always been used for a car and this has enabled me to work since I left school, be employed, employ others and accept a judicial appointment. If I use a wheelchair or a scooter to "walk" once I get to my destination I should not be penalised. *</i></p> <p><i>I will made every effort to fight for the retention of the higher rate on the same basis as it is now and I know that there are hundreds of others who are appalled by any suggestion that wheelchairs might be taken into account and will do the same.]*</i></p> <p><u>The care components*</u></p> <p>As in the case of the mobility component many unjustified care awards are made on paper. The introduction of medicals would minimise this.*</p> <p>The question of aids and adaptations is far more relevant to the care component. I suggest that the availability of the cheaper and more easily available awards could be taken into account. Eg it would not be unreasonable for a claimant to acquire (from the state or privately) a raised toilet seat should that obviate the need for another to help to go to the toilet. It would not, however, be reasonable to expect a claimant to make physical alterations to their accommodation to make a bathroom into a "wet" room so that they could shower using a shower chair instead of being in reasonable need of assistance to get in and out of a bath.*</p> <p><u>Conclusion*</u></p> <p>Don't make change for change's sake. DLA is not perfect but it works perfectly well if awarded correctly. Why spend millions re-jigging a benefit when millions could be saved by ensuring that medicals are used ab initio. There is no guarantee that PIP would be any better than DLA so leave it alone but tighten up the procedures</p> |
| EM349             | 08-Feb-11     | <p>Dear Mr. Moore, The Government is proposing to replace Disability Living Allowance (DLA) with Personal Independence Payment (PIP). This will be introduced 2013/14. I would like to respond to the public consultation particularly for those with a spinal cord injury and hope you could consider these views to help form your views on these changes?*</p> <p>The main potential changes are*</p> <p>There will be no automatic entitlement to PIP except for those with a terminal illness.*</p> <p>The two components of Mobility and Daily Living will each have two rates.*</p> <p>Applying for PIP will automatically mean being assessed by an independent medical examiner.*</p> <p>To be awarded PIP you will need to have had a Spinal Injury for six months.*</p>  |

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|                   |               | <p>Entitlement will stop after 28 days in hospital but the Consultation paper says that the Government will work with Motability to ensure that Motability agreements are supported.*</p> <p>Once in receipt of PIP you will be periodically reassessed.*</p> <p>*</p> <p>I have the following comments to make: *</p> <p>At present the mobility element of DLA will cease on admission to Residential Care.*</p> <p>1. Currently there are three rates for the care component of DLA. Moving to two rates for Mobility and Daily Living could mean a reduction towards the lower level with the previous Middle Rate being rounded down.*</p> <p>2. Spinal Cord Injured (SCI) are wary of an Independent assessment by a medical examiner as the SCI often has more knowledge of their condition than even their GP or Community Occupational Therapist*</p> <p>3. A paraplegic SCI can be discharged post accident within 4 months of injury and despite qualifying for PIP would have to wait a further 2 months before being able to apply. This could lead to problems meeting the person's care and housing needs.</p> <p>4. SCI are very dependent on cars supplied by Motability and it would be essential that PIP could support the hire or lease agreement should the person be hospitalized for more than 28 days. The Motability scheme is also used by some SCI to lease powered wheelchairs or scooters which can be vital in meeting their local mobility needs*</p> <p>5. SCI might not like to be reassessed periodically as it would serve as a reminder of their disability and a review of their static situation (since there is no cure for SCI) would seem pointless and in some respects hurtful.*</p> <p>6. The use of a wheelchair could be viewed as part of that person's ability rather than its essential use to get around. This is our interpretation of a very unclear statement.*</p> <p>This could mean that your needs would be assessed on your abilities in the wheelchair rather than the fact you need a wheelchair to undertake anything at all! Best Regards,</p> |
| EM350             | 08-Feb-11     | <p>I am very worried about the new PIP. I have had a letter telling me that the DLA I am on is for life. My needs have not changed so why do I have to go through a whole new assessment. It is a total waste of money and is alot more hassle for me.*</p> <p>I have enough barriers in my life anyway. I am worried that you are cutting down peoples rights to mobility allowance. I know alot of disabled people who are in work and other people who are not in work - cant work. It is wrong to make disabled people work if they cant.</p>   |
| EM351             | 09-Feb-11     | <p>Hi I read your message with regard to cuts in DLA with interest. I am unable to attend the meeting in Dundee but I would like to air my views with regard to DLA to you and hopefully they can be passed on to the relevant person.*</p> <p>· If your child is getting a full support package at school then s/he might lose their DLA payment; I would like to know who decides what a "full support package entails" I have 5 Deaf children who are BSL users and they DO NOT receive a full support package at school. They have access to a BSL support worker on a part time basis but she is only one person expected to support 16 children. It is normal practice for teachers to have little or no signing skills far less BSL communication skills and Deaf awareness. Translation from written English to BSL which is paramount is not available in any school that I know of.*</p> <p>· If you have access to hearing aids, loop systems and fire alarms from the Council, you might lose any DLA payment you get now; Just because my children have hearing aids forced upon us by the Government does not mean they can hear. My children are BSL users and as such should be treated not as hard of hearing kids who wear hearing aids but profoundly Deaf children. Having a hearing aid does not mean you can hear.*</p> <p>· If you might be assessed by people who do not know about deafness.</p>   |

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|                   |               | <p>I think being assessed by people who are not Deaf aware is an infringement on my human rights. How can you assess a cultures needs if you know nothing about that culture?*</p> <ul style="list-style-type: none"> <li>A DLA award for my children means my wife and I can access educational resources enabling us to empower our children in a predominately hearing world. Unlike hearing children, most Deaf kids are not interested in sitting in front of a television for hours on end being entertained. Every weekend my wife and I take our children to museums, places of interest, Glasgow science centre. Sports activities.....all of which cost not only money to access but travel expenses too. A large chunk of DLA is spent on accessing Deaf events, without which my children would be completely isolated from their culture and without peer communication.*</li> <li>Another important expenditure is dental care.....most dentist do not provide interpreters and it is up to me to me using my DLA to pay the interpreter fee's which as you know is not cheap. My children's grandparents live in Finland, unlike hearing kids my children cannot simply pick up a phone and call them. We have to take out children to see their grandparents, once again DLA enables my children to access every day things that hearing people take for granted.*</li> <li>As English is not my children's first language my wife and I use DLA to access a translator enabling my children to understand and learn written English. Education in this country for Deaf children is not geared to their cultural and BSL needs therefore the only option for parents like myself is to access DLA enabling us to pay for extra home support and tuition Regards</li> </ul> |
| EM352             | 09-Feb-11     | <p>Dear Sirs My Name is [REDACTED] and I care for [REDACTED] who is my Ex wife I do this unpaid I provide allsorts of support for [REDACTED] from transport to cooking and all other general caring duties.*</p> <p>*</p> <p>Because has dystonia which means that that she can have good days and seriously bad days when she cant move or cope with general day to day activities but if she was assessed on a good day then this could be preserved as not requiring the DLA. There is a progression in her condition and it this carries on then it could become a need for her to have a full time carer and the need for me to asses my commitments to a full time job at the moment I do provide more then 40 hours of support to her a week as well as holding down a full time Job.*</p> <p>*</p> <p>Should I have to reduce my hours in my Job then I would like to think that you as the government would provide a safety net for me.... I have never asked for any support in my caring duties and therefore have been saving you money in providing caring care for her. I feel that by means testing carers would devalue the work that we do and put too many in to a poverty trap that could be caused *</p>   |
| EM353             | 09-Feb-11     | <p>I am a carer for my wife who has Multiple Sclerosis. After many years of working full time both locally and away whilst supporting and funding my wifes care her condition reached a level where I had to cease work to provide full time 24 hour, 7 days a week care for her. At present she receives DLA and I receive Carers Allowance. We are both extremely worried at the Governments plans to change DLA and Carers allowance. Firstly as CA is based on my wife receiving DLA I am terrified that this will lead to my CA being stopped. If that happened I see no way to continue providing care and this would mean my wife needing to go in to full time residential nursing care. Having previously spent a long period working through the old system, where a doctor who did not know your disabilities, problems and issues, worked through a "tick list" and where twice my wife was turned down because she made exceptional effort to attend a "medical", which each time resulted in days of recovery from the physical effort and probably caused the onset of a relapse due to the stress of the events. She has now got DLA and despite being essentially bedridden for much of the time and relying on me for all her living requirements is now left with the worry of another Gov't</p>   |

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|                   |               | <p>overhaul which does not seem to be aimed at improving the situation of seriously disabled people and their carers but instead panders to the " their all scroungers" viewpoint of the tabloid press and the rich Westminster clique.*</p> <p>When, during their election campaigns all 3 leaders of the parties stated that they thought the present situation and payments to Carers was unfair I, like many others was naive enough to think they would actually do something to improve the situation not make it worse.*</p> <p>Please do NOT make changes to Carers Allowance and DLA which will mean the move of my Wife to state funded residential care and essentially the break up of my family. Do the decent thing and make carers allowance a living level payment for the Carers of this country who save society £87 BN each year. Regards</p>   |
| EM354             | 09-Feb-11     | <p>I am a full time carer as well as being in full time employment. My sister works for the local authority and has done so for the past 22 years. She has never claimed any benefits except for the DLA allowance of attendance allowance (£70 per week) and the Mobility Allowance (for which we gave up to get a mobility car for her). She is in a wheelchair with Friedreich's Ataxia, a neurological disability.*</p> <p>At present I work 37.5 hours per week and she works 35. From 4.00pm until 7.00am my sister is my responsibility and I am very concerned that you are considering removing the small allowance she is able to pay me for caring for her. It would seem that all governments (labour, conservative etc) hold all family members to ransom in that the carer would not want to place their disabled family member into care which would cost the authorities an extortionate amount of money. I am not allowed a carer's allowance as I am in full time employment. I believe that all allowances for disabled and carer's should not be included in any government cuts. Many thanks</p>  |
| EM355             | 09-Feb-11     | <p>Dear Sir/madam, I am writing to you with great concern. I am ver very concerned that proposals have been made to review DLA and other work associated benefits. My wife is in receipt of DLa both elements at the higher rate*</p> <p>She has a chronic spinal condition and can only get about with the use of the disability car and her disability scooter. The use of these items and associated costs use up most of her benefits. I am concerned about possible interference with arers allowance as I am a necessary part of my wifes day and can just about afford to be at home. *</p> <p>If the review system is simply to get back into work those who are able i cannot see a problem. THE CONCERN WE HAVE IS THAT AS USUAL THE PEOPLE WHO ARE MOST VULNERABLE IN OUR SOCIETY ARE THE MOST AFFECTED. WE ARE CONCERNED THART ANY ADJUSTMENT WITH DLA WILL RESULT IN LESS INCOME AND MAYBE WITHDRAWAL OF OUR NECESSARY CAR . THIS WHOLE IDEA NEEDS THINKING THROUGH MORE AND THE VULNERABLE AND CHRONICALLY SICK LEFT TO WALLOW IN THEIR OWN PROBLEMS WITHOUT SERIOUS FINANCIAL INTEREFERENCE.*</p> <p>PLEASE REPLY*</p> <p>YOURS MORE IN HOPE [REDACTED]</p> |
| EM356             | 09-Feb-11     | <p>Dear Sirs, My name is [REDACTED]. I care for my husband, [REDACTED]. We are really struggling for a number of reasons. About 4 years ago, our house was flooded, and by husband had to take out a loan to make it habitable. He has cancer, diabetes asthma and mobility problems. *</p> <p>As part of refurbishing our house, the council arranged to have a new heating system installed under the HEES scheme. Four nigh storage heaters were installed, but I had had asked for heat pumps, which were about the same price. I offered to pay any extra but was told that heat pumps were not allowed under the scheme. The first winter, even with the heaters turned up full, we could not get the house warmer than 12C. When we got the electricity bill in the Standing order went up from £70 / month to £179 / month. We can not afford this so have turned the heating off. My husband</p>  |

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|                   |               | <p>has been told by his oncologist that he is likely to die of pneumonia unless we can keep warm. *</p> <p>Although there is a bus that passes our house, we can not use it as there is no bus stop and the council says that there is no place to put a bus stop, so we have to use the car to go absolutely everywhere. I heard the transport minister say on radio the other day that people should get new cars to beat the fuel price increase. How does he expect people in our position to buy a new car? We are barely managing to survive. Yours sincerely,*</p> <p>This is our situation before your cuts.</p>  |
| EM357             | 09-Feb-11     | <p>Dear Sir/Madam, I write to you with great concern over proposed changes to the DLA and Carers allowance.*</p> <p>My daughter was born 28 years ago with physical and learning difficulties. I am her full time carer my Husband, her Dad had to give some of his work hours up to help me more as she is too heavy to lift on my own, without her DLA and my carers allowance we would not be able to afford basic needs. Carers allowance must be outside the universal credit, Thank you yours sincerely,</p>  |
| EM358             | 09-Feb-11     | <p>I am very concerned that any cuts in DLA payments would affect my son more than he can cope with. [REDACTED] has Aspergers syndrome and receives Direct payments to pay for carers expenses. Already I subsidise him quite a lot, and give him a lot of care and attention...Because I am on a pension I cannot claim anything for myself. At the moment he is living on a very tight budget and has little or no money left for buying anything except basic living costs. His situation would be made very much worse if he should lose the lowest care element of his DLA Yours sincerely</p>   |
| EM359             | 09-Feb-11     | <p>I am just emailing to list a few key points for concerns I have about changes to DLA. whilst I know reform is long overdue, there are some things I hope can be taken into account.*</p> <p>1) People with family or friends with Carers are completely dependent on them. (I am, even typing this would have been difficult). It is currently very difficult to see someone who is giving up their life to look after you constantly short and worrying about money. The current levels of Carers Allowance are too low and leave many living in poverty. However, if this money is taken off people on DLA then it just shifts the worry to the person needing the Care.*</p> <p>2) Carers should be eligible for extra help with heating and TV licences. Many of them give up their lives and careers to look after a family member or friend and are left struggling in poverty.*</p> <p>3) The current DLA forms and assessment (for those of us who are really needing it) are very difficult and stressful. There is the constant worry of what how you will manage if your money is cut or even worse stopped. Some health problems are irritated by stress. *</p> <p>4) It is a waste of time and money constantly re-assessing people who will never get any better. (for example someone with 3 missing limbs) or likely to need Care for the rest of their lives because of mental health issues) Your consultation document mentions only Cancer and terminal illness as circumstances for getting permanent benefits however for some of us the issue is more complex. I have Chronic Asthma, Fibromyalgia, Arthritis in several places, High blood pressure, Bladder problems and within the last year or two my thyroid is stopping working, as well as digestive problems and IBS. None of these are ever going to get any better and the best I can hope for is to have my illnesses managed to a point where I can cope with the pain and still have some quality of life and Hopefully not get any worse. Last year I was given an Indefinite Award (I think it was Incapacity Benefit. I get this because I have worked all my life until illness made it impossible 10 years ago (I am 50 years old). As already pointed out the process can be stressful and difficult for the Claimant and in my case a waste of time and money for the Government. Therefore, there needs to be Benefits available</p> |



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|                   |               | <p>for those who will not get better other than terminal illness.*</p> <p>5) Any benefit reforms should take into account the fact that anyone pretty well housebound are using more electricity and their tv all the time. They should (in my opinion) get the extra money towards heating and help with TV licences that pensioners get. None of these are available to those of us on Incapacity Benefit. Oddly those on Income Support (or ESA, the more modern benefit, do get the heating allowance) Those of us who have worked all our lives are penalised for working.*</p> <p>6), lastly more should be done to ensure those who really need benefits get them and get them within a reasonable amount of time. I did not know how ill I was until I collapsed in a street 10 years ago, breaking both arms, my wrist and my ankle in the process. I went for 3 months with no money because I did not know I was entitled to Benefits then left with a further 3 months because thats the time it took for me to be assessed.</p>  |
| EM360             | 09-Feb-11     | <p>i am extremely concerned about the changes, proposed as life is hard enough for people who are disabled and often just as hard for those of us who look after them i myself do not get carers allowance for my disabled husband as i work a wee part time job. .life is demoralising enough and its very hard to watch someone you love become depressed and dependent on other people.</p>  |
| EM361             | 09-Feb-11     | <p>The following are my comments, as an individual, in answer to the questions posed in the consultation document.*</p> <p>1. The two sections of DLA, viz. Mobility and Care summarise the problems faced. The inability of a person for example to travel across London on the Underground or to participate in a journey around parts of the country by train (as Michael Portillo has recently done on BBC 2) are completely frustrating. There are alternative modes of transport, but they more often than not come down to travelling in a private car. On the Care side, it is often impossible for somebody to be out and about without their carer, as any normal independent person would do, as for example they have reduced use of their hands to attend to personal matters. There are, of course, laws which attempt to standardise travelling arrangements (e.g. low loading buses) and entry to buildings, but when one is in a wheelchair they constantly face an enormous number of obstacles to partaking in what should be independence.*</p> <p>2. The 'passport' to Motability vehicles, free Road Fund Licences and Blue Badges is a vital link to independence and should be maintained.*</p> <p>3. The use of a private car, particularly where I live in rural Herefordshire, is imperative in being able to get about, and the cost of fuel is becoming more and more prohibitive. Cars are necessary in many rural areas as there are just not any buses, and where there are buses they are not always adapted for disabled people which means bus passes for the over 65s cannot be used. Additionally, the cost of adapting a vehicle (hoists or ramps for wheelchairs) is a personal cost. Anything to do with adaptations or aids for disabled people are often prohibitively expensive compared to an equivalent article which can be used by physically normal people. Furthermore, the cost of adaptations to a home in order to move around or even balance are costs which other * people would not face. Often a journey, say to a holiday destination, will take a lot longer for a disabled person to carry out and therefore more overnight stops might be necessary.*</p> <p>4. I cannot see that having two rates will make a great deal of difference.*</p> <p>5. So many medical conditions have widely varying symptoms but come under the same heading or medical description. I think that all entitlements should be based on an individual's needs and circumstances so long as a professional medical assessment takes into consideration the person's underlying illness and its probable development.*</p> <p>6. I think the following, which is quoted from the Consultation document (para 25) is a good stab at this point - "Our initial proposal is that the assessment should consider activities related to an individual's ability to get</p> |

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|                   |               | <p>around, interact with others, manage personal care and treatment needs, and access food and drink". However, the problems a disabled person comes across in daily life are continually varying depending on where they are and what they choose to do.*</p> <p>7. This last severe Winter has been an absolute nightmare for many disabled people, particularly those suffering from neuro/muscular diseases, as muscles which hardly have any movement in them normally, have just refused to work at all. Things do improve to an extent when the weather warms up. Therefore a person's worst situations need to be taken into account.*</p> <p>8. Disabled aids and adaptations can offer some help and assistance to disabled people, but can never be counted as a suitable alternative to the natural body in assessing how a person can achieve normal everyday activities. Therefore they should not be taken into consideration when * assessing a person's level of disability. Whether a person pays for or is provided with aids is another matter entirely.*</p> <p>9 -11. Filling in the current form is a nightmare and needs to be much reduced in size. The whole process should major on communication through a professional healthcare person who is able to assess the difficulties disabled people face in attempting to lead a full and independent life.*</p> <p>12. Different disabled conditions require different frequency of reviews. Some diseases are clearly a lifetime incapacity and others improve or may even disappear over time.*</p> <p>13. I have no idea. This is probably a matter to be considered in line with question 12. where any condition which might possibly improve has a time limit placed on any award period.*</p> <p>14. Disabled people in this day and age need all the help they can get. Anybody applying for benefit, most probably has no idea of the amount of help which is available through their local Social Services departments or local councils. The type of services which are most useful are e.g. * Occupational therapy departments, emergency telephone services, (in my case) Herefordshire Carers' Support and other Carer charities. I have also received a great deal of support from the Citizens' Advice Bureau. Details of all these types of assistance should be given to any applicant for P.I.P.*</p> <p>15. A person's GP or hospital consultant should be pro-active and would be best placed to advise on support and information available in any case.*</p> <p>16. The main aid which is currently 'provided' by DLA is a means of transport through the Motability scheme, which seems to be hugely successful. Here, of course, the DLA mobility component partially pays for the car and any adaptations to it. Currently, if a person needs an * aid such as a wheelchair they pay for it but of course the DLA they receive indirectly partially funds this. Aids, including wheelchairs, are also available through the local Occupational Therapy departments for long term hire. There are also Warm Front grants. Minor adaptations to a person's home are often paid for by the local Occupational Therapy department, but major work is usually paid for by the individual. I think that the Motability scheme should continue and there might be a case for other similar schemes to be introduced, but I doubt any aid other than a motorcar would be as universally useful or acceptable.*</p> <p>17. Not sure.*</p> <p>18. Again, clearly the Motability scheme and the Blue badge are of great importance. Although gradually the Blue Badge scheme is being more and more misused. Also the Radar key to public toilets is most useful. There are certain exemptions to VAT on disability aids and adaptations, but these are not always so easy to obtain and should be more available on items or services which are clearly specifically useful or needed by a disabled person.*</p> <p>19. A most backward step as the subjects I have mentioned in 18. go some way towards making life bearable at times.*</p> <p>20. I have no idea what other assessments in respect to disability benefits are currently made. But clearly if there was one office which had the whole of</p> |

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|                   |               | <p>the detailed information regarding a person's disability that could be shared by other departments or health authorities. Clearly, any disabled person would have to understand this when they made an initial application.*</p> <p>21. I have no understanding on what differences in race, culture, religion or sexual orientation might have on a disabled person applying for PIP. I cannot think there would or should be any difference.*</p> <p>22. So often choice is not a luxury which can be enjoyed by a disabled person. The whole thing boils down to being unable to lead a full, active and independent lifestyle, enjoying the choice, control, freedom and expenditure levels of a healthy person, in both their mobility and in being able to manage for themselves in the home and whilst travelling. It is incredibly difficult for a disabled person to compete in today's society, and they so often have to accept whatever is handed out to them by way of restrictions imposed by outside uncaring factors and service providers. A partial solution is achieved by receiving help either from aids and adaptations which can be used by the disabled person and/or by being helped by some other person or carer. All this costs money which is currently partly provided by DLA together with its passport to other services and benefits, and help by Social Services. The thought that this current help may well be diluted or taken away by this re-assessment process is very frightening to many fragile and * vulnerable people. The sooner the disabled community can be reassured that their future is secure - the better.</p> |
| EM362             | 09-Feb-11     | <p>I am as Carer for my wife who is in receipt of DLA. I am concerned that the new proposals are having the effect of making her even more anxious than she is and that many more are feeling the same *</p> <p>We have read accounts that the agency of doctors are out of touch with needs of those who are disabled and create a barrier of mistrust. I think the Government has within it's power, to consult with organisations that represent carers and the disabled themselves, to discover the real issues that apply to the provider and the recipient and work to a satisfactory and value for money conclusion. This has never been achieved, so why don't you seize the opportunity for once now by amending your proposals and bring in those who know.</p>   |
| EM363             | 09-Feb-11     | <p>I write to express my views on the Government's consultation on replacing Disability Living Allowance: I am 76 years of age and living on a very small income from my state pension and out of a small amount of capital which brings in no interest whatever. I support and care for my common law partner who suffers from a severe psychological disorder and is under frequent medical attention and constant medication. My partner receives the lowest Disability Living Allowance and does not receive any carer's allowance which means that I am responsible for the entire care and cost of looking after my partner.*</p> <p>If this small Disability Living Allowance were to be reduced I would not be able to cope financially and the entire liability would be out of my hands and fall upon the state. I therefore write to express my fear and dismay that any reduction for <u>genuine</u> cases may be considered, and I can only hope that the consultation will be dealing with the matter with a view not to cutting assistance from the most vulnerable in society but by helping the <u>genuine</u> recipients of the DLA and, hopefully, with a view to aiding them and their carers much more than at present. *</p> <p>I wish to make very clear that I believe that Government should not be making any cuts to the DLA and the Carer's Allowance benefits. Yours faithfully,</p>   |

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| EM364             | 09-Feb-11     | <p>Dear Sir I am just letting you know how worried my wife and I are at the proposed changes to DLA and telling you the reasons why. I am carer for my Wife, [REDACTED] who has uncontrolled Epilepsy, arthritis and deafness. She has Seizures most days but these are made much worse by any stress and I have to ensure a daily routine which is constant and this secures her the best results for her condition. Obviously she takes her medications too but by giving her a secure and stable environment she has improved over the years and has only a few seizures daily/nightly rather than the 100 or so she had formerly. Any changes to her environment causes a great increase in frequency and severity of her seizures and my role is to protect her from the outside world as much as I can. This is a great strain on me and I never have a day off although some days are better than others.*</p> <p>I want you to consider the impact this will have on my wife and others in her condition. The worry and uncertainty is very unsettling and makes life enormously hard for both of us but as her carer I take the brunt of these changes in protecting her from the worry. So I have double the anxieties. This stress you are placing on us by these changes will impact on us and I hope you will consider this in your consultations. Sincerely</p>   |
| EM365             | 09-Feb-11     | <p>Hello, My name is [REDACTED], and I have two problems regarding the proposed change from Disability Living Allowance (DLA), to be replaced by a Personal Independence Payment (PIP).*</p> <p>I am in receipt of DLA on my own behalf, but there are problems regarding my wife, [REDACTED], in addition to that. I qualify at present for DLA at top level for mobility, and lower level for care. My wife qualifies for care allowance at the higher level because of mental problems. She suffers from Alzheimer's Disease and vascular dementia, and is, at present, in residential accommodation, because, for health reasons I am unable to care for her at home. Since she was detained on two occasions under Section 3 of the Mental Health Act, she is, at present, protected by Section 117 of the Act, and her care is provided jointly by the NHS and local authority (Doncaster MBC).*</p> <p>The award of DLA to myself came about as a result of myocardial infarction in 1996, which left me with angina, and consequent limitation of my abilities to function normally. I did not realise that this was the case initially, and continued to work as normal (or to attempt to work as normal). This proved to be impossible, and I subsequently requested early retirement from my employer. It was during this process that I was advised to apply for DLA. Because of my request for early retirement, my employer requested an independent medical examination, which was carried out by BUPA Occupational Health in York. I was also examined by an independent GP in regard to my application for DLA.*</p> <p>As time has gone on, my situation has worsened, and I have become more limited in what I can achieve. I am limited in regard to lifting and carrying, and require assistance in tasks such as changing bedding, or moving heavier objects. In this respect, family members stand in for my wife, who clearly is unable to assist. Just to complicate matters, I spent some time in the Renal High Dependency Unit at Doncaster Royal Infirmary in 2009, suffering acute renal failure, and needing dialysis as a consequence. This illness impaired my abilities in unexpected ways, leaving me with joint problems that flare up at times, and limit my abilities even more.*</p> <p>*<br/>The problems that I face if there is a change in allowance affect me in several ways:*</p> <p>*<br/>Although my wife is presently in care, and as a result, her DLA is suspended, there is always the future possibility that her care provision will change, and any succeeding costs will have to be borne privately. In this case, reinstatement of the suspended DLA would be vital in order to help to meet the costs involved. Would P I P cope with this possibility?*</p> <p>I live alone, but get excellent support from my family, but this support is limited by them not living locally. The only practical way that I can stay in</p> |

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|                   |               | <p>touch with them all is through the use of a car. My current status for D L A helps enormously with the running cost of a vehicle, and, as I generally need to use my car for shopping, for example, the issue of a blue parking badge is important to me. I can, and do, use public transport for local journeys, but this is of no value if I need to transport anything but the lightest items.*</p> <p>In addition to mobility issues, there is the matter of cost of living at home, especially when those costs are related to disability. I am thinking about the extra costs of heating and so forth, as I feel the effects of cold, and particularly cold and damp weather, and this seems to have been exacerbated by renal problems.*</p> <p>There are other, physical, elements of home management that have become impossible. Although I can manage meals well enough, the difficulty in reaching up or down to access cupboards and storage increases, and it has become impossible to manage tasks in the garden, which means that I have to employ the services of a gardener. I am reaching the point that I am considering employing some form of home help, as pushing around a vacuum cleaner is becoming difficult.*</p> <p>I now have difficulty in getting out of the bath; although there is an overhead shower, this is not of practical use in winter, as it cannot deliver water at a suitable temperature and pressure to replace bathing. This means that I have to consider either replacing the bathtub with a walk-in bath, or I have the bath removed, and invest in some sort of wet room arrangement.*</p> <p>* </p> <p>What concerns me, apart from my own and my wife's needs, is the impact that the loss of an anticipated £1Bn will have on carers in general. When I cared for my wife full-time, it really was full-time, as she was inclined to night wandering, as well as daytime demands. I was 'on call' for her for 24 hours a day, 7 days a week, a total of 168 hours. Even at minimum wage rates of about £6 per hour, I calculate that my value to the government was thus around £1000 per week, as with many others who care without complaint. Losing income that can help to provide extra services would be a calamity, and it is shameful that the government now seems to be targeting those in society that are the weakest. We all understand the need for savings to be made in the economy, but I find it to be intensely irritating that, say, the banking industry, which brought about much of the present problems, appears to be relatively untouched by events. Perhaps I am not the only one who feels that we just have to look on helplessly whilst we are being disadvantaged once again.*</p> <p>I am a constituent of the Leader of Her Majesty's Opposition, Mr Edward Miliband, and a copy of this email will be sent to him for consideration. Kind regards,</p> |
| EM366             | 09-Feb-11     | <p>I am a full time carer for my elderly mother who suffers with dementia and short term memory loss beside a history of mini strokes the general frailty of a 91 year old grandmother.*</p> <p>I am concerned over the way assessments are carried out and am afraid that if she was assessed on a good day by someone not experienced in dementia care that she might well be misdiagnosed meaning she would be at risk of losing her benefits.*</p> <p>We live in a rural area and have no piped gass supply resulting in us depending on LPG which has doubled in price in the last 3 months meaning horrendous heating bills as she needs the heating far higher than my wife or I who care for her would need. If we or she were to loose any benefits then we would be forced to reduce the care we by in for her to ensure her safety and well being.*</p> <p>We are dismayed at the cuts being proposed to disability benefits when all the time we are being told the vulnerable and those at risk should be protected and provided for. The NHS and Social services are being saved millions of pounds by carers looking after family and friends rather than the authorities. Just this chirstmas we took my mother home from hospital 2/3 weeks early because there was no place at a rehab hospital locally for her and her mental state was deteriorating with being just left to vegitate in a</p>  |

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|                   |               | <p>hospital bed not even being sat out on a regular basis. This saved the NHS probably in the region of £1500 a week, yet they refused to supply adequate incontinence pads for the two weeks over the holiday period saying it was our responsibility to buy what we needed until the local neighbourhood team could assess her.*</p> <p>It is imperative that the Carers Allowance should remain outside the Universal Credit as all carers need to be recognised for the contribution they make to society and the saving they make on behalf of the general taxpayer.*</p> <p>Please do all you can to ensure the carers allowance remains available to those who need it and recognise the contribution they make to society.</p> <p>Yours</p>   |
| EM367             | 09-Feb-11     | <p>Dear Sir/ Madam I am a carer for my elderly and fragile parents who lives in Kensington-London and are 87 and 86 years of old respectively. The new proposal for replacing Disability Living Allowance( DLA) with Personal Independence Payment (PIP) will have a a dramatic effect on me and my parents life and increase our worries and despairs. *</p> <p>1- My parents will be more disturbed and worry by those new regulations, reassessment, managing those payments and bureaucratic process which would be an extremely hard task in their conditions. *</p> <p>2- The latest government financial guidelines already affects the proficiency of the people working in social service and NHS, therefor my parents will have to deal with less experienced and busier individuals for reassessments to experience the new procedures which not only costs more for NHS and social services. but also may affect their entitlement and eligibility's for DLA ranking. *</p> <p>3- Replacing DLA would add extra pressure, strain and concern about required help and support of carer's loved one. Carer lives, mental and physical health have already been stretched to the limits and this enquired and unnecessarily problem would have a devastating effects on their mental health and consequently on their ability of performing their duties,*</p> <p>4- Withdrawing DLA from those people who are in great needs will dramatically affect their financial ability to buy the good, medical and nutritional supplies which their well being and health is undoubtedly depends on them.*</p> <p>5- We (carer) provide support and help and looking after our relatives out of love and passion. These new changes will involves us in new bureaucratic process and undermines our unconditional support of our loved ones. We are saving billions of pounds every years for government which are irreplaceable emotional, physical, not to mention the financial in specially in these economical climate. These new regulations will discourage us and will have negative effects on our inspiration and will to continue our support.*</p> <p>I would appreciate it if you consider my concerns and millions of cares like me by performing all necessary legal process to stop theses change and replacing DLA with Personal Independence Payment (PIP).*</p> <p>Thank you very much for your time and consideration. Best Regards</p> |
| EM368             | 09-Feb-11     | <p>Dear sir My name is [REDACTED], I have cared for my wife [REDACTED] on 24/7 basis for the past seven years she had a subarachnoid hemorrhage, she is unable to take care of herself at all. without her DLA, £483.20 and my carer's allowance of £85.01. per month plus a small pension from the post office of £322.10 less £60.00 tax a month this is all we have to live on if you the goverment take or change this very small amount of money she will end up in full time care in a home and I will be out of our one bedroom flat, because without this money we cannot afford the ground rent and the services charges so please think very hard before you play with peoples lives. and also take long hard look at the surgeons who play GOD, and than walk away and leave the state to pick up the BILL, for there mistakes. kind regards</p>   |

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| EM369             | 09-Feb-11     | <p>Dear Sir, We care for &amp; have cared for our hearing impaired - sight impaired son for 46 years. We lost carer's allowance when my husband reached the age of 65 years when he received the old age pension. We receive no outside help at all &amp; I consider it an absolute disgrace that we lost this allowance because we received a benefit to which we had contributed by regular payments. I hesitate to consider how much we have saved successive governments over the years! Disabled living allowance should be left as it is or if possible improved as the quality of life for someone disabled in this way depends very much on we his parents: i.e.his carers. As the years advance the problem gets more difficult : yet we cope: we have no choice. We think of others in a similar situation &amp; empathise with their plight. When we pass on : as indeed we will: we dread to think what will happen when his care is reliant on what ever government is in power: it will be in God's Hands because from our experience there will be precious little help from anywhere else. It is particularly important to keep the element of income support as this has a knock on effect on many aspects of his life. D.L. A. should mean what it says: Disabled Living Allowance not selective allowance as it would be if these retrograde changes are allowed to take place. Yours sincerely,</p>   |
| EM370             | 09-Feb-11     | <p>To whom it may concern, I am writing out of concern for myself and my son. I receive the the <u>Low Mobility Rate and the High Care Rate of DLA Indefinitely</u>. I suffer the following conditions; *</p> <p>Bulimia Nervosa; Severe Psychiatric Conditions, delusions etc; Moderate to Severe ME; Spinal Injury; Degeneration of Spine and Loss of Curvature; Chronic Inactive Bowel problems which mean I have to do water enemas every day to prevent my bowel blocking; I am registered disabled and have a Blue Disabled Badge; Multiple Allergies/Sensitivities to foods and chemicals *</p> <p>I have already had DWP Medicals and assessments and proved I am worthy of my DLA and that my conditions will not get better which is why I was awarded my DLA for an Indefinite period. I should not have to prove I need it when I've already done this and have all the medical evidence which backs up my conditions. I need my DLA to help me to get about, and to buy organic food to help my dietary problems and I have to buy gluten free foods and dairy free foods. I cannot use public transport due to my mental health conditions and my mobility difficulties, we need to be able to get out and about as staying in the house makes my conditions worse, I have to get out and we therefore need to be able to run our car which we couldn't do without my DLA especially with the cost of fuel nowadays, my DLA is vital because going out with my husband helps my depression and suicidal thoughts and I can't binge and vomit if I'm out, so the car helps prevent me from self harming!*</p> <p>My [REDACTED] year old son is in [REDACTED] Hospital in [REDACTED] in a PICU (Psychiatric Intensive Care Unit) on a section 3 of the Mental Health Act. He had a bad psychotic breakdown last August and has been in hospital ever since, and he's likely to be in hospital for up to a year. My son has suffered from the following conditions for the last 20 years; *</p> <p>Paranoid Schizophrenia; Dual Diagnosis; Learning Disability; Bipolar Disorder*</p> <p>Although my son is 39 this October, he has a mental age of 15, a teenager, but he lives alone in the community when he's not in hospital, and he needs a lot of support and help to keep him on the straight and narrow and we have to guide him daily and speak to him at all hours of the day and night in order for him to get through each day. My son has been getting DLA for many years, he gets <u>Low Rate Mobility, Middle Rate Care Indefinitely</u>. He cannot go on public transport as he thinks people stare at him due to his paranoia and he just can't cope, so he has to have Taxi's everywhere, to get his shopping, to visit friends, to visit us, everywhere he goes. He finds it too difficult to walk half a mile down the street to the shop because of his Paranoia and fear of being attacked, (as he has been attacked several times), because if he thinks people are starring at him, he shouts at them</p> |

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|                   |               | <p>and then gets attacked and puts himself at risk and in danger. He also has metal plates in his shoulder and leg from accidents, and he finds walking painful. He struggles but wants to live in a flat on his own with support, he was in care homes over 20 and hated it and there was no care in the homes. My son is an extremely vulnerable adult who will always suffer from his disorders, they are life long disorders, he will never get better and will always struggle. If my son had to see a DWP Dr and was asked questions, he would either say he's ok, or tell the Dr to mind his own business and to F— off depending how he was on the day, <u>he effectively has no voice to deal with interviews of this nature and the stress of having to go to such an interview even with support, would make him so stressed, it would cause a relapse in his mental state!</u> *</p> <p><u>Very Vulnerable people like myself and my son who suffer from Severe &amp; Enduring Mental Health problem, and who have been granted DLA for an Indefinite period, should be exempt from these proposed tests !*</u></p> <p>For the Government to put such vulnerable and at risk Mental Health Sufferers through these proposed tests is sheer cruelty and stupidity, and will result in many suicides because they just will not be able to cope with the worry and the upset of having to go through it all! On behalf of my son, myself and all other Severe &amp; Enduring Mental Health Sufferers who have been granted their DLA for an INDEFINITE period, and, proved via medical support letters, and or DWP medicals, please make these people EXEMPT from these tests, otherwise the Government will end up with blood on their hands and there will be many suicides and people relapsing! Kind Regards</p>  |
| EM371             | 09-Feb-11     | <p>To whom it may concern, I am writing to give my views on the Government's proposed changes to the benefit system - namely Disability Living Allowance and Carers Allowance. I care for my husband [REDACTED], who is diagnosed with Schizophrenia and Psoriasis; and despite being only 40 years old has in the past year been diagnosed with Cardiomyopathy and Left Ventricular Systolic Dysfunction; possibly due to his extensive medications for his mental illness.*</p> <p>I am extremely worried about [REDACTED] reducing his benefit allowance as his conditions are long term and can be acute in nature requiring hospitalisation. Thankfully the past year he has managed, through medication and health professional support to stay out of hospital; but requires weekly reviews from a CPN, 6 weekly appointments with the cardiac specialist nurse, psychiatrist and GP; 3 monthly reviews from the dermatology consultant and yearly reviews from the cardiologist. In the past 3 years, he had spent at least 4 months of the year in hospitals across Lothian.*</p> <p>[REDACTED] becomes very breathless, and has difficulty managing the stairs. He frequently suffers chest pain, with or without exertion. We are in a private let house as we cannot afford the deposit on a mortgage. We recently moved properties as [REDACTED] was having trouble managing the stairs to the 3rd floor flat we used to rent. This has been recommended by the GP, but has involved a raise in rent.*</p> <p>I work full time as a nurse, but thankfully due to the additional stress of my caring responsibilities have been redeployed to a job within NHS which provides me with some autonomy to allow for emergency leave to care for [REDACTED], by either making up time lost or taking leave at short notice. I am diagnosed with depression, which my GP has accounted to my circumstances. My employer is compassionate to my living circumstances and caring responsibilities which allows me to adjust working hours around my caring responsibilities. I am not entitled to carers allowance, as I am said to earn too much, and have been told "how can I care for someone when I work full time". Every evening and night I care for [REDACTED]. Sometimes he can be up all night, wanting to discuss his paranoia, or requiring monitoring of his breathing and chest pain. The disability living allowance benefit allows me to take [REDACTED] to his families' houses for respite for me, allows me to pay for his transport and my petrol when he requires to attend appointments, and gives us some leeway in our finances</p> |



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|                   |               | <p>to allow for some respite for me to socialise without having the responsibility of caring for [REDACTED]. During the days, [REDACTED] stays in the house; he has not worked for 5 years due to his mental illness, and now his cardiac conditions means there is little likelihood that he will ever be able to work again.*</p> <p>In 2003, [REDACTED] was awarded DLA - high rate care and low rate mobility - indefinitely due to his mental illness and his inability to cope with working. I am afraid that going to another medical review will cause him anxiety, and unnecessary distress and if he is having a "good day" on the date of his review may not satisfy the medical examiners about the severity of his illnesses and how they affect his quality of life. Since this DLA rate was made indefinite he has recently been diagnosed with his heart condition which I have mentioned to the DLA system but not pursued, as I feel he is getting the right financial support for the severity of his illnesses.*</p> <p>I understand the Government has to make cuts - I work for the National Health Service and am witnessing first hand the effects of Governmental cuts, to the detriment of patients and service users. However I feel that sometimes the wrong people are targetted and assessed. My husband has severe illnesses, and would not like to think these would be not be taken into account in this review. Please could you get back in touch with me about any changes in the benefit system as any reduction would undoubtedly have an impact on the quality of life I have with [REDACTED], and our ability to manage our finances. Yours sincerely,</p>  |
| EM372             | 09-Feb-11     | <p>Dear Sir or Madam, I am responding to the consultation as an individual. Regards*</p> <p>Question 1 Very low income, lack of suitable and assessable housing, lack of money to make adaptations to my home, isolation in a rural area, inaccessibility of buildings – steps/no lifts/no wheelchairs and porters(NHS) etc, a disabled person mobility difficulties to access services in the community, pain and tiredness due to disability. *</p> <p>In the UK today, discrimination, victimisation and harassment are big problems if you are disabled or care for a disabled person. In the street, often it is a stranger who mistreats you. The government comments that disabled people are benefit scroungers and media portrayal of disability has made the problems worse. The government and opposition parties should be setting a good example to UK citizens.*</p> <p>Question 2 DLA mobility and care component helps me slightly to have some life but without the money I would not survive. Middle rate care component is £47.80 per week and the carers allowance is £53.90, totalling £101.70 if a family member looks after a disabled person. This is £5290 per year or £2.91 per hour assuming the carer does the minimum of 35 hours per week. Many carers do more than this as continued care is needed throughout the day. *</p> <p>If the new benefit is means tested based on the carer's savings, family carers are like to have to walk away. This means that the disabled person or social services will be paying at least the minimum wage for their care at nearly £6 per hour. This means that the care will cost £6 per hour x 35 hours x 52 weeks = £10830 – more than double what it costs now. Care home fees are very expensive assuming there are places for the elderly and disabled to go to. *</p> <p>Carers should be valued and the benefits paid to the disabled person and carer does not compensate them (as a family) for loss of earnings if the carer was in paid work. A significant proportion of carers have chronic medical conditions and disabilities themselves. They find it difficult to get time for themselves – to attend medical appointments, have their hair cut etc. They struggle to cope and care. Funding cuts means respite care is already very limited.*</p> <p>Disabled people should have the choice of who looks after them. Carers should be valued and paid appropriately for the work they do. I wonder whether MPs will work for no pay?*</p> <p>I think current DLA benefit and carer allowance is fit for purpose today and is</p> |

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|                   |               | <p>very good value for money. DLA three rates for each component should stay. See response to question 3.*</p> <p>Question 3 Everything costs more. For example *</p> <p>We had to move into a more suitable property and the costs were met by us. Occupational Therapy has lent safety aids and equipment as accident prevention is important and to help disabled carers care for someone who was very ill 41 years ago. This is to prevent the carers suffering injuries. The cost of structure changes to the home has been paid for by us. The cost of car adaptations has been met by us. I have been helping to provide care since a young child despite having disabilities myself since a young child.*</p> <p>Fit people can walk, cycle or take the bus. I cannot walk to the bus stop. A fit person chooses to drive a car to the shops, take their children to school and themselves to work. I don't have a choice due to mobility problems and would be house bounded without a car. Fuel prices have gone up significantly. In the 1970's there was a car allowance for those people who worked. If you were on this allowance, you were moved to mobility allowance when this was abolished. I disagree that DLA is a disincentive to work.</p> <p>Discrimination, unsuitable workplaces and mobility difficulties/fatigue are significant barriers in getting a paid job. However it is easier to get suitable voluntary work. If you work, a prepaid prescription certificate of £104.00 per year is charged for very essential medicines. Epilepsy drugs exempt someone from this charge but you are not told about this. However, most essential medicines are not on the exemption lists.*</p> <p>There is no fuel allowance for heat if you are not a pensioner. Pensioners receive a fuel allowance to assist them with the cost but heating oil prices have increased significantly. Insulation grants only cover cavity and loft insulation. *</p> <p>As health services have been centralised in Oxford, increasing fuel costs and then car park charges make attending hospital appointments expensive. When you get there you have difficulties getting a wheelchair and a porter. The JR has reminded reception staff they should be more helpful.*</p> <p>Both my mother and I has significant long term health problems and in November 2010 my mother had a heart attack – the cause disability not diet. It takes longer to do everyday tasks and the tasks cause pain and fatigue. The hospitals here will discharge a disabled person when their carer is too ill to look after them as the bed is needed. There needs to be more financial and practical help for disabled people and their carers if the care is long term and/or the disabled carer is caring for a disabled person. It is a massive strain on us and our health suffers as a result.*</p> <p>Question 4 I find the current DLA system very straight forward. The present DLA form is understandable. It is important that the new benefit recognises that some people are in a lot of pain as a result of their medical conditions/disability. *</p> <p>Removing the low rate care component will indeed save the State money but the NHS is likely to have to deal with the consequences of falls, burns, more heart attacks and strokes if financial help is withdrawn. Savings will be made to the DWA budgets but health and care budgets will probably come under pressure. The disabled person could end up more disabled because an accident has happened because DLA or its replacement has been withdrawn.*</p> <p>Doctors, physiotherapists and Occupational Therapists will advise patients who have mobility difficulties and upper limb disabilities about hot food and carrying hot pans as there is a significant risk of burns to patients/disabled person. The above medical professionals do not want to see patients in pain and having to have burns dressed each day if they are luck enough not to need a skin graft. Again accident prevention saves the NHS money. *</p> <p>Oxford University is undertaking research regarding heart attacks with patients who have arthritis/inflammatory disease as blood platelets seem to be more sticky –description to patients. The last thing people who are at risk of a heart attack and stroke need is to be told they have to have a microwave and eat hot ready meals which are very high in fat, salt and sugar</p> |

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|                   |               | <p>etc. -a very bad diet if it is all the time and a high risk diet will probably lead to a heart attack or stroke. The doctors do advise that ready meals are bad for you so why the government think they are suitable for disabled people is beyond belief as it will be a burden on the NHS. There should be a right to a hot meal that is healthy and cooked from basic ingredients – it also must taste nice and in the absent of salt you need to use herbs and spices. *</p> <p>If the new benefit is based on the needs and circumstances of the individual apply, having two rates per component is a further barrier that prevents disabled people participating in society and leading independent, full and active lives. DLA three rates for each component should stay.*</p> <p>Question 5 There should be automatic entitlement for some conditions as listed but the needs and circumstances of the individual should be taken into account. Multi-disability makes life very difficult. A disability is a long-term medical condition (lasting more than a year). If a disabled person uses a wheelchair or crutches, a person who does not have upper body or limb disabilities will have more mobility than someone with upper body and limb disabilities. *</p> <p>Everyone that needs help due to a disability should get the benefit they are entitled too. If budgetary savings have to be made it should be made elsewhere – e.g. well off pensioners should not been eligible for the winter fuel allowance and child benefit should only be paid to poor parents earning less than £25,000. Some people have children as they get benefit for them.*</p> <p>Question 6 The following activities are essential:*</p> <p>Access to food and drink including being able to go shopping and cook a hot meal made from basic ingredient and that's healthy; bathing and dressing; going to the toilet; taking prescribed medication and being able to attend GP and medical appointments; living in a warm and clean accommodation; being safe from harm; being able to do household tasks that you can do with aids and equipment; having odd job help e.g. changing light bulbs and batteries in smoke detectors etc: having hobbies and being able to attend community groups and events. All of the above are basic needs of any human. *</p> <p>There needs to be a different approach to help disabled people work – home working schemes for disabled people only etc. Paid work is likely to be part time but at least it is contribution towards the cost of living with benefits picking up other costs. It is easier to get suitable unpaid voluntary work for a few hours. This is work and a contribution to society. If you work, a prepaid prescription certificate of £104.00 per year is charged for very essential medicines. Epilepsy drugs exempt someone from this charge but you are not told about this. However, most essential medicines are not on the exemption lists and disabled people have to find the money to pay this charge.*</p> <p>Question 7 Conditions such as rheumatoid arthritis, the patient may have long periods of time when the disease is in remission but can be very ill if the person has a flare-up. It can take some time (over a year) to find another effective drug. The new assessment needs to take into account the health of the benefit claimant during the assessment. The assessment process needs to take into account NHS clinic waiting lists. *</p> <p>Question 8 To take aids and adaptations into account would require the medical professional to visit the disabled person's home to make an assessment. Adaptations should not be taken into account because most aids help with mobility, safety and living tasks and are essential. If a disabled person uses a wheelchair or crutches, a person who does not have upper body or limb disabilities will have more mobility that some with upper body and limb mobility. *</p> <p>Aids may be easily obtainable but Occupational Therapists and Physiotherapists tell disabled people and their carers how to use the aids and where grabs rails etc should be fitted. *</p> <p>Question 9: The current DLA form is understandable. The form should be a paper form filled in by hand as it contains personal medical information. Electronic forms completed on a website may save the DWP money but it will cost the claimant.*</p> |

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|                   |               | <p>The DWP should, as a government department, be able to communicate with disabled people and their carers. There needs to be more community advocates to help filling in the form but budget cuts to the CAB mean less help is available. *</p> <p>Question 10 The DWP must ask for information about the disabled claimant's GP as medical tests such as scan results are important to establish eligibility. It is just a case of photocopying NHS letters or notes made by healthcare professionals, in many cases. *</p> <p>Question 11 I think there is no benefit to the claimant for having face-to-face discussions with a DWP health care professional. If you have a disability, all the information the DWP needs can be provided by the NHS. It is cheaper to pay the GPs for copying NHS letters than pay contracted medical professionals, a receptionist and renting an office. In addition the Oxford office is very difficult to access due to its location with no parking. Claimant travel expenses and the administration of it is yet another unnecessary expense. *</p> <p>Vulnerable people who have had strokes or have learning disabilities should not have to attend face-to-face interviews. People with spinal disabilities find it difficult and painful to get to an assessment centre. The DWP would have to arrange many home visits. There is no need for a face-to-face consultation when the NHS and other professionals already have the information.*</p> <p>The medical professional for ESA fills in a computer form. However, this form is not fit for purpose and a contracted medical professional has said it would be easier to write a letter for a benefit claimant with spinal disabilities. Scan results etc are important if you have spinal disabilities. Tribunal hearings are costly and the DWP should strive to get the decision right in the first place. *</p> <p>Question 12 All the evidence the DWP need can be supply be the NHS. Vulnerable people who have had strokes or have learning disabilities should not have to attend face-to-face interviews. People with spinal disabilities find it difficult and painful to get to an assessment centre. *</p> <p>If a surgical operation improves a disability, the GP should notify the DWP. The surgery's computer system should remind the GP. The DWP should also understand medical reasons why the NHS do not offer a surgical operation for some patients/benefit claimants. This means they have to live with disability. There should be different types of review depending on the disability of the benefit claimant – a stroke patient who has suffered paralysis 41 years ago is not going to recover.*</p> <p>Question 13 There should not be penalties because the DWP should be proactive in obtaining the information it needs to make a decision on entitlement of DLA or its replacement. Perhaps, writing to the GP asking whether there has been any change since the last review? GPs receive copies of reports from NHS consultants, physiotherapists etc.*</p> <p>Question 14 The CAB gave advice that I could be eligible for DLA. The CAB is facing significant fall in government funding and less help and advice is likely to be available. *</p> <p>Question 15 Minority claimant should be treated the same. A translator may need to be provided if the claimant cannot speak English. Written information needs to be in different languages, Braille and audio tape etc. *</p> <p>Question 16 We had to move into a more suitable property and the costs were met by us. Occupational Therapy has lent safety aids and equipment as accident prevention is important and to help disabled carers care for someone who was very ill 41 years ago. This is to prevent the carers suffering injuries. The cost of structure changes to the home has been paid for by us. The cost of car adaptations has been met by us. I have been helping to provide care since a young child despite having disabilities myself since a young child. If you work, a prepaid prescription certificate of £104.00 per year is charged for very essential medicines. Epilepsy drugs exempt someone from this charge but you are not told about this. However, most essential medicines are not on the exemption lists.*</p> |

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|                   |               | <p>Question 17 N/A*</p> <p>Question 18 DLA has not helped us access disability services. The GP makes a referral and has given advice. Universal credit is a system which will force/ensure more disabled people into poverty. Their savings will quickly be used and disabled people are less likely to live in the community. There is already an NHS bed blocking problem in Oxfordshire. *</p> <p>Financial help has been very important. Life is a challenge when you have a disability particularly when all family members have significant health problems. It likely the disabled person is already accessing other services.*</p> <p>Question 19 The GPs are already referring disabled people to other services.*</p> <p>Question 20 The GPs are already referring disabled people to other services. The DWP needs to request the information rather than carry out its own assessment.*</p> <p>Question 21 Saving money by altering DLA is false economy. To change the system costs money and a system is in place to review DLA decisions. Medical advances have saved people's lives and as a result more people are living with disability. *</p> <p>Question 22 Can I correct the following in the guidance document:*</p> <p>"Assessing the likely impact that impairments and health conditions will have on individuals overtime is often very difficult. For example, while a stroke may have a significant impact immediately after its onset, many individuals will recover and suffer little or no effects in the medium to long term". To be awarded DLA, a claimant who has had a stroke probably has some paralysis. Overtime, the tendon's and muscles in the paralysed limb or limbs tighten and this causes significantly more disability (not less). i.e. the foot drops and/or goes into spasm, the nails bite into the palm of the hand with the risk of infection. When it is severe like this, surgeons will operate but the problem is that the muscles and the brain have memory where the hand used to be and eventually the benefit from the operation goes. I am surprised that the DWP is not aware of the difficulties faced by disabled people.*</p> <p>I feel that new personal independent payment is about reducing the numbers that claim benefit rather than disabled people participating in society and leading independent, full and active lives. *</p> <p>Please would the DWP keep details of medical conditions confidential.</p> <p>Thank you. Yours sincerely</p> |
| EM373             | 09-Feb-11     | <p>Hello, Once again, instead of making our lives simple there is another initiative to check on us and make us reapply for the DLA every year. In my opinion, this is absolutely disgraceful. The DLA forms are really hard to fill in and time consuming so there needs to be a change in this field. However how can the government claim to support people with disabilities if they have professional interviews every year to decide whether or not to give the DLA to individuals? My son [REDACTED] is [REDACTED] and he has autism and his condition will not change. He will live with it for the rest of his life. Will I need to prove this every year by facing a professional and answering silly questions? Will they be checking on what I spend DLA money on next? He needs specialised equipment, Speech and Language Therapy and more clothes than other children. Who is going to pay for that? I would like to oppose this proposal.</p>   |
| EM374             | 09-Feb-11     | <p>Dear Sir/Madam My partner and I are both carers, We care for my son who has aspergers &amp; dyspraxia and my partner's mother who has alzheimer's they both live with us. I work part time as a support worker, we get working tax credit and also carers allowance, it can be a struggle both mentally &amp; financially. My son attends college and his DLA has helped buy his equipment ie a laptop(he finds it extremely difficult to write with a pen &amp; would not be able to keep up), mobile phone(has been used in a few emergencies) etc. My partners mother needs 24hr care, she is unable to do the simplest of tasks herself.(her attendance allowance bought a wheelchair &amp; also pays for her to go to a day centre once a week) My son and my</p>   |

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|                   |               | <p>partners mother both have thier good &amp; bad days, I fear if they are seen on a good day they maybe assessed wrongly &amp; and would lose these benefits, If that were to happen we would not be able to financially support them both. These benefits enable us to support them and keep them at home within a loving family. As I have stated I am a support worker &amp; most of my work is with people with disabilities, I see first hand how these benefits help people. I feel the Government should not be making cuts of £1 billion to disability benefits as this would have a devastating effect on many people. Carers are paid £53.90 for what can be a very tiring &amp; mentaly exhausting 100-140hr week.(Nobody should have to work this many hrs for so little) I feel Carer's Allowance must remain outside of the Universal Credit. Carer's save the UK a huge amount of money every year with the care they provide and it would be wrong to take away Carer's Allowance from some carers by means-testing it, as this would leave some carers without any recognition of their contribution. Yours sincerely,</p>  |
| EM375             | 09-Feb-11     | <p>My husband is severely disabled with progressive MS he is unable to walk and has no use in his hands and arms so needs someone help him 24 hours a day. There is no other way around this. He receives DLA at the highest rate for both components. We are entirely dependent on benefits and so this allowance is vital for us to alleviate the extra expense involved in severe disability. I am over 60 so cannot have carers allowance. People in our situation are reliant on DLA.*</p> <p>However I think there needs to be a rethink about how this allowance is granted as we personally are aware of very many people who receive this allowance on the higher rate who patiently obviously should not. One couple we know both receive DLA on the highest rate and have a Motability car each when the are both fully mobile.*</p> <p>The process of self assessment employed at present is open to abuse as it is obvious that people will always exaggerate what they need when they know doing so will result in more money and certain concessions. New claimants find this more difficult but there are so many who were granted DLA some years ago when it was easier to receive and if they were assessed now would not qualify.*</p> <p>If the assessments are done sensitively and take into account individual needs the system would be much fairer than at present and only people who really need help will receive it. Perhaps there should be a sliding scale of what amount is granted according to level of disability rather than withdrawing it completely for those with variable health problems. Please do not penalise genuine claimants because you need to cut costs, just make the system fairer and more compassionate.</p> |
| EM376             | 09-Feb-11     | <p>1. The "reforms" seem to be largely driven by the desire to save money by reducing the number of awards and this is couched in terms of ensuring that benefits are targeted at the most needy and general lofty and worthy assertions that actually ring pretty hollow to those in receipt of the current benefit.*</p> <p>2. The consultation mentions the misconceptions about the purpose and conditions for receipt of the benefit - this is no reason to change the criteria so radically. Clarification could be made public through an awareness campaign - that in fact more people are actually eligible than claim because of these misconceptions eg that it is a bar to working.*</p> <p>3. Just because more people claim than was first envisioned does not mean that they do not need help, particularly with mobility - maybe modern medicine has again given people more expectations that they can do things rather than accept their "lot" and sit in a wheelchair all day doing nothing.*</p> <p>4. I know some people who qualify for DLA at present and live in permanent fear that it might be taken away from them. They have overcome many obstacles and considerable and permanent pain in order to maintain their mobility and the benefit helps them to extend their lives and keep as active as they can within the community. Unfortunately they stand to become victims of their own courage and success in keeping going - with the help of</p>  |

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|                   |               | <p>their cars and other support when they need it and risk being told that they are able to manage well enough without the mobility benefit, which is their lifeline.*</p> <p>5. It is difficult to believe that this is anything other than a simple cost cutting exercise. It would be more honest to set a maximum figure for this benefit and, as with community care budgets in local authorities, it would be obvious that many people who need care are unable to have it so only a fraction of those who need DLA stand the faintest hope of getting it.*</p> <p>6. WHY DOES NOBODY SEEM TO TAKE INTO ACCOUNT THAT RESTRICTING PEOPLE'S MOBILITY AS THE PROPOSALS WILL DO WILL UNDOUBTEDLY RESULT IN GREATER COSTS ON OTHER PARTS OF THE PUBLIC . I AM THINKING PARTICULARLY OF THE HEALTH SERVICE WHEN PEOPLE DETERIORATE AND FALL VICTIM TO DEPRESSION, OBESITY AND OTHER PROBLEMS THAT OCCUR WITH THE NARROWING OF INTERESTS AND HUMAN CONTACT THAT WILL INEVITABLY RESULT FROM YOUR POLICY CHANGES. NOT TO MENTION THE FACT THAT (Incidentally I reckon that the free bus passes for pensioners must save a vast sum of money in such costs as well as taking trade into the areas we are able to visit).*</p> <p>7 How on earth are you going to ensure that the QUALITY of your Healthcare Professionals is of high standard? Many people were subjected to degrading and humiliating assessment procedures and it seems highly likely that the same will happen again this time round.*</p> <p>Those who were awarded DLA for life as their conditions were intractable and progressive, then had that commuted to indefinitely and they have to go through the ordeal of yet another re-assessment. Yours faithfully *</p> <p>Citizen - doing voluntary work helping people complete DLA and AA forms.</p>  |
| EM377             | 09-Feb-11     | <p>I am writing to contribute to the consultation process presently taking place. I am prime carer for my husband who has chronic heart disease, diabetes, thyroid disorder and associated difficulties. I also support my son who has asperger's syndrome, his condition leads to a lot of complex problems within his life and inevitably affects our lives too.*</p> <p>My main concerns are that assessments will not be carried out by people with specialist skills and in this area I am particularly concerned as there are few people within general medicine who have a full in-depth knowledge of autistic spectrum disorders and mental health problems.*</p> <p>Additionally my husband whose health has gradually deteriorated over an eleven year period and who I have been told could literally die at any time is worried that he is going to have his disability living allowance removed, the fact that this may be a remote possibility does not remove that worry from him and impact on his health, the knock on effect of this is that he needs more care/support/understanding and my burden is increased. There is indeed a possibility that my husband would qualify for higher rates of disability living allowance than he claims, he does not go through that process as he doesn't feel well enough to undertake the process involved, at the moment he at least has his life.*</p> <p>As a carer I am never able to fully relax or rest, I am on duty 24/7 and am frequently exhausted. I believe that living with so many problems and demands that stress inevitably affects my health too, if I am unable to carry on then the role I fulfil would need to be passed to Social Services. I am past retirement age and no longer receive Carer's Allowance and as such am already struggling to meet my own needs. I also find that what money I do have subsidises the needs of my husband and son, it is due to extreme care on my part that we survive and that they are cared for. If there is an intention to reduce allowances then the added worry may make me a patient rather than a carer.*</p> <p>There has always been a statement from Government that Carers are valued and supported by government and that they actively save the country money, the latest proposals seem to fly in the face of these statements. It would not be good for the country or for disabled people if the value and service of so many people particularly retired carers was ignored and</p> |

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|                   |               | benefits cut for those they care for. It is cheaper to have people cared for at home than within the care system and for this to happen there is a need for carers who are supported.   |
| EM378             | 10-Feb-11     | <p>i am a concerned parent caring for my 15 year old son who suffers from severe aspergers syndrome/High Funtioning Autism and live in south belfast , i read with dismay the concerns of our local support group who highlighted the forth coming DLA reforms .*</p> <p>i am worried that these changes will impact heavily on the benefits of people like ourselves which could possibly result in lost of benefit both dla and carers allowance which is so over the top i would challenge any goverment associate who may not be directly in contact with a person with a (lifelong) disability such as autism to step into the shoes (FOR JUST A WEEK)of any parent carer who is unfortunate enough to have a child with one of many conditions that effect their every day lives such as autism ....i tell you they would not last a minute because in my particular circumstances it is no walk in the park with challenging behaviour just one of the many issues associated with the above mentioned disability , there is no justification in reform as there is a danger of plunging carers and the persons suffering from all sorts of condition s into an unnecesary maze of stress*</p> <p>The care that that most genuine carers give is unpresedented ,but what the goverment is planning on doing here is surely like locking the gate after the horse has bolted senario !!!! at the initial introduction of these benefits all issues concerning it such as eligibility and grounds on which it is awarded should have been clearly set out back then and set in concrete ....not years down the line !!</p> |
| EM379             | 10-Feb-11     | <p>Dear Sir I am a 61 year old carer for my wife who has received 2 liver transplants for chronic active autoimmune hepatitis, she was first diagnosed in 1980 and since that date was prescribed a cocktail of drugs for immunosurpression. It was these drugs that brought on at first skin cancers and then the cancer spread internally, to this date she still receives constant care for the skin cancer and is at present receiving chemotherapy for secondary cancer of the lymph system. I maintained full time employment for the first 15 years and payed for every single drug therapy she received ending up with no savings left and thousands of pounds in debt, unfortunately I could no longer juggle work commitments with the demanding hospital schedule my wife had to go through, so I became a full time carer. I have been mean tested for every benefit we now receive but my own health has deteriorated to such a degree that I struggle to give the support she so desperately needs. I use every penny of the DLA and carers benefits just to get by daily. I am terrified that the changes that I hear proffered so lightly about on the news lately will impact on our present levels of benefit and I strongly urge you to listen to those organisations that lobby on our behalf and please consider the consequences of your actions where people like me (and there are thousands who care 24/7), when we ask you to leave these levels of benefits alone, better still pay the levels that any other worker would expect for these hours. kind regards</p>                                  |
| EM380             | 10-Feb-11     | <p>Dear sir or madam , Re changes to D L A , as a severely disabled person i am very worried about how these changes and possible decrease in benefits may effect people like me as i need said benefit to pay for carer and to help run my car as without these two things life would be intolerable Having lost one leg and the other being of very limited weight bearing capability and numerous associated problems , ie frozen shoulders and post traumatic stress this constant barrage of venom from the press and perceived attacks</p>  |



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|                   |               | from governments is nothing short of soul destroying for many severely disabled people ....yours faithfully  |
| EM381             | 10-Feb-11     | <p>I am a carer for [REDACTED] who has had M.E. for many years and I felt that I had to right regarding the changes that you plan to make to the disability living allowance benefit. I am concerned about the independent medical assessment that is going to accompany the new benefit called the personal independence payment, will this medical test really be fair?. I ask this because the company has re-employed the company that currently run the assessments for the dla benefit. They have a terrible success rate, out of those assessed by them as not disabled around forty per cent have their claims reinstated or awarded a higher amount upon going to tribunal, which in itself is a crass waste of taxpayers money. I also feel that to assess someone in thirty minutes and not take any notice of their previous medical history from their G.P. who may have known the patient for years is simply ridiculous. I know that many doctors are prejudiced against M.E. and other certain conditions as they do not believe that they exist and will have based their own opinions on the person before them rather than from a medical viewpoint, which makes the assessment biased and flawed. In the case of [REDACTED] and many people like her with M.E. and other debilitating conditions which can vary from day to day, what if the assessment is done on a day when they feel a bit okay in themselves will they be deemed as not disabled by the doctor when the next day the person can be bed bound?. The higher mobility component is essential for [REDACTED] as without it she would be housebound like many other disabled people. I think that taking away a disabled person's ability to be able to socialise, integrate within their community and travel about freely like an able bodied person when they are well enough to is in breach of their human rights to bar them from the ability to be independent and could also be seen as discrimination against disabled people under the disability discrimination act. As in [REDACTED] case as with many other disabled people their dla goes towards buying medication and specialist treatment that they need but they cannot get full access to them because they are not available on the NHS. No genuinely disabled person wants to be in the position that they are in, they did not choose to be disabled, like alcoholics and smokers who use a range of services within the NHS and cost the government and the taxpayer millions of pounds a year. I hope that this is genuinely thought out and the rough areas that I and many others will outline are ironed out before this benefit is put into practice. The government has vowed to protect the vulnerable and the needy, but in practice is this just a cost cutting exercise specifically targeting this very area of society?. A concerned voter and carer</p> |
| EM382             | 10-Feb-11     | <p>I set out below my comments on the Government's proposals*</p> <p>Question 1 Problems and Barriers -In my view one of the main problems to living a full and independent life would be a lack of financial security. If the DWP manage to target benefits effectively, as it intends, then it is no good bleating on at a later stage that beneficiaries have become "benefit dependant" As someone who has lived with Parkinson's disease for the last 14 years my symptoms have sometimes been ameliorated by drugs and surgery, however the underlying condition with Parkinson's is to get worse. I can't imagine anything more worrying than to constantly be looking over my shoulder because I might be better today than I was yesterday, then to have my benefit called into question only to find I am worse tomorrow. What I have valued is the stability of the present system. *</p> <p>Question 2: What should stay the same - The proposal to move to a more individually tailored benefit is predicated on the premise that DLA is overly complex, subjective and poorly targeted. However assessing each individual</p>  |

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|                   |               | <p>applicant will add to the complexity and will by definition be even more subjective As a consequence it is likely to be less well understood than the present system. It should not be assumed that Personal Independence Payment will target the benefit more effectively. If like Personal Health Plans PIPs grant an overall lump sums to be spent as the beneficiary chooses, is the DWP willing to accept that in some cases the money may not be spent to help with independent living?*</p> <p>It is also dependant on tranches of money being made available to those who meet certain criteria. The DWP must expect that in the early stages the allocation of monies may need to be re-adjusted. Motability should remain. *</p> <p>Question 3: Extra Cost - It is not necessarily extra cost that is the problem, it is more the lack of income to pay for the extra cost. Extra cost for me and my wife (carer) is the cost of train travel every other month, from Cambridge to London to check my deep brain stimulator (£52 cheap day return) + meal. First class rail travel should be free for those with a blue badge. (like senior civil servants) Membership of local council run leisure centres should be free to all beneficiaries*</p> <p>Question 5: Should some conditions have automatic entitlement - Yes definitely. Any condition which is terminal, or any condition which is degenerative for which there is no cure, and where symptomatic relief is transitory. Eg Parkinson's; Huntingtons disease; Motor Neurone disease; Multiple Sclerosis; Blindness. What is the point of re-assessing people who have satisfied the conditions for benefit and whose condition can only stay the same or get worse?*</p> <p>Question 6: Prioritisation - This should be a matter for clinicians*</p> <p>Question 7: Fluctuating Conditions - It should be the responsibility of the beneficiary on the advice of their clinician to report any <u>significant or permanent changes</u>. Like the driving licence for older people. The DWP will need to keep up to date with modern authoritative clinical opinion.*</p> <p>Question 8: Aids and adaptations - I do not know. Oscar Pretorius can run 100 meters in an Olympic time. It should not be assumed that everyone can achieve this level of success.*</p> <p>Question 9: Form filling - No comment*</p> <p>Question 10: Supporting Evidence - The applicants Consultant should supply supporting evidence. In the case of Parkinson's the Nurse Specialist could also undertake this.*</p> <p>Question 11: Face to Face Discussion - Often done in the past, less than satisfactorily in my opinion, by Regional Medical Officers and their successors. My experience is based on anecdotal evidence of fellow Parkinsonians who failed to convince the MO at the first hurdle but whose applications were subsequently approved. The presiding officer need not necessarily be medically qualified but does need a deep understanding of the condition they are assessing. They cannot and should not be expected to be "expert" in all conditions. For instance, I know more about Parkinson's and its treatment than my GP, who acknowledges this. I know little or nothing about other conditions.*</p> <p>Question 12: Frequency of Reviews - Reviews are irrelevant for those who have an incurable degenerative condition. Other conditions would need to be reviewed in accordance with the prognosis.*</p> <p>Questions 13 -17: - No comment*</p> <p>Question 18: Passports - Establishing a level where beneficiaries can be passported to other benefits/services would be an important, helpful and cost effective use of public money. In addition to train travel and gym membership already mentioned, heating and cold weather payments should be targeted at the disabled and the poor and should be a means tested benefit for others. Free prescriptions sight tests and dental treatment should also be passported benefits. *</p> <p>Questions 19 -21: - No comment*</p> <p>Question 22: Other comments - I agree with the proposal to leave those aged 65 who continue to be eligible for DLA unchanged, the reasoning for this is sound. Although Parkinson's is characterised by tremor or freezing, it</p> |

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|                   |               | <p>is not just a movement disorder people with Parkinson's also often have to contend with sleep deprivation and anxiety, the drugs essential for movement have devastating side effects, such as hallucinations, delusions, problems with cognition, hyper sexuality and obsessive behaviour such as gambling. A test such as can you pick up a £1 coin from the floor without falling over fails completely to assess the applicants abilities. Assessors should consider applicants when at their worst not when they are at their best. Greetings by assessors such as "how are you today" and which elicit the answer, "very well thank you" should not be interpreted literally. Social courtesy should not be misused in this way,*</p> <p>The DWP should exercise caution and not be over zealous in its attempts get people back into work. Proper account will have to be taken of the jobs market locally as well as the intellectual capacity of the beneficiary.*</p> <p>From my own experience, as a self employed management consultant, I had an income protection policy, which paid up without fuss when I could no longer do my job. I had one visit from the Insurance company to establish my claim and a second visit a couple of years later to "see how I was" Are their lessons here that could usefully apply? It has taken me 8 hours to draft this!</p>   |
| EM383             | 09-Feb-11     | <p>Dear sirs, I am writing to you to express my concerns about the replacement of DLA with PIP. I have two children aged [REDACTED] and [REDACTED] who both have autism (classic Kanner autism) and, the case of the eldest, complex and multiple learning difficulties, and the youngest, severe learning difficulties. Both children require 24 hour care have no verbal communication, display challenging behaviour and lack any sense of danger, as such they currently qualify for higher rate DLA care and mobility allowances.*</p> <p>I am very concerned that the introduction of a medical test to assess DLA will be biased against those with learning disabilities, especially in assessing the mobility component of DLA. How can a doctor in a small room assess the fact that such young people are a danger to themselves and others when out and about, and how their variable condition affects them day to day? When completing DLA forms we have the opportunity to include supporting documentation such as social services risk assessments and sensory profiles to support our claims. We also feel that attending such an appointment would be very distressing for our children, as they find new places and situations very difficult.*</p> <p>Should the new PIP result in a reduction of benefit for either of them it would have significant consequences for the family. My husband and I have both been full-time carers for a number of years. Our family is constantly strained to the limits of endurance; cuts in the household income, accessibility to transport and services may well strain it past breaking point. Instead of saving money such cuts would result in the government in having to provide residential care for my son and daughter which would cost far more per annum than it would to provide the support we need. Yours faithfully,</p> |
| EM384             | 10-Feb-11     | <p>Dear Sir / Madam I went to a DLA Consultation meeting held at [REDACTED] deaf centre last week.*</p> <p>I have copied out all the questions from the Easy to Read version and I have typed in my response and the document is attached. The replies are my own personal views, and not those of the people present at the meeting. I would be grateful if my name is not used as there does not seem any need for a person to add their name and address to the document. Best Regards*</p> <p>*<br/> Question 1 : DEAF PEOPLE COME ACROSS BARRIERS TO COMMUNICATION IN THE HEARING WORLD. NEED MORE DEAF AWARENESS AND MORE MONEY TO SUPPORT DEAF COMMUNITY. MUST STOP DISCRIMINATION*<br/> Question 2 ; THE SAME, NO CHANGE.*<br/> Question 3 : MONEY ON COMMUNICATION AIDS. SOME BIG COMPANIES MOVE JOBS TO INDIA FOR EXAMPLE. DIFFICULT FOR DEAF PEOPLE, AS IT IS NOT FACE TO FACE ANYMORE.*</p>   |

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|                   |               | <p>Question 4 : KEEP THE SAME*</p> <p>Question 5 : KEEP FOR DEAF, BLIND AND PARALYSED PEOPLE AND WHEELCHAIR BOUND PEOPLE *</p> <p>Question 6 REPLY : NEED TO REGISTER ALL DISABLED PEOPLE. REINTRODUCE THE 'GREEN' DISABLED CARD AS A PHOTOCARD. NEED GP TO VERIFY THIS.*</p> <p>Question 7 : DOCTOR OR A SPECIALIST TO DO A REVIEW EVERY 3MONTHS OR 6 MONTHS AND REPORT SENT TO DWP.*</p> <p>Question 8 : NEED TO KNOW WHAT AIDS ARE AVAILABLE FROM THE MANUFACTURERS. CATALOGUES SHOULD BE AVAILABLE AND SHOW COSTS.*</p> <p>Question 9 : NEED FOR PEOPLE TO BE REGISTERED DISABLED. VIDEO IN DOCTORS SURGERY, HOSPITALS, TO RAISE AWARENESS*</p> <p>Question 10: A DOCTOR OR SPECIALIST CAN HELP. HEALTH PROFESSIONAL OR SOCIAL WORKER WHO KNOWS THE PERSON ASKING FOR BENEFIT. FAST TRACK BENEFIT.*</p> <p>Question 11: IF YOU ARE DEAF, AND MEETING FACE TO FACE, THE PERSON MAY NEED AN INTERPRETER. THE ONLY TIME IT WOULD NOT BE RIGHT IS IF THE PERSON IS IN HOSPITAL.*</p> <p>Question 12: THE DWP NEED AN UP TO DATE DATABASE WITH A CLAIMANT 'FLAGGED' FOR CHECKING. POSSIBLE EVERY 3MONTHS OR SOONER. THE CLAIM SHOULD DEPEND ON THE NEEDS OF THE PERSON, THEIR HEALTH, AND DISABILITY (ALL THREE).*</p> <p>Question 13 : THE DWP CAN ASK FOR A REVIEW WITH AN INDEPENDENT PERSON. NEED A DATABASE SET UP. THE TECHNOLOGY IS THERE. MAYBE EXPENSIVE TO INTRODUCE.*</p> <p>Question 14: DEAF PEOPLE MAY NEED AN INTERPRETER. BLIND PEOPLE NEED PERSON TO READ NOTES. NOTETAKER NEEDED FOR PHYSICALLY HANDICAPPED PEOPLE MOST PEOPLE MAY ALREADY HAVE HAD HELP AND ADVICE. *</p> <p>Question 15: SOME PEOPLE GET THEM FREE FROM THEIR LOCAL AUTHORITY. SOME PEOPLE PAY FOR THEM. SHOULD BE ALLOWED A ONE-OFF COST. *</p> <p>Question 16 : THE PARENTS OF THE DISABLED CHILD TO GET THE BENEFIT TO PAY FOR AIDS OR ADAPTIONS AS A ONE OFF COST.*</p> <p>Question 17: AT THE MOMENT PEOPLE WHO RECEIVE DLA CAN GET OTHER BENEFITS. POOR SERVICE FOR DEAF PEOPLE. IF OTHER BENEFITS CUT THEN DISABLED PEOPLE CANNOT LIVE AN INDEPENDENT LIFE.*</p> <p>Question 18: DISABLED PEOPLE SHOULD HAVE A REGISTERED DISABLED PHOTOCARD WITH A PIN NUMBER. CAN SHOW THIS AND GIVE PIN NUMBER AT HOSPITALS ETC.*</p> <p>Question 19: THERE IS ALSO THE WELFARE RIGHTS ORGANISATION TO CONSIDER. NEED CONSULTATION WITH DIFFERENT GROUPS AT A FORUM.*</p> <p>Question 20: IT IS ABOUT TIME THE DWP LOOKED AT PEOPLE WHO ARE ABLE, AND DISABLED, WHO ARRIVE FROM OVERSEAS AND CAN CLAIM AFTER 6 MONTHS LIVING IN THIS COUNTRY.</p> |
| EM385             | 10-Feb-11     | <p>Sir/Madam, I respond to this Consultation Paper as an individual, age 67, having been diagnosed with Primary Progressive Multiple Sclerosis in 1995 and been in receipt of DLA for some years and specifically the middle rate care component and higher rate mobility component from 31/10/2005. The time scale of both these entitlements are described in annual letters "About the amount of money we pay you" by the Department of Work and Pensions as "indefinitely". *</p> <p>At the beginning of December 2010 I entered into a 3 year agreement with "Motobility" for the lease of a car, with adaptations to assist me in catering for my disability, for which the whole of the higher rate mobility component of my DLA is paid direct to "Motobility". *</p> <p>I did raise the issue of the last government's Social Care Green Paper on proposed changes to DLA with my MP Alistair Burt and he kindly sent me a</p>  |

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|                   |               | <p>copy of the record of the debate in Parliament, as recorded in Hansard, and I will forward a copy of this email to him for his information.*</p> <p>The proposal to radically reform DLA announced in this Consultation Paper comes as surprise to me as the Conservative's pre-election manifesto pledged to protect it. The Government now tells me that the current DLA expenditure is "unsustainable" and they want to cut the number of people receiving this benefit by 20%. On the basis of the numbers identified this approximates to over 360,000 disabled people losing their DLA. I recognise and have no objection to checks and balances being introduced in the DLA process I do however have some comments on the proposals outlined in the Consultation Paper.*</p> <p>From my reading of the document the Government will introduce "Personal Independence Payment" in place of DLA in 2013/2014 but are still considering whether to reassess my case(as I am over 65). It is suggested however that I may continue to receive PIP if my needs continue(Chapter 2 para 10). This entitlement is to be the subject of a "new ,fairer,objective assessment"(Chapter2 para 4)which will be subject to periodic reviews( Chapter2 para 5. This therefore leads me to be uncertain about my likelihood of future entitlement. I have to say that despite all the research undertaken to date I am unaware of any cure having been discovered for Primary Progressive MS.*</p> <p>The apparent lack of any recognition in the Consultation Paper that there are disabled people who have been diagnosed by competent medical practitioners to have medical conditions which, I suggest, don't need to be re-diagnosed/reassessed other than those identified in Annex 1 can only lead to increased costs in a what will clearly be a very expensive exercise.*</p> <p>In terms of mobility further uncertainty is raised for current recipients of the mobility component of DLA by the vague proposals, outlined in paras 25 and 26 of Chapter 2, for the future assessment of entitlement to the mobility element of PIP.*</p> <p>The new assessment process is a significant movement of the goalposts by government, from a position where one currently understands the word "indefinitely" in the DWP's annual letters of DLA entitlement and as a result have been able to confidently forward plan one's investment in alterations and adaptations to the home and in the purchase of aids to cater for reduced dexterity and mobility in and around the home environment to one where I am now faced with total uncertainty as to if, when and how this situation will have any clarity for me going forward.*</p> <p>The actions my wife and I have taken in the home environment and in respect of my mobility needs in recent years and the forward planning we have envisaged for the future have been influenced by my receipt of DLA. The level of uncertainty for the future now created by the proposals outlined in this Consultation Paper creates a further stressful situation for us. Stress exacerbates the MS condition and is one symptom/circumstance which we already strive to relieve on a daily basis.</p> |
| EM386             | 10-Feb-11     | <p>I am now extremely concerned about the consultation on Disability Living Allowance. I am in danger of losing my independence and ability to remain living in the family home due to the removal of my home care service by local government cuts; now, in addition, I face the prospect of losing my mobility when I am forced into residential care.*</p> <p>My condition is complex and medical constraints mean that I can only be away from home for periods of three to four hours at a time. By meticulous planning of my care provision and the use of my own transport I manage to chisel out periods of time when I interact with the world outside in a meaningful way. Removal of a flexible care service and of my own transport will destroy my life.*</p> <p>On the DLA consultation – the Disability Living Allowance was clearly a successful benefit that enjoyed good uptake. I am shocked that the Government could consider fanning the flames of misunderstanding and prejudice against disabled people by withdrawing assistance. The Government claims to protect the most vulnerable in Society. It appears that</p>  |

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|                   |               | <p>they do not protect the second most vulnerable. Need is need and should be met with assistance in a civilized society. The Big Consultation in Norfolk clearly showed a desire among Norfolk people to preserve a meaningful social service for its vulnerable citizens.*</p> <p>Disability is complex and varied and can be greatly increased by the combination of medical and social factors. The combined effect is unpredictable and difficult to quantify by objective tests alone. It is, therefore, essential to listen to the disabled person's subjective comments and place them at the centre of the decision making process. Medical staff are used to tackling individual health issues and are notoriously bad at taking a holistic and long-term approach to problems. Care must be taken not to medicalise our social service.</p>   |
| EM387             | 10-Feb-11     | <p>To Whom It May Concern, I would like to take this opportunity to state that whilst I have been in receipt of DLA since 2002, it has enabled me, at times, to live a fulfilling, worthwhile and rewarding life and has provided me with the resources necessary to alleviate some of the personal suffering I have experienced as a result of being a manic depressive.*</p> <p>It has provided me with care, which I believe has been superior to that I would have experienced in a nursing home, which may have been the case before the introduction of DLA. The money given to me through DLA has meant that I have been able to pay for central heating, water and lighting and also a nutritious diet (when I am capable of preparing it-or buying it in town). *</p> <p>I very much support the Personal Independence Living Plan in some ways, as it is not a move in the direction of institutionalised care, but rather in the opposite direction. I wholeheartedly agree with the the increased emphasis on work, and I am wondering how this fits in with Disability Working Tax Credit. By 2013/2014, I may have been lucky (and have worked hard enough) to gain meaningful employment. So I do not know whether I will be taking advantage of the Personal Independence Living Plan when it is introduced. However, I am a bit confused about why DLA is now putting the emphasis on Cash Payments. Does this mean that benefits will be paid via a payment book or girocheque? I would have thought this might cause some people difficulty. My bank has always processed all my benefit payments on time and because of direct debits this has meant that I have not had to endure the stress and worry of paying my utility bills directly. Indeed, the services offered by my bank have supported me with my disability. However, I have had payments books in the past, and assuming I can make it to the Post Office, I would have no problem with this if it is necessary.*</p> <p>I think the emphasis on increased contact with the GP rather than hospital consultants is a good idea. I could not cope with going to the hospital for my last visit with my Consultant Psychiatrist-so she had to come and visit my home. The amount of contact with Doctors and Nurses over the years has meant that I find it increasingly more hard work to see a Medical Professional. I would worry about a face to face meeting with a DLA Medical Professional for months, and this would aggravate my condition very badly. I am also increasingly aware about how much it costs for me to receive medical attention. Whilst working, I did a feasibility study on telehealthcare. Would it not be possible for me to be medically assessed over the telephone?*</p> <p>I don't know if more ongoing assessment is required for the Personal Independent Living Plan. Whilst I have no problem about giving information about my particular health condition, continuous assessment would cause me a lot of worry and anxiety.*</p> <p>I strongly support moves that are being introduced so that DLA is not necessarily stopped on entrance to hospital. I once had to repay DLA, which was a lot of money, and I understand now that it is possible to pay the hospital directly without stopping DLA Benefit. *</p> <p>There has been some rumour, that the mobility component of DLA is to be stopped. However, the consultation document does not appear to be stating that this benefit will change.*</p> |

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|                   |               | <p>I was a bit upset, in a way, to discover that DLA will change in 2013/2014, as I had read in the media that the benefit was going to be retained, whilst other benefits would come under the umbrella of Universal Credit. But I realise, now, that the benefit is to be retained in some form and would be reformed in 2013/2014. I have been awarded DLA indefinitely.*</p> <p>Yours Sincerely,*</p>  |
| EM388             | 10-Feb-11     | <p>I am responding to the Department for Works and Pensions Public Consultation concerning the Disability Living Allowance Reform. I am giving a response in my capacity of parent and carer of three disabled children. One has Aspergers, Dyspraxia, Dyslexia and Dyscalculia. Another child has Aspergers, Developmental Co-ordination Delay Disorder, and severe Dyslexia. The other child is incontinent and is currently undergoing an assessment for Aspergers. I am also responding as a part time care for my sister who is paralysed from the chest down.*</p> <p>Question 1 – If the disability is a mental health issue such as Aspengars, then the barrier that prevents the person leading independent, full and active lives is the disability itself. The general assumption in the proposal is that to lead an independent, full and active life is geared around the person working but the mental health disability can prevent people getting jobs and which no amount of aids and adaptations will help with. Their mental health may prevent them getting a job in the first place particularly if because of their impaired health capability, they do not have basic qualifications such as GCSE Maths and English which a lot of jobs have as a minimum requirement. A lot of persons with mental health disabilities may only be able to do volunteering jobs that are low responsibility, few hours and more importantly no pay.*</p> <p>Question 2 – I am unsure.*</p> <p>Question 3: The main extra costs that disabled people face are *<br/>aids and adaptations they require *</p> <p>This covers both aids and adaptations for both physical care e.g. an electric tooth brush because they are unable to use a normal toothbrush and mobility and mental care.*</p> <p>*<br/>Cost of hiring someone to help care for their needs*<br/>*</p> <p>They may require specialist food which is more expensive than normal foods i.e. gluten free *</p> <p>Cost of respite care for the main carer.*</p> <p>Question 4: While having just 2 rates for each component will make it simpler; there is cause for concern in that it may group people together with widely varying needs. How do you compare mental heath disabilities with physical disabilities?*</p> <p>I am concerned that people who currently fit into the middle rate of care allowance will be pushed into the new bottom care allowance rate and hence lose out when they have more care needs than some of those people in the existing bottom rate.*</p> <p>Question 5: Some health conditions and impairments should mean an automatic entitlement rather than be based on the needs and circumstances of the person applying. The person may have to wait quite a long time before being assessed and an award being granted and the health condition and impairments will significantly affect their lives from the beginning. The individual may not be able to pay for the extra costs as a result of the disability from day one that the award would help pay for.*</p> <p>Question 6: Activities most essential for full and active lives includes *<br/>Personal Hygiene. *<br/>e.g. washing / brushing teeth / toileting *</p> <p>*<br/>Personal Care*</p> |

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|                   |               | <p>Are they able to care for themselves ; keep themselves safe and secure*<br/>*</p> <p>Communicating and understanding others*<br/>Are they able to understand speech ?*<br/>Are they able to take part in a conversation with another person or more than 1 person ?*<br/>Are they able to understand the written word ?*<br/>Are they able to use writing as a method of communicating i.e. are they Dyslexia ?*<br/>*</p> <p>Getting Around*<br/>Are they able to go from one place to another safely by themselves ?*<br/>Are they able to use public transport by themselves ?*<br/>*</p> <p>Money*<br/>Are they able to understand the concept of money ?*<br/>Are they able to budget their own money successfully ?*<br/>Are they able to use a bank account in their own name ?*<br/>Are they able to understand the concept of bank cards / credit cards / loans and mortgages ?*<br/>*</p> <p>Question 7: The assessment should take the worst base line of the impact of the disability on the activities of the person i.e. it should be based on the worst impacts of the condition to truly reflect the impacts. This is because the worst impacts affect all of the person's life because they have to be prepared for the worst impact of their condition to happen and they have to have the financial and physical support ready for the worst impacts.*<br/>*</p> <p>One of the major concerns with any possible face to face assessments is that the assessment may be done on one of the good days and hence give a misleading impression of the impact of the disability on the person's life. The assessor should take into account verbal and written evidence of the worst case scenarios rather than just on the person sitting in front of them.*<br/>Question 8: No, the assessment should not take account of aids and adaptations the person uses. The whole point of the benefit is to help with the extra costs of the disability and the aids and adaptations that the person uses are extra costs above what a non-disabled person would use and need.*<br/>These aids and adaptations need to be maintained and cared for and often insured, all of which is extra costs above what a non-disabled person would need. If an aid and adaptation were to break down the person would want to use DLA to either replace or repair the item and if the award is not sufficient to do this because the assessment took account of it, then the person may not be able to replace or repair it and may be discouraged from getting the aid and adaptation in the first place.*<br/>Question 9: One of the problems with the existing form is that it has a lot of text boxes where you are required to enter your own words. This can make it very subjective and depends a lot on how good the person is at explaining their condition and problems. This leads to some people getting an award because they are good at explaining themselves and others not getting the award if they are unable to communicate effectively their problems and issues. This issue could be overcome if the text boxes could be replaced with tick boxes as much as possible. This would then cause issues because tick boxes are unable to cover every situation but it would be better than the existing free format text boxes. *<br/>Question 10: I think that in all cases the best supporting evidence and the person best placed to provide this is the person applying for the award as they know their condition and disability best. Their evidence should be considered above that of any health care professional. After that, the next best placed would be the professionals that work closely with the person on a long-term basis such as the GP and social worker as they are aware of the</p> |



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|                   |               | <p>person's disability over a long-term period.*</p> <p>Question 11: One of the benefits the face to face meeting would bring is for the person to be able to verbally express their disability and problems to a professional that it may not be possible to express on a claim form. Another benefit is that professional would be able to see for themselves the issues and problems that the person faces. However, there are a number of difficulties that a face to face meeting will bring:*</p> <p>*</p> <p>Is the professional qualified to make an accurate assessment of the disability and problems? The issues faced by a person suffering from a mental health disability would be greatly different from that faced by someone in a wheelchair. The professional doing the face to face meeting must be qualified to judge the disability. This is of vital importance.*</p> <p>What happens if on the day of the face to face meeting, the disability is not at its worst i.e. the person is having a good day. The professional will not be able to get an accurate picture of the disability and this may affect the award given. This is particularly true of mental health disabilities where a single face to face meeting will not give an accurate reflection of the problem whereas the evidence provided by the social worker would because it is based on the issues and problems over a long-term period.*</p> <p>What if the person is unable to communicate effectively due to their disability? What impact will this have on the face to face meeting and hence the professional opinion.*</p> <p>*</p> <p>Question 12: I think that the idea of reviews is a good one in that it makes sure that the award is still correctly given to the correct person.*</p> <p>Question 13: The method of reporting changes in circumstances should be simple and straightforward but at the same time should be able to cope with changes in both physical and mental disabilities. Also the turn around time of responding to the changes in circumstances should be as soon as possible so that people do not then have problems with over and under payments.*</p> <p>Question 14: Due to widely varying causes of disabilities and the need to claim the award, the type of advice and information varies widely and I am concerned that offering guidance to people may make the application confusing. Also, I would think that people would already have tried active and positive steps towards improving their disabilities prior to attempting to claim the award so in fact the advice and guidance may be not relevant.*</p> <p>Question 15: I am very concerned about the requirement to access advice and support being made part of the requirement to get the award as the advice and support may not be appropriate. Who would decide the advice and support that must be followed and would they be knowledgeable enough in the disabilities to know whether it is appropriate in the individual case. I am also concerned that the system may automatically remove the person's award because they failed to follow the advice and support without knowing the individual reason behind the failure.*</p> <p>Question 16: In my case, the DLA is used to fund some of the aids and adaptations because the aids and adaptations tend to be quite expensive and hence we must use the DLA to pay for them.*</p> <p>Question 17: The main point to make is that the carer's opinion and statements must be given priority as it is the carer who looks after the child 24 hours a day 7 days a week and who understands the real problems of the disability both in terms of the impact on the child and also the impact on the family. Also, please note that not all children are taught in schools. A significant number are home-educated and receive DLA because of their disability. The eligibility must take account of this.*</p> <p>Question 18: DLA is vital at getting access to other services / entitlements and discounts. It is a proof of the person's disability to gain access to the other benefits. It means that you don't have to prove that you have a disability ever time you require the other benefits.*</p> <p>Question 19: The links to other benefits and services is very vital. One of the important links to other benefits is the link to carer's allowance. If this link is</p> |

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|                   |               | <p>broken, then a lot of carers would be unable to afford to give the disabled person care and that would mean more burden on the state to provide this care which would come at a far greater cost.*</p> <p>Question 20: While the idea of combining different assessments is on the whole a good idea, great care needs to be taken to make sure the assessments being combined are compatible. Also there is a concern that the failure at one assessment may mean a whole range of benefits and services would be denied to the person. The person's right to privacy and data protection issues will need to be paramount when deciding what information may be shared between agencies. There are too many examples of data being lost and misused for the utmost care not to be taken on this issue.*</p> <p>Question 21: I am concerned that the whole basis of the proposal is about getting disabled people to work which on the whole is a good idea but it must not be at the expense of the person. Not all people with disabilities can work and those who can work may be only able to do certain jobs at certain times such as volunteering jobs which do not pay. I am concerned that the proposals will force some disabled people to seek work when they are not in a condition to do so and then penalise them if they don't find work.*</p> <p>The whole point of the proposal should be trying to help people to help themselves, not force them to work if they cannot. I am very concerned that the proposal may push genuinely disabled people into poverty by withdrawing benefits that they currently rely on. Thank You</p>  |
| EM389             | 10-Feb-11     | <p>Dear Sirs 1. I am writing to express my concern about the cuts and Reforms to DLA because although I cannot see how any fair-minded person with judgement could doubt that my daughter, aged [REDACTED], should qualify, I still have grave doubts about these plans. My daughter qualified for DLA prior to school age and I had to renew the application every 3 years. It was quite a difficult and time-consuming procedure, involving several professionals. At age 16 she was awarded DLA For Life because it was recognised that her condition would not improve. *</p> <p>As I approach the end of my life, like many in my situation, I am naturally looking for as much peace of mind as a parent and carer can have when leaving a very vulnerable, handicapped son or daughter, so dependent on the goodwill of others, at all levels. The DLA award For Life was significant to this especially as it is recognised nationally and links in to other relevant areas of care and funding etc. Losing this would deplete her life chances significantly. As I am sure you will understand, DLA is a crucial element to my daughter's life and well-being, as it undoubtedly is to others in a similar situation. Certainly it seems quite unreasonable for those Awards of DLA 'for Life' should be 'wiped out' in this way.*</p> <p>Naturally, when a 'For Life' award is cancelled after only 14 years, it does not give one much confidence in the meaningfulness of any alternative plans. *</p> <p>2. Like everyone, my daughter has good and bad days and it could well be, again, like others – that the full extent of her condition – Learning Disability with Autism – is not appreciated when she is assessed. I understand others may be much more at risk of this than she is and sympathise with their predicament.*</p> <p>3. Although I have been fortunate to manage to work part time, I have only ever been paid for 47 weeks a year – with no payment for August. However, to allow me to have some money in my account each month, my earnings for 47 weeks are divided over 12 months. This resulted in my not being eligible for Carer's Allowance. It has been difficult and stressful to juggle caring with work but I strived not to be a burden on the state or dependent on 'means testing' which I would have been had I not worked, even though mine is a comparatively low-paid job. However, I accept I have been lucky manage to remain in work throughout the whole of my working life. However, my caring role has restricted my career, earnings and hours of work considerably and this has affected my pension adversely, too.*</p> <p>I do feel that the Carer's Allowance is such a help to those who depend on it and find it very hard to comprehend how or why there should be any desire</p> |

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|                   |               | <p>to remove, limit or reduce this, especially bearing in mind the tremendous amount of money carers save the state each year. Surely people should be encouraged and enabled to care? Most carers are at the very low end of the financial spectrum – indeed the earnings criteria to qualify ensures this is so. Any reduction or limitation of Carer's Allowance can only result in a loss to the disabled people they care for at present. The effect of this could well exceed any savings made.*</p> <p>4. I am amazed, so very disappointed and distressed at the variety of plans to deprive the disabled of their benefits, their carers and level of care currently received. There is so much rhetoric about equality but unfortunately this does not seem to extend to the disabled. These cuts and changes will devastate the lives of so many who have done nothing to deserve it. Although benefits may not remedy a disability that does not mean one should stop trying to alleviate the disadvantages.*</p> <p>I am sure there is a degree of abuse, as there is in every walk of life, at every level – which should always be borne in mind. However, this could surely be reduced significantly by Reviews etc, rather than this shattering effect on the lives of the majority of claimants who are absolutely genuine by such drastic and draconian measures? Implementing the system change and monitoring will surely be a vast expenditure?*</p> <p>5. The removal of Carer's Allowance through means-testing will reduce the numbers of those able to care, who also have to live themselves. Carers are already known to be disadvantaged by their caring role in many ways. Surely Carer's Allowance should be excluded from the Universal Credit Proposals? Yours faithfully</p>   |
| EM390             | 11-Feb-11     | <p>I am the parent of a profoundly disabled child who will turn 16 shortly after your proposals are due to be implemented and I would respond to some of your questions as follows:*</p> <p>4. I find the current benefit/rates easy to understand.*</p> <p>5. Claims should be based on individuals needs and circumstances as many conditions can affect people in different ways and result in a broad range of needs.*</p> <p>6. Priority should be given to those unable to do any activities for themselves - getting out of bed by yourself is a good place to start for essential activities. Being able to communicate and understand should also be considered here.*</p> <p>7. Maybe a better link with health care professionals so that you are automatically advised by them.*</p> <p>8. Consideration needs to be given to the fact that maybe some people don't realise what aids and adaptations they are eligible for/could easily obtain.*</p> <p>9. Make the process for renewals easier where the individual has been born with the disability and they will remain with it for the rest of their life. I appreciate that needs and circumstances may change and there has to be a review process but for the most profoundly disabled, this should be more straightforward.*</p> <p>11. While I appreciate it is out of respect, your consultation document implies the individual will be able to have a discussion. Carers should have been given more credit.*</p> <p>12. There should be less reviews (and less cumbersome reviews) for individuals with disabilities they have been born with and won't recover from.*</p> <p>13. Sometimes coping with the change is hard enough without having to remember to keep the Department informed, you will never get everyone to do this. In addition, it can be a number of years since a form was completed so individuals may forget what they originally advised or they may simply not know what sort of things to advise the Department about. In the case of an individual on the highest rates of mobility and care, if things change for the worse they may consider it not worth advising the Department as they know they can't get additional money.*</p> <p>14. Yes it would be helpful to provide other advice and information as part of</p> |

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|                   |               | <p>the benefit claiming process as many people are not aware of what is available, especially when first applying and often other help is only stumbled upon by chance.*</p> <p>16. It depends on what the aid/adaptation is. Some of these are considerable in cost and/or may need certain knowledge/expertise.*</p> <p>17. Your consultation refers to an active life but doesn't consider the basic day-to-day things which may be an overwhelming part of a disabled persons life and, in the case of children, how this impacts on normal family life. For some, particularly children when their needs are still perhaps being understood, there are regular hospital appointments/hospital stays/surgery required. This may mean a parent/parents not being able to work due to caring responsibilities. Some specialist care may not be available locally, involving much travelling (and associated costs) as well as impacting greatly on family life, particularly that of siblings and this may involve great difficulty and/or childcare costs. For children with complex needs, ongoing reviews are required, often spread across a number of different hospitals and this is time consuming and costly. There are also the costs and time involved in organising medication - how much time these "simple" things take should not be underestimated as well as possible costs of transport. Families with children with profound needs rarely spend a day not speaking to a health care professional and this is very time consuming. Everyday basic tasks like shopping, cleaning etc are more difficult when you are caring 24/7 and, when your child is in hospital or recuperating, these problems are exacerbated. There is nothing normal about life at all and the disabled child requires all your energy and time and, referring back to a previous question, are families supposed to remember to advise the DWP of what's happening in amongst all this? Unrealistic. Any reform needs to consider all aspects of a disabled persons day-to-day life and the impact this has e.g. tube feeding, epilepsy, challenging behaviour etc etc.*</p> <p>18. DLA and the Blue Badge Scheme and the Motability Car Scheme should be better linked. At present you need to have at least 12 months DLA remaining to renew your Blue Badge or motability vehicle but frequently there is not, involving a request to the DWP for an early DLA review and usually a period with no blue badge or having to extend the lease on your current car. This is a laborious and frustrating process and while the link is a useful system, it needs to be better co-ordinated.*</p> <p>19. Life is hard enough, it is really helpful if just one small thing is made easier.*</p> <p>20. Just make the process easier for individuals with profound life-long conditions.*</p> <p>22. Sounds good in theory. I like the idea of a review for all as I get frustrated by the complicated process I go through to renew DLA for my son who was born with profound life-long needs, and my renewal can be delayed while checks are made, yet I know there are many fraudsters who seem to get the benefit easily - are the same rigid checks not made for everyone?*</p> <p>With regards,</p> |
| EM391             | 10-Feb-11     | <p>My Name is [REDACTED], I am the parent / primary carer living in Essex, I am very concerned about losing my Carer's Allowance and my daughter losing her DLA. My daughter is aged [REDACTED] and has been diagnosed in the Autistic Spectrum Disorder, she has complex learning difficulties, and attends a special school, and she has limited social skills, challenging behaviors, speech, and communication &amp; language difficulties. I need to help my daughter manage the difficulties that she has with daily living, her personal care, she needs someone to be with her when outdoors &amp; to keep an eye on her. Her mental development is significantly behind her chronological age and understanding. She needs to be able to access her after school/holiday clubs and other charity run special clubs and events, where she can interact with her peers, as we live in a rural area we incur considerable extra travel costs taking our daughter to all the various locations to partake in these events. Attending these events has helped our daughter to improve her limited social skills and is an important element in</p>   |

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|                   |               | <p>aiding her into fuller inclusion into the community and a source of enjoyment to her. Some members of the family have moved away and she likes to keep in regular contact with them, as a teenager she would like to text, which she is unable to do, and the process of explaining herself on the telephone is very time consuming, not always successful and requires many repeat phone calls for her to clarify the initial conversation, all of which adds up to further extra costs. She still requires a high level of personal care and the care component pays for those areas of care. I am worried that my daughter will lose her DLA, which will result in her losing her independence and full inclusion into society. As our Daughter suffers from a mental health condition and complex learning difficulties which is very hard to assess on an initial meeting, we have had medical and non medical professionals make incorrect assumptions which has resulted in poor or total inaccurate assessments of her needs, each time that this has happened it has meant that many hours of both our and the Professional time has been spent in insuring that the assessment is correctly reviewed. *</p> <p>My spouse has chronic long-term health issues and in constant pain, this means that he is only able to gain employment in a low paid job, but needing to work long hours. The carer's allowance therefore is needed to subsidise the household income and also to enable me to access complimentary treatment for my long health term issues. I believe the Government should not be making cuts of £1 billion to disability benefits because of the devastating consequences it could have for disabled people and carers, and also that the Carer's Allowance must remain outside of the Universal Credit. Carers save the UK £87 billion every year with the care they provide and it would be wrong to take away Carer's Allowance from some carers by means-testing it, as this would leave some carers without any recognition of their contribution. Regards,</p> |
| EM392             | 10-Feb-11     | <p>1. Your response: Inadequate support. Equipment that is not funded through social or educational services is more expensive. Continual assessment to provide you are entitled to services or benefits. *</p> <p>2. Your response: The process should be made easier as filling out about what you are unable to do is distressing but this shouldn't take away the three levels of support.*</p> <p>3. Your response: Everyday equipment is more costly e.g. mobile phones adapted for a person with a visual impairment. Specialist equipment not supplied by social services is expensive. If you need someone with you to do activities increases the cost *</p> <p>4. Your response: You will make it very difficult for people who get the lower levels to get benefits. These are usually people, who are managing to cope with their disability but suffer and struggle everyday. This is likely to make them give up managing and then move them into higher levels of need.*</p> <p>5. Your response: Yes, with the provision to amend the claim based on individual need.*</p> <p>6. Your response: All activities and they should all be recognised*</p> <p>7. Your response:*</p> <p>8. Your response: No*</p> <p>9. Your response: Make the questions clearer and recognise not everyone fits the same box.*</p> <p>10. Your response:*</p> <p>11. Your response: Some healthcare professional do not understand how the person's disability affects their life especially when a unique case. *</p> <p>12. Your response: With sensitivity*</p> <p>13. Your response: Be explicit*</p> <p>14. Your response:*</p> <p>15. Your response:*</p> <p>16. Your response: No *</p> <p>17. Your response: You experience a lot of costs as they are continually growing out of things.*</p> <p>A sensitive form as filling out the form means a loss of hope. *</p> <p>18. Your response: We were never told about DLA and it was my own</p>  |

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|                   |               | <p>knowledge that allowed us to apply for it. Having got DLA it has never passported us to other services or entitlements.*</p> <p>19. Your response:*</p> <p>20. Your response: One generic assessment.*</p> <p>21. Your response:*</p> <p>22. Your response: Your changes are likely to make the lives of people with a disability harder</p>  |
| EM393             | 10-Feb-11     | <p>1. The barriers and problems that prevent claimants from participating in society and leading independent, full and active lives are the need of hands on assistance to be able to do social activities many of which enhances their well being such as swimming, short college courses. Going shopping rather than someone doing the shopping. Acceptance from society by providing full accessible premises with accessible toilet facilities, despite the DDA this is not fully adhered to.*</p> <p>2. It is of my opinion that all of Disability Living Allowance (DLA) should stay the same. What is needed and should have been carried out from the onset is looking into those with short term impairments i.e. those with bad backs, an accident at work that caused a broken leg, rather than spending billions on looking at every claimant. This approach would have been far more cost effective.*</p> <p>3. There are several main extra costs that claimants face such as batteries for electric wheelchairs, which can cost in the region of £500 to £600. Control units for electric wheelchairs can cost in the region of £300 to £600. The wheelchair voucher scheme does not cover these costs and for many, such expenses are borne by the claimants themselves. It can and does eat away at the savings and given that the savings of a person who is on benefit will not be allowed to exceed £1,000, the chances of one being able to save for necessities and go on holiday is near on impossible. *</p> <p>4. The new two rates per component will not make the benefit easier to understand and administer because disabilities are very complex and therefore not providing the wide range of needs.*</p> <p>The disadvantages or problems of having two rates per component could cause inappropriate levels of support *</p> <p>5. Some health conditions and impairments should receive automatic entitlement to the benefit and not based on the needs and circumstances of the individual applying. This is because many health conditions and impairments are permanent and normally these health conditions and impairments do deteriorate in time, therefore the entitlement to the benefit would be constant and it would therefore be a pointless and a financial drain to keep assessing such claimants. *</p> <p>6. Prioritising support to claimants who are least able to live full and active lives depends on the claimants perception of an active life and that can only be asked by the claimant themselves. However, a rule of thumb could possibly be to ascertain as to whether the claimants' psychological mind would be impaired by not leading a full and active life. One would think that the activities, which are most essential for every day life are ones, that provide a good psychological well-being and full filled life for the claimant.*</p> <p>7. The new assessment cannot take account of the variable and fluctuating conditions because you are not able to define in two groups which will be so diverse regarding the claimants conditions to ascertain who has variable and fluctuating conditions. If those with long term conditions were given automatic benefit and those with variable and fluctuating conditions were awarded another benefit, then perhaps you could follow your proposals.*</p> <p>8. The assessment of a person's ability should not take into account of any aids and adaptations they use because these aids and adaptations</p> |

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|                   |               | <p>can very often only be used in certain environments and impair the claimants' ability to carry out an activity in a different environment.*</p> <ul style="list-style-type: none"> <li>· None should be included as different environments can cause the aids and adaptations to be used inadequately,*</li> <li>· Aids and adaptations should not be taken into account whether the adaptations and aids are already being used or not. The claimant has more than likely gone through the process of requesting aids and adaptations and been rejected due to the cutbacks. What gives this consultation the green light for a claimant to be considered eligible for aids or adaptations when many are being told already that they are not eligible?*</li> </ul> <p>9. · The process of applying for benefit for claimants would be best met by providing simple terminology and no misleading questions that can easily cause a claimant to misinterpret what the questions are asking. The closed question format is not the way forward and for many claimants and the terminology for those with learning difficulties just makes the filling out of such forms even harder still.*</p> <ul style="list-style-type: none"> <li>· You can improve the information about the new benefit so that claimants are clear about what it is for and who is likely to qualify by being TRANSPARENT. You have not disclosed to claimants regarding the new benefit for example, what actually the new 'daily living' component comprises of. Is this care, is it support, is it personal care, what does this component actually represent. The mobility component is also very vague with regards to what it actually represents. Is this the car scheme under Motability, is it enabling the claimant to get financial help to get on buses and trains. Only through being TRANSPARENT will claimants know what it is for and who will qualify.*</li> </ul> <p>10. The supporting evidence with regards to a claim is best come from the claimant themselves as many claimants have a group practise surgery and do not see any one General Practitioner (GP), to provide an up to date medical account of the claimant. This can lead to wrong medical accounts being submitted.*</p> <p>11. · The benefits or difficulties that such face-to-face discussions can bring to the claimant is stress, anxiety if the process is held in a strange environment. Also talking to a stranger about personal issues can be extremely daunting for any claimant especially if they have learning difficulties or mental health issues.*</p> <ul style="list-style-type: none"> <li>· The circumstances in which it may be inappropriate to conduct a face-to-face meeting with a healthcare professional – either in an individual's home or another location is where a claimant may need to lie down during the discussions due to their medical condition. The claimant may need to take medication that they are unable to take during the course of the discussion. The claimant may be unable to engage in discussions due to medical conditions that cause them to physically wonder of from time to time.*</li> </ul> <p>12. · A review should only be carried out if the claimants medical condition is NOT permanent i.e Spina Bifida, Muscular Dystrophy, Cerebral Palsy. To carry out reviews on such claimants is not financially viable. The only time a review should be carried out on permanent medical conditions is when a claimant writes in to inform the department that their condition has worsened. Other claimants who do not have permanent medical conditions should be reviewed depending on what their medical conditions are i.e. if it is a sprained ankle, broken leg or bad back the review should be in line with their doctors notes as to when they would be fit again.*</p> <ul style="list-style-type: none"> <li>· Only as mentioned above, for those who have non permanent medical conditions they should be reviewed in accordance with their doctors or hospital notes as to when the claimant is said to be fit.*</li> </ul> <p>13. The new system Personal Independence Payment would be best adopting a reminder to claimants to inform the Department of any changes. Many claimants have on going medical issues and even if the changes are occurring psychologically they are tied up with what is happening to them, than to think, we have to inform the Department. Also those with learning</p> |

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|                   |               | <p>difficulties and mental health issues would have problems remembering that changes to their medical condition need to be reported.*</p> <p>14. The types of advice and information for those claimants applying for Personal Independence Payment needs to be clear and precise and it would be helpful making sure that everything is explicit when providing this as part of the benefit claiming process.*</p> <p>15. Where appropriate advice and support would be useful to the majority of claimants and the minority who might not otherwise taken action at Welfare Rights, Citizens Advice Bureaus. All the aspects of the benefit would need to be featured and nothing should be avoided.*</p> <p>16. . Currently claimants are funding their own aids and adaptations through their savings, financial assistant from friends and families and grants from various charities. It is an enormous financial stress to the claimant as cost for such aids and adaptations are extremely high.*</p> <p>. There should be a cost from Personal Independence Payment and it should NOT be a one-off because these aids and adaptations are being used constantly and do wear out and do not last forever. *</p> <p>17. : The key differences that should be taken into account when assessing children is that the emphasis should be with discussing such assessments with parents or carers. The life skills of children change as the child gets older and therefore such assessments should incorporate such changes.*</p> <p>18. DLA has never been able to provide access to other services or entitlements this is because claimants needs are extremely varied. PIPs will find it hard too because of the same reason, although it is important to be able to provide access to other services and entitlements. Yes there are things you can do to improve these passporting arrangements and that is by using such bodies as Welfare Rights and Citizen Advice Bureau (CAB)*</p> <p>19. There would be huge implications for claimants and service providers if it was not possible for Personal Independence Payment to be used as a passport to other benefits and services. Getting about would be extremely difficult as without carers for some claimants such an activity would not be possible. There are some access via passporting to venues such as swimming, cinema and gyms. There is also the need of transport access, which via passporting would provide and of which is essential. Access to certain health facilities is via passporting. So disbanding passporting via Personal Independence Payment would encroach upon a claimant's liberty to a life, which is the right of every human being.*</p> <p>20. Disability benefits or services should not be combined, as the complexity of the various disabilities would not be covered. To avoid bureaucracy and duplication regarding a claimant has to involve the individuals NI number and assessments and services crossed referenced via the NI number.*</p> <p>21. The said proposals could have an enormous impact on the different equality groups because of your plans to only allow healthcare professionals to assessments. Equality groups provide a far greater input with regards to claimants needs on a more social aspect.*</p> <p>There is a need to listen to the claimants with regards to developing the policies you have in mind. The policies that stand at the moment are infringing on claimants rights to a life. The policies are taking the system back to the 1940s when disabled people did not go out, not just because venues were not accessible but also because they did not have the financial means to live a fulfilled life. We need to more forward not backwards.*</p> <p>22. Your response: It is of my opinion that these proposals do not reflect the needs of the genuine claimants and it is a reflection of saving money rather than making a system better to avoid fraud. The proposals are also not a reflection on independence rather than taking the independence away.*</p> |



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| EM394             | 10-Feb-11     | <p>1. Your response: My answers are all from the view of a mother with a daughter diagnosed with Multiple Sclerosis aged 19.*<br/>Due to the extreme fatigue of MS full time work may not be possible. Part time work should be more easily available for disabled people and not just in low paid jobs.*</p> <p>2. Your response: MS is at present incurable and it is appropriate that DLA should be given for life. Constant reviews cause needless pressure and fear that the lifeline of DLA could be taken away.*</p> <p>3. Your response: Extreme physical fatigue and issues with concentrating for prolonged periods amongst other symptoms mean that working full time may not be possible.*</p> <ul style="list-style-type: none"> <li>• In our case my daughter's University course has taken 5 years instead of the usual 3 with greatly increased costs.*</li> <li>• As she cannot walk far, there is an extra cost for needing a car, petrol and taxis. Parking costs should be *</li> <li>• When finding accommodation she is restricted to choosing somewhere close to campus or place of work with increased cost.*</li> <li>• Arranging a holiday –cost increased due to need to consider accessible accommodation.*</li> <li>• Supplements to diet eg. vitamins.*</li> <li>• Prescription costs (surely they should be free with MS)*</li> </ul> <p>4. Your response:At present through being on the highest rate, my daughter has access to Motability, which is a lifeline. This also means she has a Blue Badge, which is crucial.*<br/>One fear is that she could lose this if re assessed in the wrong rate.which enables her to drive and maintain some independence.*</p> <p>5. Your response: I believe a diagnosis of MS should automatically mean an entitlement. For most people it affects your life every day.*</p> <p>6. Your response:*</p> <p>7. Your response: This question is particularly relevant to MS. In my daughter's case she can sometimes walk short distances and at others such as in the evening may have no strength to even walk to the bathroom and has to crawl. The 2 extremes can happen within the same day. Within a day a sufferer can have 'mini relapses' or a major relapse can strike at any time and put one out of action for months.*<br/>MS does not go away even though it may be less of a presence at times.*<br/>It would be a retrograde step if sufferers had to keep re- applying just because they had a couple of months when their MS was better or worse. It would be totally wrong to assess her by the way she may walk in with a seemingly normal gait. A doctor cannot possibly assess an MS without spending days or weeks in their company and living with the challenges that depression, vertigo and a host of other MS symptoms bring. Even a neurologist does not take the time to find out how a patient really is. *<br/>So how to assess?*</p> <ul style="list-style-type: none"> <li>-if a patient has a definite diagnosis of MS and the condition has been considered severe enough to put the patient on a drug for highly active MS, this should be enough to give DLA permanently.*</li> <li>-the GP should be asked to confirm the diagnosis.*</li> <li>- the patient should confirm that they need the help of DLA*</li> </ul> <p>8. Your response:*</p> <p>9. Your response: The form is indeed lengthy and complicated! When helping my daughter with it, I found we seemed to have to repeat the same information in different questions.*<br/>I think it could be made clearer that you will not lose DLA if you manage to do some work.*</p> <p>10. Your response: The GP. The patient. A relative.*</p> <p>11. Your response: Again I am concerned that on one meeting a disabled person may be judged as not needing DLA if, like many MS sufferers they walk in with an apparently normal gait and do not at that particular time look 'ill'. They are not seen on the days when they are incapable of doing</p> |

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|                   |               | <p>anything other than lie in bed all day. This is the problem with a fluctuating condition. *</p> <p>The interview should not be in the individual's own home. It is an invasion of privacy.*</p> <p>An interview might help someone who finds it difficult to write down their problems.*</p> <p>I would be horrified by the idea that one interview would decide the individual's whole future entitlement to DLA. The interview would be source of a huge build up of stress, which in MS sufferers actually makes their illness worse and in some cases could even cause a relapse.*</p> <p>12. Your response: If the condition is a well documented condition such as MS and there has not been a miracle cure, there should not be any need for reviews, which would cause fear and anxiety.*</p> <p>13. Your response: People with MS cannot report changes in their condition, which fluctuates during each day. There is no point in saying they are feeling better for a couple of weeks and the next week they could be in bed for the week with no energy at all.*</p> <p>14. Your response: *</p> <p>15. Your response: Not sure what you mean.*</p> <p>16. Your response: eg? Possibly.*</p> <p>17. Your response:*</p> <p>18. Your response: DLA has been a fantastic help in negotiating the maze of the benefit system. It has been a true life saver and we have been so grateful for it. It has enabled my daughter to live with some independence.*</p> <p>A lot of work needs to be done in improving dealings with the DWP in relation to Income Support. It has been a full time job trying to access the other benefits due to inefficiency and lack of continuity of staff. They will not use e mail, which would help us to contact them efficiently and ensure responses. Letters I have sent are apparently never received on more than one occasion. Letters which have apparently been received are not replied to. Instead one has to wait on the phone for hours and may eventually speak to someone in a distant call centre. This person is usually unable to help and promises a manager will ring in the next 3 hours . These calls are never received. Due to an error by the DWP regarding a couple of hours work done and declared in the summer, which was in any case a weekly amount below the permitted weekly earnings, an amount has been deducted for the next 8 months for non existent work. Phone calls and letters had no success and even an appeal has produced no feedback. *</p> <p>You are concerned that people on DLA realise they can work but it was not worth the couple of hours my daughter succeeded in doing for the approximately 50 hours trying to sort out the DWP's mistake.*</p> <p>I give you this detail as an example of how wonderful the DLA is in its continuity and lack of admin . *</p> <p>As for Income Support , Housing Benefit etc they are truly helpful too but can be taken away each time one moves and not re instated for months. A lot of staff are involved but the system does not work and claimants are treated with no respect. *</p> <p>There is a huge advantage to the DLA permanent payment.*</p> <p>19. Your response: Frankly it would not be possible for many disabled people to cope as DLA does give access to the other benefits without which many would have no income. It is necessary to make things easier for genuine claimants , who do not all have a mother to spend days trying to sort out benefits and DLA helps tremendously in accessing these.*</p> <p>20. Your response: The diagnosis of well documented diseases such as MS could be shared.*</p> <p>21. Your response*</p> <p>22. Your response: It is important to keep the DLA.*</p> <p>It is important to have a simple , non means tested benefit which is for life for lifelong diseases.*</p> <p>There could be 2 categories.*</p> <p>A separate category could be made for such permanent and fluctuating</p> |

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|                   |               | <p>diseases as MS which are given the benefit for life.*</p> <p>Other conditions could be reviewed such as immobility due to a hip problem causing disability which then may be improved by surgery.*</p> <p>Means testing positively discourages saving. The current rule is over £6000 savings, £1 is taken away from Income Support for every £250. So for every £250 savings, you lose £52 a year!*</p> <p>What interest rate is this assuming you get? About 25 per cent interest!*</p> <p>This is totally unfair and should be reviewed. *</p> <p>The changes you propose run a huge risk of penalising the most vulnerable with incurable, permanent conditions such as MS. DLA has worked very effectively for my daughter and given her some dignity and independence. It is a simple benefit which does not stop the recipient working or saving. Please keep it.</p>   |
| EM395             | 10-Feb-11     | <p>Hello, I understand that there is a need to reform the system, but there are times when the suggested reform is a step too far.*</p> <p>As the father of child with Asperger's Syndrome I find the proposed review process and assessment system ill thought out. A face to face assessment for someone with any form of Autism would be interesting. In these cases the <i>infrequent</i> assessment should be carried out by the GP, clinical psychologist or paediatrician who knows the individual. Meeting a person who is unknown can increase anxiety and make the disability totally unmanageable for a considerable period. Moreover, meeting a person who is unsympathetic can be very off putting and result in an inappropriate assessment. I say this based on my dealings with my local LEA. It took several years to gain a statement of special educational needs for my son. The head of assessment at the time was very unsympathetic and stated on more than one occasion that she could not provide a statement because there could be a child with more needs than my son. It should be remembered that Autism does not get better as it is with the person for life, and unlike visible disabilities that feature throughout the discussion document, can not be improved with aids. *</p> <p>I find the intention to share information across departments and assessments to be worrisome, especially with respect to special educational needs. Sometimes the persons carrying out assessments for special educational needs are not qualified to carry out assessments, and sharing information in these circumstances. I recall that my son's statement was rejected by my local LEA because his clinical psychologist did not use the word significant. Some of the information provided can be of a very sensitive nature and there are certain laws and covenants that must be respected.*</p> <p>I find the proposal to move away from the negative aspect of a disability worrying. I would have thought that a component of any replacement benefit should cover the worst days as it is the worst days that greatly affect the person with the disability rather than the good days.*</p> <p>I suggest that the Bercow report is read before any legislation is drawn up.</p> <p>Yours sincerely,</p> |
| EM396             | 10-Feb-11     | <p><u>Question 1</u> Lack of Mobility. ; Inaccessibility of places. ; Lack of a carer if you need one. ;Social isolation. ;Dependency on others. ; <u>Low income</u> – sometimes lifelong - unable to build up a pension because of inability to work)The prejudice&amp; stigma attached to both visible and invisible disabilities, leads to unreal expectations equals either too high or too low - from both employers or others making success at a job application or interview for example impossible in many cases.; <u>Depression &amp; mental ill health</u> are difficult enough to cope with conditions in themselves but the extra stress caused by a physical disability often leads to - depression and breakdown.; <u>E.g. Form filling, problems in the system of claiming</u> together with pain &amp; sometimes lack of mobility or social isolation, can all further contribute to mental health difficulties.; <u>School separation</u>-many disabled children are separated from others in mainstream schools or because they have to attend special schools-this does not help with social integration or stigma.</p>   |

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|                   |               | <p><u>Hospitalisation and medical appointments</u> as well as the follow up from them, often take up a great deal of time and energy. This prevents regular commitments either to social or work activities.*</p> <p><u>Question 2</u> Keep DLA name as it is well known; We agree that DLA /PIPs should <u>not</u> be means tested or taxed and it is most important that the choice of how it is spent also remains.; Applications for PIPs should continue to be based on the claimants own Doctors and Consultants medical advice or from information gathered from other health workers or from the wider community e.g. friends and carers.; Entitlement should remain automatic for terminal disease and also for certain other conditions e.g. blindness, hearing disability, M.S. Muscular Dystrophy.; Keeping the different levels for care and mobility is essential-and adding to them by one level to the mobility component highly desirable.; Awards should continue to be assessed and administered by Central Government, retaining the standard levels of payment at regular monthly intervals. These awards should increase annually to keep pace with the increase in the cost of living.; Responsibility to advise the administering department should remain with the client. ; Easy continued <u>free</u> access to an information line for help with filling out forms and guidance through the application process and forms should continue to be available in different languages.; Retention of the Motobility scheme-which could be widened to include other forms of transport.; The higher rates of awards should continue to act as a gateway to other benefits, e.g. Blue Badge Scheme, Council Tax rebate and free bus passes.*</p> <p><u>Question 3 *</u></p> <p>Extra heating and lighting costs, as disabled people are often at home more both in the day and evening.*</p> <p>Special diets and nutritional needs e.g. diabetes, vitamin B or D deficiency.*</p> <p>Provision of suitable transport, e.g. the cost of purchase and running of a car including any necessary adaptations-this might mean using the Motobility scheme or for others being able to have a free bus pass rather than having to pay to take more bus rides. Taxis are costly and often do not have ramps. Taxis with ramp adaptations are often not easily available.*</p> <p>Disabled people often benefit from having <u>extra therapies</u> and these can act as a way of “keeping going” or/and maintaining mobility e.g. physiotherapy, osteopathy, gentle exercise /hydrotherapy. However, because of the health problem concerned the person is likely to need more of these therapies and sometimes they will be ongoing - all of which increases cost.*</p> <p><u>The extra cost of paying for a carer</u>, cleaning, gardening, decorating, D.I.Y. and the many odd jobs that cannot be carried out by somebody with a disability e.g. moving heavy items, changing the curtains, going into the loft as well as other household support-ironing, washing and shopping for example.*</p> <p><u>Paying for either ongoing physical care</u> or ad hoc personal care during or after illness or after periods of hospitalisation.*</p> <p><u>Clothing suitable for people with a range of different disabilities</u>, can include front opening or Velcro fastenings, plastic protective coverings or special footwear and hose.*</p> <p><u>Personal care supplies</u> e.g. incontinence pads, nappies and special creams for skin suppleness and to prevent bedsores.*</p> <p><u>The cost of home adaptations</u> e.g. having an extra room or W.C. added on the ground floor or having a shower or wet room installed. In addition there may also be the high cost involved in moving to a ground floor flat, bungalow or sheltered accommodation.*</p> <p><u>There are extra costs incurred from wear and tear on the home</u> and furniture or bedding e.g. more frequent washing of sheets, clothing as well as wheelchair damage to floors and walls. It follows that special flooring and adapted furniture/furnishings are also sometimes required*</p> <p><u>Holidays</u>-there are extra costs for disabled needs e.g. transport and accommodation.*</p> <p><u>Prescription costs</u> are likely to be greater because more prescriptions are often required for complex health conditions.*</p> |

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|                   |               | <p><u>Question 4 *</u></p> <p><u>There should be three levels for mobility</u> and care so that a person can work to improve their health, so as to go to the next level down, thereby reducing dependency. *</p> <p>To have just two levels would represent too big a gap and act as a disincentive to work towards this reduction. A three level system should not imply that being on one level for one component, would automatically mean that you would be on the same level for the other component. It is also very important to note that in a two level system, not everybody would be able to be fitted into either of the two levels because of varying symptoms and health conditions.*</p> <p>It follows that it is also important to be able to move to a higher level/rate if symptoms increase.*</p> <p><u>A three level system is in line with an Occupational Therapist type assessment-</u> a pre-completed O/T assessment could then be used (with the claimants agreement) as a major part of any applicants award assessment, or obviate the need for one altogether-therefore reducing time and cost.*</p> <p><u>Question 5*</u></p> <p><u>Entitlement should remain automatic for terminal disease</u> and also for certain other conditions e.g. blindness, hearing disability, M.S. and Muscular Dystrophy.*</p> <p><u>Entitlement needs to be on the grounds of disability alone-</u>as that in itself always causes problems and difficulties in life. Other circumstances should not be taken into account, either those of a support or financial nature- i.e. <u>awards should not be means tested.*</u></p> <p><u>Question 6 *</u></p> <p>It should be accepted that some disabled people will never be able to live full and active lives. That said suitable housing and shelter with secure tenure and adequate income are pre-requisites for activities which are essential for everyday life.*</p> <p>*</p> <p><u>These are:-</u> Being able to have a properly cooked meal regularly, being able to sleep well and regularly and to feel safe at home, being able to keep self, home and clothes clean, to have social contact and activities - hobbies, interests, visiting relations/friends – being able to go out of home, having a telephone and computer for communication, and a radio and TV for company and accessible entertainment purposes.*</p> <p>Being able to keep a pet or a working animal e.g. a guide dog *</p> <p><u>Questions 7 &amp; 10</u> By allowing the claimant to use supporting evidence for their application for example using medical information from their GP or Consultant, and reports or social &amp; community evidence e.g. from carers or diaries-of symptoms or medical appointments.*</p> <p>*</p> <p>By allowing the evidence of employers, teachers/ complimentary therapists, social services, Occupational Therapists in the assessment process, but ensuring that the clients worst days and times be taken into consideration. *</p> <p>It would be helpful if the forms were less repetitious and of shorter length, also-benefits advice should be easily available, either face to face or on a <u>free</u> telephone line. The process should also have shorter waiting times*</p> <p>The assessment process should be carried out by a team of regularly employed doctors or nurses-part of a team within a Government department, and doctors should not be brought in on an ad hoc basis as is at present the case.*</p> <p>Appeals and tribunals should be made less formal and easier to access.*</p> <p><u>Question 8</u> No, aids and adaptations should never be taken into account for an awards assessment. Because aids and adaptations often take a great deal of extra time and energy to use - therefore it would be unfair to see someone using a wheel chair for example as mobile in the usual sense*</p> <p><u>Question 9</u> It would be helpful if the forms were less repetitious and of shorter length, also-benefits advice should be easily available, either face to face or on a <u>free</u> telephone line. The process should have shorter waiting</p> |

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|                   |               | <p>times.*</p> <p>Tribunals should be less formal*</p> <p>There should be leaflets/forms at all GP Surgeries, Social Work Departments and Post Offices.*</p> <p>Put information about the new benefit on TV and Radio before and when it is first introduced, and then as part of ongoing information service.*</p> <p>Train GPs and hospital Doctors, as well as other health professionals to mention this benefit.*</p> <p>Assessing doctors should not just turn up without warning.*</p> <p><u>Question 10</u> By allowing the claimant to use supporting evidence for their application for example using medical information from their GP or Consultant, and reports and social/community evidence e.g. from carers or diaries-of symptoms or medical appointments.*</p> <p>By allowing the evidence of employers, teachers/ complimentary therapists, social services, Occupational Therapists into the assessment process, but ensuring that the clients worst days and times be taken into consideration. *</p> <p><u>Question 11</u> A doctor should be used where complex cases are involved, nurses and other professionals e.g. O/T could be used for less complex cases providing they were given adequate training with regard to the nature and difficulties caused by disability.*</p> <p>An assessment would probably take over an hour, or in some cases more time and second appointments need to be allocated for more complex or distressing cases.*</p> <p><u>Carers-or an advocate, or supportive person should be allowed to be present at an interview. *</u></p> <p>This would help as claimants cant necessarily articulate very easily. *</p> <p>A translator or signer may also be necessary. *</p> <p>There should be a choice of where the interview should be held-at home or in an office-but if in an office it should not be up flights of stairs unless there is a lift. *</p> <p>The cost of a taxi or other form of transport should also be provided.*</p> <p><u>These sessions should be as informal as possible to take account of peoples pain, stress and anxiety-and should not be about ticking or filling in a pro forma. Nor should the claimant feel that they are on trial.*</u></p> <p>*</p> <p><u>Question 12</u> Yes-the following would be circumstances in which a face-to-face interview would be inappropriate. If someone is terminally ill or in hospital, or is unable to communicate for themselves.*</p> <p>Some religions don't allow women to speak to males for example.*</p> <p>It is not appropriate to interview a young child regarding a claim, this would have to be done by an adult responsible for their care.*</p> <p>Similarly, an adult with learning difficulties for example might either need to have an appropriate adult present to answer the questions and/or represent them. *</p> <p><u>Question 13</u> The terminally ill should not be re-assessed.*</p> <p>The claimant should be allowed to report if they are feeling better or worse, this is a matter of personal responsibility.*</p> <p>Reviews should be variable-someone who has a serious condition e.g. Multiple Sclerosis should not be reviewed unless they request it, but claimants with other conditions might be reviewed after a standard period, or again if they request it. *</p> <p><u>Question 14</u> Don't change the name of DLA as it is well known.*</p> <p>The claimant should be allowed to report if they are feeling better or worse, this is a matter of personal responsibility-a telephone help line should be <u>free</u> and easy to access in order to do this.*</p> <p>It should be recognised and acknowledged that some claimants would have difficulty in reporting a change in their circumstances-because of their condition e.g. bi-polar or other mental health conditions especially, but not exclusively. In such cases perhaps a box could be ticked on the application form asking if they wish to be sent a pro forma at intervals to help them to do this. THERE SHOULD HOWEVER BE NO QUESTION OF PROSECUTION</p> |

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|                   |               | <p>IF SOMEONE FAILS TO REPORT AN IMPROVEMENT BECAUSE OF THE ABOVE. *</p> <p><u>Question 15</u> Yes, it would be helpful to have advice and information about the application process, this could include:- a leaflet with every application form, explaining the whole application process and saying how to contact a <u>free help line</u> who would say where to get advice, or give advice and help to fill the application form in.*</p> <p><u>Questions 16</u> A leaflet and application form should be available in all GP surgeries, Social Workers Departments. Post Offices and noted on all communications from Government, e.g. at the end of a tax return form- Put on the such forms - do you need a DLA or other benefit application form? or include a leaflet about the benefit with the forms*</p> <p>THERE SHOULD BE NO REQUIREMENT OR COERSION to take or agree to a medical opinion on how to treat a claimant's disability or other health condition as this infringes <u>personal freedom</u>, and the right to treat any health problems in the way an individual may choose.*</p> <p><u>Question 17</u> By grants from the Local Authority for housing adaptations; Social Services – Occupational Therapist provision; Motability; Hospital loan; Own savings; Charitable loans*</p> <p><u>Question 18</u> Yes, there should be provision for one off costs under the new PIP scheme for large expenditures e.g. moving home, computers or a costly item to help with disability such as a mobility scooter, but not instead of or included as part of an award, it should be over and above any regular payments. *</p> <p><u>Question 19</u> It is not appropriate to interview a young child regarding a claim, this would have to done by an adult responsible for their care.*</p> <p><u>Schooling</u> – special needs children often have extra costs eg.aids at a mainstream school or the cost of special schooling e.g. transport to and from school for the child, but also for the family to visit if the school is residential.*</p> <p><u>Personal care supplies</u> and needs e.g. nappies, rubber gloves, transport, relief care and special diets.*</p> <p><u>Question 20</u> PIP would be most important to disabled people as a <u>gateway to other services and benefits</u>.*</p> <p>1) High rates of mobility awards should equal a free bus pass and a Blue badge entitlement*</p> <p>Higher award rates should equal automatic access to council tax discount.*</p> <p>These gateway benefits should be put on the DLA/PIPs information leaflet.*</p> <p>The above keep people mobile, independent and also help with mental health- it follows that without them people would become more dependent and isolated. *</p> <p><u>Question 21</u> When a claimant applies for sickness type benefits information could be shared (<u>but only with claimants agreement</u>.) it could go towards a DLA application. The reverse would also be true.*</p> <p>*</p> <p><u>Question 22</u> A monetary award could help a disabled person to be, and feel more integrated into the local community. *</p> <p>Help with the costs of schooling – special needs children often have extra costs. E.g. aids at a mainstream school or the cost of special schooling e.g. transport to and from school for the child-this could help integrate disabled children more into the educational process.*</p> <p>With face-to-face interviews there should be a choice of male or female interviewers for reasons of ethnicity and religion.*</p> <p>Cultural, religious and gender differences should also be taken into account to help alleviate the problems of minority groupings.*</p> <p>The forms should be in other languages and a translator should be provided where necessary.*</p> <p><u>Question 23</u> An advocate should always be allowed to help with assessments and reviews etc.*</p> <p>No one should be coerced to take medical treatment or advice etc this is an important issue with regards to <u>personal freedom</u> and erodes the individual's right to treat their condition in the way they feel best including the use of</p> |

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|                   |               | <p>complimentary therapies.*</p> <p>PIP should not be administered by a Local Authority, but continue to be administered by Central Government and awarded on grounds of disability only, and not in any way means tested.*</p> <p><u>There should be three levels of award for both mobility and care. Keeping the different levels for care and mobility is essential-and adding to them by one level to the mobility component highly desirable.*</u></p> <p><u>DLA represents a real lifeline to many people-it is the difference between having self respect (or not) and between having a reasonable lifestyle and level of mental health rather than having to live on a very low income for long periods. It stops claimants being dependent on others and also on Government provided services.*</u></p> <p><u>This independence end would continue on the condition that a claimant would have the freedom to spend the money as they would choose-it treats people with the respect and dignity that they should have. It keeps costs to the authorities down especially with regards to mental health, as having a physical disability and all that that entails can easily cause mental ill health and breakdown. Extra stress can be caused from dealing with forms, hospital situations and the illness or disability in itself.*</u></p> <p><u>Allowing one off payments under the new PIP's scheme for items of large expenditure would help with financial stress and long term low income issues, but should not be instead of or included in an ongoing award.</u></p> <p><u>Receipts should be provided by a claimant after the purchase of the item in question.*</u></p> <p><u>A claimant in a care home should not be deprived of financial assistance to get out and about, as this is really important for the maintenance of mental health, and having a full and active lifestyle.*</u></p> <p><u>PIP's should continue after age 65 for everyone-this would save on the cost of changing to Attendance Allowance for example.*</u></p> <p>Applications and assessments for PIPs should not be processed by private companies, but instead continue to be administered by Central Government, and to take into consideration the claimant's choice of supporting evidence.*</p> <p>Claimants of DLA who have been given lifelong awards should not have to be reviewed-there is good reason for the awards.</p> |
| EM397             | 11-Feb-11     | <ol style="list-style-type: none"> <li>1. Many people with learning Disabilities are unable to learn and understand skills as one day they cope but the next day or the next week or an hour later they are unable to remember or understand what has taken place. This is the nature of their disability and does not become cured.*</li> <li>2. If a person is identified as having a severe Learning Disability throughout their life the Disability Living allowance or its replacement should continue for life.*</li> <li>3. Carers need to be paid in order that the person can be kept clean, warm, fed and clothed . Carers are needed to keep the person safe , healthy and occupied often as a travelling companion when the person needs to access any appointment or leisure or activities outside the home.*</li> <li>4. Not too sure but there are already various rates*</li> <li>5. Severe Learning Disability is incurable as are some physical conditions. These people should have automatic entitlement unless some new treatments are discovered.*</li> <li>6. High quality human carers who can use initiative and have enthusiasm. Plenty of human company and activities in groups as people with LD have difficulty making and sustaining friendships*</li> <li>7. I am not sure as Learning disabilities tend to be consistently there all the time.*</li> <li>8. If a person needs adaptations in order to have mobility or communication they should be available but they are likely to still need the extra money to lead their life.*</li> <li>9. I have no experience of filling in the forms as my daughter has been on benefits for 25 years .*</li> <li>10. The care plans and Annual review information should be consulted for several previous years. Therapists and medical and educational experts</li> </ol>  |



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|                   |               | <p>may be needed Also Common Sense*</p> <p>11. My daughter would find this difficult unless she already knows the health professional well and feels totally at ease. Otherwise she 'freezes' or becomes hysterical.*</p> <p>12. For people whose condition has remained fairly constant over the previous 5 years perhaps a review every 5 years. there should be different types of review depending on the needs of the individual.*</p> <p>13. Many people with Learning Disabilities do not understand money or any number concept so they would be unable to comply here.*</p> <p>14. The information will need to be given to the Family or paid carer in many cases see 13.*</p> <p>15. There needs to be an independent advocate involved in most of the last points*</p> <p>16. I do not know*</p> <p>17. families should be responsible for answering many points with help from professionals*</p> <p>18. NHS prescriptions ,glasses, bus passes I think ID cards would help people who are not fluent in communicating*</p> <p>19. Where would the extra money come from. My daughter frequently needs new glasses and has regular medication so would be out of pocket compared with non disabled working people*</p> <p>20. Severe Disablement Allowance and DLA mobility*</p> <p>21. The lowest group are people with Learning Disability regardless of any other inequality so they need the greatest amount of help.*</p> <p>22. Your response:</p>   |
| EM398             | 10-Feb-11     | <p>1. Your response: Much ignorance regarding learning disability in the general population is a huge barrier to disabled people. Not enough accessible / wheelchair adapted Public Transport. Primary and Secondary schools that are NOT fully wheelchair accessible. Sixth form Colleges, Tertiary Colleges and Universities that are NOT fully wheelchair accessible. Education establishments should ALL be accessible; it would make a world of difference. *</p> <p>Sports venues that are NOT fully wheelchair accessible are disgraceful. Hospitals – yes I have been to Guys hospital in London and tried to get to the finance office to claim transport costs, and had to get my son in his wheelchair up about 12 steep steps.*</p> <p>2. Your response: Yes – the arrangement with Motability to exchange the mobility component of DLA for a leased car on the Motability scheme. It is brilliant and my son could NOT live without it. The arrangement for some people to have their DLA awarded indefinitely, as my son has, this too should stay the same. He has lifelong disabilities – physical and learning that will NOT change. I am very grateful that his DLA has been awarded indefinitely as the filling in of those horrendous DLA forms is abominable.*</p> <p>3. Your response: Activities to fill my son's day – swimming, horse riding, gym sessions, cooking group etc... These all have to be paid for. He needs to exercise as much as he can to keep him fit and well. He has been denied consistently a place at a Day Centre in our town by Social workers. So we have a care agency here at home to support and care for him, they need to organise a weekly timetable for him to keep him busy, stimulated and included in society and our community. He has to be driven around in his Motability car and he spends more than the average person on petrol, as he cannot use public transport because he is a wheelchair user. He also needs tripod walking sticks taken wherever he goes. My son also pays for all the meals that the carers eat whilst they are supporting him. This is a considerable cost. My son needs his clothes washing a lot more than average, he is clumsy and spills food and drink on a daily basis. He gets much colder when he sits watching tv so we have to have the heating up higher. Because my son has a considerable learning disability he cannot work, he cannot claim housing benefit as he still lives at home with me his mum, so I am still financially supporting him in his housing costs. This is because there is NO suitable supported living housing with a wheelchair</p> |

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|                   |               | <p>adapted shared house in our town. He contributes half of the utility bills as it is only him and me living here and I am a full time degree student and work part time. We live in a council bungalow. My son has to pay for the carers to go on holiday with him; this means he has to pay double the costs of a single person! My son breaks numerous items of clothing in his attempts to dress/undress himself. He has broken countless zips, buttons, fastenings, pockets, straps etc. these clothing items need replacing. He has broken many many TV's, video recorders, DVD players, remote controls, toys, CD players etc. because of his autistic, obsessional behaviour. He has also broken furniture, crockery lights etc. So we have had to buy extremely robust solid wooden furniture at great expense. He also needs things like personal cleansing wipes for the toilet as he cannot manage his own personal care. *</p> <p>4. Your response: I don't know enough about what this may mean in the long run. My son needs care 24 hours a day – he cannot be left alone at all. I think people like this should get the highest rate of care component, and it should be much increased!*</p> <p>5. Your response: Disabilities vary considerably and I think everyone should be treated as an individual and their needs should be considered likewise. Background reading about individuals and their case notes/ medical records FIRST would be essential reading and save time later on.*</p> <p>6. Your response: Having a named, highly trained, consistent SOCIAL WORKER would be great! Access to speech therapy – for some reason, some person somewhere doesn't think my son needs speech therapy whilst I think he does! He could really benefit from a computer that is specially designed for disabled people, how to get it? Who knows? Our Social worker is as dumb as anything – she knows very little about my son's disability and doesn't seem to want to either.*</p> <p>I have tried for the last 5 years to get my son regular Physiotherapy but it is IMPOSSIBLE!! He needs regular, professional Physiotherapy and hydrotherapy as he has a significant physical disability.*</p> <p>My son needs a wide variety of activities, trips, etc. organised for him as he is unable to do this himself. He also needs group involvement, which he gets (in a v.minor way) from his once a week, 2.5 hr. sheltered work place. He would love to go for more but the Social workers say he can't, due to funding. *</p> <p>Suitable, appropriate, respite facilities - my son who is 23 has been in the past to very inappropriate respite locations with people who are much, much older than him. He was also physically attacked by another service user whilst at respite, and he had significant bruising. It was a completely inconsistent environment for him.*</p> <p>The local council WILL NOT FUND AN ADAPTED KITCHEN for my son because they say he does not 'need' it as he has support workers and me cooking his meals. But when he was at College he cooked in an amazing adapted kitchen and loved preparing and cooking meals. Yes, he needed a lot of support to cook, but it was within his capabilities. At home he is denied this activity because the council REFUSE to put in an adapted wheelchair accessible kitchen.*</p> <p>The activities most essential to daily life for my son are:*</p> <p>Washing, dressing, eating, cooking (see above), shopping, physiotherapy, exercise, educational activities, hydrotherapy, trips, TRANSPORT, group involvement, CHURCH LIFE, music, communicating, having friends to socialise with, cultural activities, watching basketball, theatre, visiting grandma, holidays, family celebrations and loads more.*</p> <p>7. Your response: I'm not sure, as my son doesn't come into that category.*</p> <p>8. Your response: Yes and No. I know full wheelchair users who can move around completely independently with no support at all; and I know learning disabled people who can 'walk' perfectly normally but need 100% help whilst out walking as they are severely autistic etc. and it would be a danger to themselves and other people if they were classed as ordinary 'walking' people. *</p> <p>My son's aids have all come through the NHS or through the local authority.</p> |

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|                   |               | <p>He would never be able to afford the adaptation of any building however, e.g. like the kitchen, as it would cost thousands and thousands.*</p> <p>9. Your response: Yes please do make the form easier!!! They are a bugger! But saying that my son has his DLA awarded indefinitely now, so that is much better. I have not seen any info regarding the new benefit anywhere! Give the info to my social worker and MAKE it her responsibility by law to inform my son and me about it.*</p> <p>10. Your response: My son's medical records are HUGE!*<br/>The consultant my son is under at the local hospital, and our GP, and our Social worker, care agency staff and of course - me his MUM who knows more about him than all of them put together!!!!!!*</p> <p>11. Your response: My son has considerable learning difficulties and he won't understand why he is being talked to, and the purpose of it. He can't tell the day of the week, the time, what tomorrow is and does not understand things that are not concrete or objects. His intellectual ability is that of about a 4-6 yr. old child. I think that the medical records that are available about my son should be crystal clear enough already to make a correct decision regarding his DLA. Also it would be completely inappropriate to interview him alone without me his mum there and a support worker. The venue would have to be 100% wheelchair accessible. He has compulsive and obsessive behaviours which are sometimes inappropriate and disturbing.*</p> <p>12. Your response: I think one review now, and another in 10 years for my son as his is a congenital disability from birth and WILL NOT CHANGE. He has already been awarded the DLA indefinitely from the age of about 14. He is now 23. He is no different now essentially from when he was 14 yrs.old. *<br/>Not sure about other people.*</p> <p>13. Your response: No idea!*</p> <p>14. Your response: Transport issues – free transport for disabled children to school. MOTABILITY. Free nappies, free bedding from Health Visitor, adaptations to their houses, RIGHTS regarding access to a SOCIAL WORKER, rights to physiotherapy, speech therapy, educational issues, housing benefit, council tax benefit. Special dental services for disabled people, rights about complaining about services, Charities who can help with holidays, equipment, emotional support etc. *<br/>RIGHTS regarding respite for carers.*<br/>Yes please send as much info out as possible as part of the benefit claiming process.*</p> <p>15. Your response: Not sure*</p> <p>16. Your response: My son has never had to pay for his aids and adaptations. I thank God every day for the NHS, for my son's free wheelchair, free tripod sticks, free Kaye posture walking frame, free orthotics, free medical treatment and consultations. I'm not sure about the option to use the PIP to meet a one of cost of an aid or adaptation. My son could really use a computer and it would make a massive difference to his life, but it would have to be a very special one manufactured by a specialist company, so maybe there would be a case for it. The cost of making our council rented bungalow adapted was £43,000! And then they didn't even put in an adapted kitchen!! So a one off payment would have had to be very large to cover that!*</p> <p>17. Your response: Generally that they have been BORN with their disabilities. Some children have acquired them through illness or accident, but most children with disabilities have been born with them. That all the parents I know are tired, worn out, and angry that this country doesn't do more to support them and their disabled children better. Coming to terms with having a disabled child is daunting and perplexing at times. Having a 40 page DLA form to fill in is almost the last straw sometimes when you have been up all night sorting out your young child who has epilepsy for example. Families with disabled children need mountains of support and encouragement.*</p> <p>18. Your response: Motability – car- brilliant!*</p> <p>I have been receiving carers allowance for 21 years because of my son's</p> |

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|                   |               | <p>disability. I wouldn't have got it unless he had been getting the highest rates of the care component of the DLA. Council tax however is a shambles! The local authority didn't do my council tax properly once my son turned 18 They didn't know about the carers disregard!! I found that out from Carers UK. Have a dedicated disability and carers officer at each Borough Council to advise correctly on what people are entitled to.*</p> <p>19. Your response: Chaos and more blooming form filling in!*</p> <p>20. Your response: That is a massive issue, and I wish all my son's info could be quickly accessed by Occupational Therapists in particular as they are the bane of our lives! We need ONE named OT, not 5 like we have had recently!!*</p> <p>21. Your response: not sure*</p> <p>22. Your response: Haven't read the public consultation and it's proposals, where is it?*</p> <p>PLEASE, PLEASE SAVE DLA AND INCREASE IT FOR THE NEEDIEST DISABLED PEOPLE IN OUR SOCIETY.*</p> <p>Men and women of courage and integrity have fought long hard battles in past years to speak up for disabled people in this country. Don't let's throw all that hard work away.</p> |
| EM399             | 10-Feb-11     | <p>I am a single mother caring for an autistic child. I unlike many work full time and put my son into out of school clubs. I am worried taht the sure start nursery in my area is going to close. There is not enough SEN holiday clubs so the council run one has been a lifeline to me. If this closes I will need to pay family members etc. to look after him whilst I work without DLA I don't know how I'll cope.*</p> <p>I work full time and always have despite my sons condition and the fact that I have not had a full nights sleep in 7 years. *</p> <p>I work for the local Council if I lost my job I wouldn't be able to pay for the clubs that my son attends without the DLA. My sons life would be a misery without these clubs. *</p> <p>My life is hard enough please don't do this to me and my child. Even the worry about this maybe happening is a terrible burden to bear.*</p> <p>I pray to god that Mr Cameron, Mr Clegg and Mr Osbourne show some compassion and humanity.</p>  |
| EM400             | 09-Feb-11     | <p>Please note my following points in response to your consultation process: I am the sole carer of my nephew with Down's Syndrome. I already subsidise his living with me rather than being placed in a care home. I believe this to be yet another ill thought plan by the coalition Government and one proposal that should not be implemented. Any changes to benefits of disabled people will have a marked effect on the ability of people like me to care for others. May I remind you that carers such as myself save the [message ends]</p>  |