

Disability Living Allowance reform consultation – email responses 101 to 200

Respondent Number	Date Received	Response
EM101	15-Dec-10	<p>1. Able to physically access services. *People not being aware of a disabled persons needs. *The needs of disabled people being voiced by non disabled academics. *The added cost of living due to a person's disability affecting their disposable income.</p> <p>**2. The mobility component and the care component.</p> <p>**3. I have a mortgage and the premium for the protection insurance is nearly treble that of a non disabled person. *I spend nearly £1000 on Electric and have spent nearly £2000 on heating oil per anum. *If I use a taxi for a 6 mile trip into the city it costs £20 each way. *Laundry costs and replacement washing and tumble drying machines they last me about 2 years if I am lucky. *I can no longer trade favours with people, I used to do manual work for a friend and get skilled work in return. I now have to employ somebody to do the plastering, electrical, plumbing jobs and also to carry out the heavy manual work my wife cannot do. *I have to plan my daily routine I incur extra costs on travel because I have to book early and pay full price. (No last minute bargains).</p> <p>**4. I think it will complicate matters and will make cause a lot of time and money to be spent on appeals.</p> <p>**4. b) I think there should only be one mobility amount, either you can walk or you can't. Any other consideration should be in the care component.</p> <p>**5. No benefit should be automatic.</p> <p>**6. Employ disabled people to interview the claimants and sit on appeal panels. *The most important action you can do is to ask the disabled people themselves what is required. Stop using expensive outside organisations, start dealing directly with the disabled.</p> <p>**7. Rank health conditions into those likely to worsen or improve and review based on that ranking. You could build in an adjustment period for people to come to terms with a disability.</p> <p>**8. The question you should ask is what would happen if I removed that aid or adaption. *If you removed my wheelchair I would be where ever you left me. *Don't forget that aids and adaptation are also used to reinforce the claimants need for assistance. A person wishing to claim mobility will use crutches or a rollator to demonstrate how disabled and unable to walk they are.</p> <p>**9. Do not send out a form, have the new claimant come to the office or a home or hospital visit (if necessary) and help them fill out the form. *Use disabled people to do this as they will be able to empathise with the claimant and know what they need to claim. Or have disabled people train your staff on what is required.</p> <p>**10. Other disabled people. **You will need to be able to tell the difference between the genuine disabled, the want to be disabled and the fraudulent.</p> <p>**11. If you cannot employ disabled people ensure that the person you send is aware of the nature of the disability. *The person should also be about the same age or older than the claimant, it is difficult to talk about sensitive personal things with someone older than your own child. *The person should be trained so that they know what to expect from highly sensitive personal issues. *I have experienced looks of disgust from Doctors when discussing my needs because they have not been prepared for the answers.</p>

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		<p>**12. AS in Question 7 Rank health conditions into those likely to worsen or improve and review based on that ranking.</p> <p>*13. It is unlikely that people will voluntarily tell you their health as improved either because they are dishonest or they are scared that it is a temporary improvement.</p> <p>*Historically it is harder to reclaim the benefit and get the same rate. You could issue a guarantee that if the person's health declined within a certain time frame they would receive the same benefits.</p> <p>**Look at people's passports, and bank statements from them you will be able to see their life style and whether that fits with their disability.</p> <p>**14. If you allow others to set up and give advice you become the fraudster's accomplice.</p> <p>*I have in the past reported to the fraud hotline centres that help fill in forms advising the claimants what to write down to ensure that they get the benefit they are applying for. They then share this with other members.</p> <p>**15. If a person needs aids or adaptation it should be paid for by the local council or DHSS</p> <p>**No, the benefit is to be towards transport or care costs not tools or equipment costs</p> <p>**16. Make a distinction for the age of a child in the care component; a parent would have to care for a younger child more and an older child less, especially during school age.</p> <p>*Make sure the care component does not pay twice for the same care.*Ensure any mobility component is calculated on what extra cost a parent would face.</p> <p>**17. I do not believe that any benefit should get anything automatically.*All benefits should be based on need.</p> <p>**18. It would help if all departments could draw up a common list of points of information they ask and this information should be centrally located on a master data base.</p> <p>*Any department should then be able to access their shared points of information.</p> <p>*For example DVLA should be able to get my name, address, telephone number etc from the database and also any medical questions on my ability to drive. The access to the medical data is limited to the common questions which would be decided by a relevant body.</p> <p>**19. I cannot think of any affect the new benefit would have on different groups.</p> <p>**20.I do not think that anybody but a person's own GP should be allowed to sign for the new benefit.</p> <p>**GP's should be statistically reviewed to monitor the number of DLA claimants in their practice.</p> <p>*The Mobility component should be looked at for people in care or in residential homes. Should the benefit still be paid or does the care provider already get paid to provide the service?</p>
EM102	16-Dec-10	<p>As a disabled person with cerebral palsy and non epileptic seizures who needs a wheelchair to get out and about and also at times in the house this consultation scares me.</p> <p>*I live independently in the community and for a number of years I also worked, my DLA enables me to have that level of independence to possibly loose my DLA would mean I would loose that level of independence and probably my home as I would not be able to afford to live in the community any more and would either end up in residential care or on the streets as would many other disabled people.*</p> <p>*You say that many people believe DLA is an out of work benefit and that you believe many people won't take jobs as they believe they would then loose this benefit. I have never heard such rubbish. I have never heard of one person be they disabled or able bodied that thinks DLA is an out of work benefit/*</p> <p>*You say that DLA creates barriers for people preventing them from working and being actively involved in society. DLA does not create barriers to work</p>

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		<p>without it I wouldn't of been able to work it helped fund my train fares and later on my taxis to and from work when I could no longer cope with catching the train.*</p> <p>*You also suggest that you now would like to change the assessment to include aids and adaptations considering use of my wheelchair isn't going to take away my cerebral palsy that I have had since birth, it's not going to remove the pain and fatigue I suffer with or stop my non epileptic seizures, instead the stress of all these changes and the stress of trying to live on possibly less money will increase my stress related seizures as it is already doing.*</p> <p>*Giving me aids and adaptations or considering them in your assessment doesn't make me more able to participate in society if I can't afford to maintain them and keep them in working order. Giving financial support that enables me to make the choice on where I need the extra funds to go does make me able to take part in life as an equal to an able bodied person. To do what you are proposing in your consultation makes me more disabled and more reliant on society.*</p> <p>*To make the cuts and changes you are proposing wouldn't enable me to participate in my community it would make me pretty much a prisoner in my own home and be detrimental to my health. As I would no longer be able to afford maintenance of my wheelchair, cost of taxi fares to get to and from places I wanted to go including doctors appointments, hospital appointments, dentist and any other appointments. I would have no life and there realistically would not be any point to me getting out of bed in the morning, because even if I had a job I would not be able to afford to get there. I also would have no social life as again I couldn't afford to go anywhere.*</p> <p>*If these changes and cuts are made I would not be able to fund my pendant alarm system that I have installed at home in case of falls etc, I would be unable to pay for my prescriptions therefore making my health conditions worse, my wheelchair would fall in to disrepair and no longer be safe to use, I could not afford to either get my shoes repaired as often as I need them repaired or to buy new shoes or possibly clothes, I would freeze in my house during winter months as I would not be able to pay my heating bills due to the extra heat I need during the winter and eventually my electric bills as I drink more hot drinks to try and keep warm instead.*</p> <p>*You also mention face to face interviews with an independent professional a person who has never met me before is not going to be able to understand my conditions, and my home set up or what I can do and what I can't do due to these health conditions in the time limit each assessment will be likely to have. As for assessments every 3 years how is that going to be saving the Government money, many disabled people that claim DLA have had their conditions since birth you assessing them every 3 years isn't going to change that if anything it could make things worse as the stress of yet another assessment to prove they are genuinely disabled starts yet again.*</p> <p>*I think a lot of the proposals in this consultation really need to be seriously thought about because changes to this fundamental benefit that enables us to be as independent as our conditions allow will have far reaching consequences that unless you have knowledge or experience of a disability you wouldn't foresee or understand.</p>
EM103	16-Dec-10	<p>I would like to make a point within this consultation for DLA.*</p> <p>*I am not disabled myself, but I wanted to write to the department.*</p> <p>*This benefit should be for working age people only, it is clearly shown that the majority of people are aged fro 16 years old to around 60 years old, (these people are definitely working age), but saying that a lot of people have the mobility component part of the benefit, this is clearly because they will not change now are in the future.*</p> <p>*I think Maria Miller MP is completely wrong with the changes on DLA, all the changes will clearly cause lots of upset and stress which can cause more health issues, so really she needs to re-think the changes.*</p> <p>*If there want to get people back into work, well there is clearly a lot more people out there who they should look at first, by doing these changes the</p>

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		<p>government are just laughing in the disabled peoples faces and that is not right, there is other people out there who should be looking at first. i.e people who leave prison should be targeted first back into work, people who have been dealing with drugs etc, should again be targeted first if they are not working. Young people who are always in trouble with police etc again should be targeted the government know who they are so why not target them instead of the disabled people who haven't asked to be like this in the first place. There is a lot of disabled people who can not walk are if they can walk they can not walk unaided, and to be told this the information comes from their GP and a consultant from a hospital, (is the government saying that these professional people are wrong).</p> <p>*The is people in wheel chairs why should these be targeted when you have young people doing crime and walking the streets daily who are not working getting away with it.*</p> <p>*YOU MUST LEAVE THE DISABLED PEOPLE ALONE AND TARGET ALL THE OTHER PEOPLE WHO CARRY OUT THE CRIME BECAUSE THEY ARE WALKING THE STREET BECAUSE THEY DO NOT WANT TO WORK -- YOU KNOW THESE PEOPLE AND IF YOU HAVE THE POWER THEN GET THESE TO WORK!!!! NOT THE DISABLED.*</p>
EM104	17-Dec-10	<p>Full of a cold, the brief version of the proposals are all I can manage! But even here, one thing concerned me:</p> <p>*It stated that the DLA "is the Department's second most expensive working age benefit, and costs</p> <p>*far more than was originally estimated". My son is in receipt of the DLA at age 7 - which is hardly 'working age'.</p> <p>*he is, I believe, to have his DLA reviewed at 8 years anyway, but this statement did not take into account the children on DLA.</p> <p>*Maybe that's in the fuller document, which I'll look at when I'm better!</p>
EM105	17-Dec-10	<p>1. Always around access, mobility, self-confidence, help and support to achieve their own needs. Comes down to lack of money to pay for equipment they need particularly as no one piece of equipment fulfils every need. Often when out and about they cannot join in because buildings have not been altered to allow 'access' despite all the laws around this issue. Many need to know where they can access disabled friendly toilets and if they can actually get into a building in the first place, or whether they can get onto a bus or onto a train!</p> <p>*2. I think some of the old rules re eligibility should remain, plus certain other well documented illness where it is obvious that people are not going to get better.</p> <p>*3. Equipment to help in their daily lives. Transport costs as many disabled people cannot use public transport, taxis, reliable cars. Some may need to wash items of clothing/bedding more, meaning higher utility bills. Often are at home more so need to keep warm, higher utility bills. Reliable cars as cannot risk getting stranded when out. Need to visit their hospital/service provider more than a non disabled person and this is costly in fuel and parking fees. Need to pay people to help care for them as many live on their own.</p> <p>*4. Difficult to say until we see what it is going to say. Could do. However people have many problems and is it possible to fit all these problems, needs into two boxes?</p> <p>*4.(b) People may not fit into either category and therefore slip through the net and then have to appeal, and re-appeal which will make the system harder and costlier to assess/administrate.</p> <p>*5. Some health conditions/illnesses are so obvious and with such a predicted (fully evidence based) pattern of 'deterioration' that they should have automatic entitlement, reduce the stress levels of the person and their family. Regarding impairments, limbs do not re-grow so as stated before limbless people should have automatic entitlement as there is well documented information in medical circles, Disablement Service Centre's that proves that limbless people go on to suffer deterioration in all their joints, shoulders, wrists, hands, fingers, hips leading to pain and again reduced mobility. There</p>

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		<p>is also documented evidence to show that many will suffer heart problems in later life due to the extra stress being 'limbless' puts on their body. If they have automatic entitlement then they can plan what they need to purchase to help them with their changing needs, knowing that over time they will be able to get the right equipment to allow them to join in as much as they can with society. By having the DLA and the attendant benefits that go with it, it will allow many recipients to remain in work therefore building up a better level of financial strength and emotional well being for the future. *In areas where there is a chance the illness/disability may get better - again these will have documented evidence, then yes, people should be re-assessed regularly.</p> <p>*6. *Ability to eat, drink and cook and prepare meals/drinks for themselves. May need kitchen units lowered if they are in a wheelchair.</p> <p>*Wash and toileting. May need help with washing and toileting as may not have mobility to this themselves. May need adaptations in the bathroom, access into different rooms when in wheelchairs.</p> <p>*Safety in their homes. Need alterations and equipment so they can remain in their own homes, ie stairlifts, walking frames, wheelchairs. Need to pay for a cleaner to keep hygienic.</p> <p>*May need help with putting on a prosthesis or looking after medical items such as catheters. May need assistance with taking tablets.</p> <p>*Social inclusion is also important and this means that these people should be able to interact with others and not become isolated in their homes due to lack of ability to get out in a car, or taxi or whatever transport is best suited to them.</p> <p>**7. There are numerous evidence based accounts of variable and fluctuating conditions documented. The assessors should be fully trained and have access to people who have these conditions – they should not just read about these conditions in books or make decisions based on set rules. General Practitioners are usually the ones people turn to and their views should be paramount. The 'person' being assessed should also be listened to and not made to feel threatened if they are having a 'good' day otherwise they will lose confidence and sink to the lower levels of their abilities. In the case of a limbless person, who are in a minority and should be in the class of automatic entitlement then the Disablement Service Centre Consultant's should be asked. A limbless person is reliant on third party input, and if the limb then fails or the interface between the skin and the prosthesis breaks down, the person cannot wear their limb – this is very often the case and the person cannot walk at all.</p> <p>**8. NO (this means that the disabled person is reliant on third party input and as is evident from many disabled people, the aids and adaptations can often fail or be inadequate for their needs.) Many people cannot afford to buy the modern lightweight aids anyway. In the case of prosthetic limb users, they are struggling each day to cope with their prosthesis. They may be able to walk limited distances but this then can break the skin down and cause stress and strain on the rest of the body, and this can lead to the person not being able to wear their prosthesis for days while they recover – they then are immobile. These conditions are so variant that it means the aids cannot be 'trusted' and therefore should not be in the assessment.</p> <p>*9. It is far too repetitive – questions seemed to just be variations of the question before. Make the form in simple clear sentences, at present it appears to be designed to completely baffle a person and many who could/should be getting DLA are put off from completing it.</p> <p>*9.(b) On websites, in GP surgery's, CAB, Charities for disabled people.</p> <p>*10. A person's GP should write a report, plus any social work team they meet in their daily lives. Also any specialist health provider team such as Disablement Service Centres, hospital inpatient teams. Their carers as well as the patient themselves.</p> <p>*11. Difficulty for the person to get to an appointment – they may be having a bad day and simply feel unable to travel or force themselves to travel when they should be at home. Transport problems. Anxiety for the person. With fluctuating conditions this will just be a 'snap shot' of the person on that day at</p>

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		<p>a precise time, not their real lives.</p> <p>*11..(b) Where there is documented evidence or a qualifying disability or illness, is it necessary?? Why put the person and their families through more stress? In these cases there will be an enormous paper trail of medical input both from GP's and the Hospital healthcare providers so why not just read these papers? More expense on an administrator or assessor which is taking money away from the disable people who need it.</p> <p>*12. This can in part be set by the type of illness or disability the person presents with.</p> <p>*As stated before various illness's have a pattern of deterioration so why does the person need to be reassessed? Unless it is to help further?</p> <p>*When a person presents with a 'disability' or illness which may get better then set timescales, yearly or two yearly?</p> <p>*12.(b) YES. *As before evidence based. Many people with disabilities need to be assessed to see how their disability is affecting the rest of their bodies – so they will need extra help over the years due to problems of overuse in other part of their bodies.</p> <p>*The reviews should be part of the PIP payment, not a review where the person feels they may lose their benefit. This review should be within the scheme and it should be made clear that the person has their benefit but this review is to see if they need more help.</p> <p>*13. Make it clear that there will be penalties for people who do not report their improvements. This can be documented in the paperwork when the award is given to the person.</p> <p>*14. *Who can apply, criteria.</p> <p>*That it is not means tested,</p> <p>*How long it lasts for.</p> <p>*What levels there are.</p> <p>*Which benefit claiming process?? Only necessary for people claiming incapacity benefit in case they have a need for it, not for people claiming housing benefits etc.</p> <p>**15. If people are not claiming it may be because they are too proud to ask for help or consider they are not ill/disabled enough to claim it, self denial of their illness (maybe in terminal cases). It would be important not to force this on them but it could/should be offered by social workers healthcare professionals to people who are eligible, maybe in a discharge from hospital pack or by a social worker/health visitor/district nurse visiting a patient.</p> <p>*16. A lot of people struggle with paying for these aids and adaptations and go without. Some on a very low income may get social help/grants. Families often help and buy the equipment, if they can afford to. However there are many middle income people who become disabled and would not qualify under the 'means testing' element but they still need these adaptations and aids. At present the mobility firms charge very highly for these items and should be encouraged to reduce their costs! In this case as stated before these people cannot buy the equipment so go without and this then reduces their quality of life.</p> <p>*Yes PIP should be able to be used to buy equipment.</p> <p>*17. Changing needs all the time. Inability to know how they may be feeling or what they want at a given time. Listen to their parents, they are the ones who know all about their children and their needs. Need to be able to be fully involved with their peers so will need PIP to support these needs, get them out and socially involved. Make sure their education does not suffer or allow them to access specialist education if necessary.</p> <p>*18. DLA has been very important in getting disabled people access to other services/entitlements. At present these entitlements are well thought out, ie the Blue Badge scheme which allows access to towns and areas where a disabled person may not have been able to reach with their limited mobility. Many people with Blue Badges will have to return to their car and drive to another area of the town and park again, in order to carry out what they need to do, if you had to pay to park this would put it outside a disabled persons means and could be looked upon as discrimination, ie preventing a disabled</p>

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		<p>person from joining in with everyone else. The automatic entitlement to a Motability car is an excellent scheme, as long as the scheme is 'policed' properly. Due to the nature of disability many people are in the lower income bracket because they are unable to work or have had to take a low paid job. They need cars that are reliable and of a size to cope with their disability. For instance people with prosthetic limbs have to have a big car or their prosthetic limb will not fit under the steering wheel. Many also take wheelchairs with them, so again they need to have the space. If it was not for motability many more disabled people would be stuck in their homes and depression could easily follow which ultimately could lead to all sorts of other lifestyle type illnesses like obesity, leading to diabetes, which in turn could lead to further amputation. Disabled people in particular need reliable cars – if their cars constantly are breaking down because they cannot afford to service them, or because they are old then they are in danger of trying to go on a journey and the car breaking down and then becoming stuck, or putting themselves in danger while trying to get help.</p> <p>*19. Just make the system far harder and involve far more administration. Disabled people, many of whom do suffer from depression and a lack of self-confidence would be faced with more forms to fill in, more people to arrange appointments with and then go and meet. This would also mean far more levels of administrative staff (higher costs to run the scheme) which is surely self-defeating? Many of these disabled people would again slip through the net and could become more 'disabled' both mentally and physically as they will just be stuck in their homes and isolated. The service providers are then faced with more and more problems with these disabled people as they become more withdrawn from society, which again increases the workload. If a disabled person is given the opportunity to join in with the chance to get out in a car, and park their car close to where they need to be their self-confidence levels are far higher and their health and well being improves. Some may be able to work and others could take part in some sort of volunteering opportunity which would both help themselves as well as their community.</p> <p>*20. I am not sure if the entitlement to Incapacity Benefit and DLA are linked but if not then these could be 'joined up' as the information will be similar. This would cut out one 'layer' of administration. Blue Badge scheme could also be linked into it and the free car tax disc from the DVLA, again another layer of administration removed and costs saved which could be used for the disabled persons direct needs.</p> <p>*21. It is important to recognise the age at which the person becomes disabled, including whether they are born with a disability because, at the moment it is likely and proven through statistics that the younger you are when you become disabled the more likely you are to lose your job and not be able to save for your future.</p> <p>*It does appear that there is a postcode lottery as far as care for different types of disability goes in the UK at present. This can play an enormous part in how well a disabled person can re-enter society or be a part of society. In some parts of the UK with prosthetic limbs delivery, there is a very poor service and many people are unable to walk ever, let alone the problems that come along when you do wear your limb for a period.</p> <p>*The system where the family used to help their parents or relatives has nearly broken down in this Country with families broken up and having to move miles away to find work. In the past it was more likely there would be a family member as the carer, unfortunately these days this does not happen so much, placing a greater burden on the state.</p> <p>*22. There are many genuine disabled people relying on this payment and they now feel under threat by these changes. I think more should be done to re-assure these people that they will still have the help they need. It is possible to have suicidal feelings when you become disabled, these can hit you at any time and to now find that the Government appears to be using a system which will have a firm in place to simply reduce the numbers of people seeking help is quite hard. I have even heard that these firms get a bonus</p>

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		<p>payment the more people they remove from the system! Please re-assure the general public that these assessors will indeed have the background knowledge and information to-do their jobs properly, fully informed and trained people, not just 'administrators' as appears to be the case from reports in the press at the moment.</p>
EM106	17-Dec-10	<p>1. Health and Safety requirements. People's attitudes. Shortage of appropriate work. Lack of trained and appropriate support e.g. care workers.</p> <p>*2. All of it - it is all relevant to aid the daily living of someone with a significant disability.</p> <p>*3. Help to support them to access transport, daily activities including basic life skills/needs and social activities.</p> <p>*4. It is only 1 less than the current care elements - see no HUGE change there!! (apart from form filling - maybe)</p> <p>*5. Yes, for some people once they have hit adulthood the likelihood of significant improvement is negligible e.g. Downs Syndrome, Autism etc - life long disabilities with little scope for significant change.</p> <p>*6. Medical issues are the easiest to ensure fraud doesn't occur - GP input, individual medical assessment. Mental health and learning difficulties via social service input, CAMHS and other professionals who have significant input into these people's lives. 1 off assessment by 'strange' professionals are NOT appropriate for non medical needs.</p> <p>*7. Changeable health conditions will need regular monitoring up dates from professionals involved via computer as this is quicker than via a paper trail.</p> <p>*8. People aren't always able to get the right aids and adaptations they need to improve their lives especially those which are means tested or expensive (LHB's and councils are reluctant to commit to these!) Adaptations/aids should not be included as they can 'break down' and a person could be in serious difficulties for quite some time before replacements or repairs are made and reassessment of need completed.</p> <p>*9. Less repetition of questions. More examples of the way questions should be answered - particularly for those with literacy difficulties.</p> <p>*10. Those who have frequent contact with them or provide for their care needs e.g. carers, GP, social worker, close relatives or friends. How they do it, what help they need to achieve it, how long it takes to complete. Stupid questions like how often can lead to ridiculous answers e.g. how often do you need support to go to the toilet? A. It depends on how often I have to go</p> <p>*11. A person with a significant learning difficulty will find this intimidating, may misinterpret the questions or not be able to answer appropriately or accurately misjudging their own abilities. If this practice is pursued they will need an appropriate advocate. If it is insisted on then when and where should be decided by the claimant and where vulnerable people are concerned appropriate support is in attendance.</p> <p>*12. A claim should be reviewed where there is a likelihood of changes occurring e.g. medical conditions which are subject to changes of any kind.</p> <p>*13. When people are notified about changes to benefits additional info should be included but unlike now it should be on a SEPARATE piece of paper and a DIFFERENT colour to the usual black and white lengthy letter received. Also, every 2 years or so send out a disclaimer which had to be signed and returned by claimant.</p> <p>*14. Help to understand the form/questions, to complete them appropriately and to ensure all their needs/difficulties are identified. Help and advice is fine IF it is easily accessible especially for those with learning difficulties.</p> <p>*15. Aids and necessary adaptations should be state funded where possible or means tested if 'desirable'.</p> <p>*16. Children need to be assessed on a regular basis until they reach adulthood. Adults with illness or disability where there is the potential for significant change should also be regularly reviewed but those with lifelong disabilities should not once they have reached adulthood.</p> <p>*17. Many services/agencies/organisations use it as criteria a benchmark for access to their services. A card similar to the blue badge scheme could be issued so that a 'DLA no' could be quoted to access services make it easy</p>

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		<p>to provide proof. Many disabled people particularly those with learning disabilities would slide even further into the poverty trap than they currently are.</p> <p>*18. A centralised database with different levels of access to various information but with HIGH security. Basic information but no details such as date of birth, bank details etc</p> <p>*19. The new benefit should be equitable for all irrespective of disability, race, gender or sexual orientation. All documents should be 'diversity' friendly. Religion and beliefs should not enter the equation.</p> <p>*20. They should be seamless, non invasive and stress free as far as possible for the claimants and any assessments should be done by empathetic and well trained staff.</p>
EM107	17-Dec-10	<p>I'm contacting you as a member of the public, but also someone who works on a day to day basis with people who are vulnerable and socially excluded.* *</p> <p>2 main points -*</p> <p>*1. You don't mention mental health once in the consultation paper I read - one of the pitfalls of current DLA is it tends to be focussed on a physical model, eg. aids and adaptations are mentioned, but not say, anti-psychotic drugs, and medication for anxiety - which can make a considerable difference to someone's daily living and mobility.*</p> <p>*2. How is PIP going to interact with Self Directed Support and the Personalisation agenda? My understanding is that SDS is meant to help people to live more independent lives, which is exactly what PIP is about. It seems to me that some people could end up receiving a huge amount of cash through both systems, which is then a massive disincentive to look at returning to work.</p>
EM108	17-Dec-10	<p>Suggested replacement of Disability Living Allowance with a new benefit.</p> <p>**I have had passed to me, electronically, a consultation form for the above. I should like to make some comments on the proposals.</p> <p>**I am pleased to see that thought is being given to changing the application form. The form was far too long and quite frankly bore very little relation to the abilities or inabilities of people suffering sight loss. It was difficult to get people to fill in the form in the way it was necessary so that the allowance would be granted. Frequently the person filling the form in on behalf of a blind person would say "oh you can do that". The tenure of the whole form was slanted towards people with physical handicaps and very little that seemed to affect those who have a visual impairment. Consequently, quite a number of blind persons were turned down for d.L.A. and had to appeal.</p> <p>**I approve the suggestion that VIPs should have a face to face interview, however in many cases I do not see the point of having regular re-assessments - particularly in cases like my own. I am totally blind and have been so since the mid-1960s. I have not formally seen an Ophthalmic Surgeon since 1972 (when an assessment of cornea graft patients was being carried out because of a new procedure). Included in the scheme should be a procedure for obtaining a re-assessment particularly where a secondary handicap may affect the situation, or a deterioration in the person's condition.</p> <p>**The documentation before me speaks in terms of making matters easier for disabled persons to continue or retain their station in the workplace, but as a retired person I still have to live and my requirements for assistance have actually increased since I was retired. Also many retired people still have a lot of input into society and are now doing work for which they are not paid. Frequently events require travelling to places not previously visited, and this can require the employment of a driver to reach the destination.</p> <p>**As the economic situation worsens shops and other facilities are being cut back on the number of staff available and for a blind person this causes increasing difficulties, and the only way to get round the problem is to employ someone on a part-time basis.</p> <p>**Independent living, means that a person has a home to be maintained, it needs decorating and maintenance. In our case we frequently need to ask a</p>

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		<p>professional to carry out small jobs - putting up a smoke detector, changing batteries in some pieces of equipment which require a small screw to be removed to gain access, and a myriad other jobs of a D.I.Y. nature. These are all matters that the D.L.A. never took into account but for someone who is disabled are a cost that has to be paid for independent living.</p> <p>**In closing might I draw your attention to the difficulties of accessing post. All blind people are assumed to have a friend who can do everything! Like attracts like, so, being a busy person myself my friends are also busy people. On occasions I have had to wait six weeks or more before I can get post dealt with. Operators are so eager to use the facilities that computer programs make available to them. Unfortunately, if shading has been used or text put in boxes or other features are used to "pretty up" a letter or form, when that document is put onto a scanner then the screen reading software we use often does not read it. Thus a deluge of forms presents a great difficulty and deadlines could well be missed. The DDA provided that everyone should have documentation in their preferred medium. The banks now do this quite well, but such organisations as insurance companies do not. Government Departments are very poor in following the dictates of the DDA, which has now been superseded by the Equality Act. *</p>
EM109	17-Dec-10	<p>I don't want dla to go it confuses disabled people if this go dose it mean more money the new benfit this hurts me writeing this if it the same then you should keep dla some people on benfit because they can t work regards</p>
EM110	19-Dec-10	<p>Suggested replacement of Disability Living Allowance with a new benefit.</p> <p>**A consultation form for the above has been forwarded on to me electronically, and . . I should like to take the opportunity to make some comments on the proposals, as follows:</p> <p>**It is pleasing to note that thought is being given to changing the application form. In my opinion, The form was far too long and quite frankly bore very little relation to the abilities or inabilities of people suffering sight loss. In my experience, It was difficult to get people to fill in the form in the way which was necessary . Frequently, the person filling the form in, at my dictation, said "oh you can do that", without having any idea of the difficulties I encountered in everyday living. In addition, . The tenure of the whole form was slanted towards people with physical handicaps and very little that seemed to affect those of us who have a visual impairment (myself total blindness). Consequently, initially (and including myself), , quite a number of blind persons were turned down for d.L.A. and had to appeal to be accepted.</p> <p>**I approve the suggestion that VIPs should have a face to face interview, however in many cases I do not see the point of having regular re-assessments - particularly in cases like my own. I am totally blind and have been so since the mid-1970s, before which time my sight was very minimal from birth. Included in the scheme should be a procedure for obtaining a re-assessment particularly where a secondary handicap may affect the situation, or a deterioration in the person's condition.</p> <p>**The documentation forwarded to me speaks in terms of making matters easier for disabled persons to continue or retain their station in the workplace, but as a retired person I still have to live and my requirements for assistance have actually increased since my retirement. Also similarly to myself, many retired people still have a lot of in-put into society and are now doing work for which they are not paid. Frequently events require travelling to places not previously visited, and this can require the employment of a driver to reach the destination.</p> <p>**As the economic situation worsens shops and other facilities are being cut back on the number of staff available and for a blind person this causes increasing difficulties, and the only way to deal with the problem is to employ someone on a part-time basis.</p> <p>**Independent living, means that a person has a home to be maintained, it needs decorating and maintenance. In our case (both my husband and myself are totally blind) we frequently need to ask a professional to carry out small jobs - putting up a smoke detector, changing batteries in some pieces of</p>

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		<p>equipment which require a small screw to be removed to gain access, and a myriad other jobs of a "do it yourself" nature. Because of our blindness, it is necessary for us to spend out substantial amounts of money on technical equipment. . These are all matters that the D.L.A. never took into account but for someone who is disabled are a cost that has to be paid for independent living.</p> <p>**In closing May I draw your attention to the difficulties of accessing post. All blind people are assumed to have a friend who can do everything! Like attracts like, so, being a</p> <p>*busy person myself, my friends are very busy people. There have been occasions when I/we have had to wait six weeks or more before our post can be dealt with. Unfortunately, from our point of view, computer Operators are so eager to use the facilities that computer programs make available to them. Unfortunately, if shading has been used or text put in boxes or other features are used to "pretty up" a letter or form, when that document is put onto a scanner then the screen reading software we use often does not read it. Thus a deluge of forms presents a great difficulty and deadlines could well be missed. The DDA provided that everyone should have documentation in their preferred medium. The banks now do this quite well, but such organisations as insurance companies do not. Government Departments are very poor in following the dictates of the DDA, which has now been superseded by the Equality Act. *</p>
EM111	19-Dec-10	<p>Regarding Section 2 paragraph 27 - "PIA takes into account adaptations and aids". This will discourage people from accepting help if they know they are going to be penalised for it. You should try using a wheelchair for a day whilst, for instance, shopping. You will find it difficult to get round aisles due to their narrowness and to people who are "blind" to wheelchair users. These are the big shops. The smaller ones you can forget altogether. It is certainly not on a par with being able bodied. *</p> <p>*Re Section 1 paragraph 5 The new Universal Benefit will "always ensure people are better off in work". This sounds very discriminatory towards people who are so disabled they are not able to work. I would point out that I currently work 16 hours weekly.*</p> <p>*I feel very worried due to the frequency of the term "affordability and sustainability". It gives the impression that to get the higher rate under the new proposals, you need to be a paraplegic on a life support machine.</p>
EM112	20-Dec-10	<p>Dear Maria Miller,</p> <p>**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. I am concerned that 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 and distress for many disabled people.</p> <p>**Firstly, the case for reform- The reasons given for DLA reform are not robust, with little evidence to support the case for reform.</p> <p>**The wildest claim to support reform is that 'evidence suggests that DLA can act as a barrier to work'. This passage is footnoted, referring to "Disability Living Allowance and work: Exploratory research and evidence review, 2010, DWP Research Report No. 648" (RR No.648). This report also finds that "the main factor affecting the employment rates of disabled people is their disability or health condition" and that "a larger than average proportion of DLA recipients also appears to be affected by the specific types of impairment that carry the greatest employment disadvantage for disabled people" – yet these findings are not reported in the consultation paper, thus skewing discussion.</p> <p>**In fact, though the report claims that there exists a "perception of disability permanently precluding work is prevalent among individuals with disabilities not already in employment", there is no evidence cited in the report that suggests DLA could be a barrier to work. The section and all references to it</p>

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		<p>in the consultation paper could be interpreted as an attempt to misdirect, and should be removed. Further, it should be noted that the consultation makes the mistake of confusing correlation with causation. Whilst RR No. 648 does provide evidence that low employment is correlated with claiming of DLA, this in no way implies that one causes the other.</p> <p>*It could be suggested that the lack of evidence pointing to a need for reform has meant that misdirection was used in an attempt to convince the public that DLA reform is necessary. In particular, the graphs presented as Figure 1 and 2, on page 8 of the consultation paper, used to show the DLA caseload increasing at an alarming rate, are flawed in many ways, not least in the fact that no baseline is established for when take-up of DLA by people with disabilities plateaued after its introduction in 1992/93. There are further issues regarding the number of Pensioners as the report ignores demographic trends to show that there is a dramatic increase in claims by people over State Pension age. This is particularly questionable since a Pensioners' eligibility for DLA would usually depend on their receipt of DLA prior to this – otherwise, they would be eligible for Attendance Allowance, as I am certain you are aware. *According to the consultation, 8% of the population claim DLA. The Office Of disability Issues estimates that 10% of the population are disabled. So, assuming that it's roughly correct the 'right' number of people seem to be claiming. There are people claiming who shouldn't be, however, they are a minority and are likely matched (if not exceeded by) the people who don't claim, either because they don't know about it or don't want it. **The core argument of the consultation paper is that DLA is a benefit not fit for purpose. Paragraph 9 on page 6 of the consultation paper states that: "DLA is a benefit that provides a cash contribution towards the extra costs of needs arising from an impairment or health condition." The arguments presented in paragraphs 14 and 15 of page 8, claiming that the benefit is not fit for purpose, do not touch upon the original purpose of DLA or offer any argument as to why it is failing to meet its original purpose. The information presented is that the DLA caseload and expenditure is a "lot more than was originally expected". No arguments are presented as to why this means that DLA is not fit for purpose. **Finally, paragraph 2 states: "We believe that now is the right time to reform DLA", yet offers no qualification or reasoning for this belief. Paragraph 3 continues by saying that: "We must ensure that our resources are focused on those with the greatest need", with no qualification or definition of the term "greatest need". This could be pointed to as a suggestion that those with "lesser needs" will have to struggle unsupported with their impairment, and that the definition of needs is at the whim of the Secretary of State for Work and Pensions.</p> <p>*I will now address the second part of the consultation paper, explaining why the reforms intended by the DWP will be harmful to disabled people.</p> <p>**Paragraph 4 of Page 11 begins by stating that: "Central to Personal Independence Payment will be a new, fairer, objective assessment, which will allow us to identify those who face the greatest need, in a more consistent and transparent manner." The previous sections of the paper do not suggest that the current DLA assessment is unfair or that it is not objective, and neither is there evidence that it is inconsistent or lacking in transparency. The current system is assessment by a variety of resources; information from a carer or support worker, the person's GP, specialist consultant or physiotherapist. Trying to slim down this evidence base to on homogeneous assessment will mean that the impact of disability on the individual is ignored. This is definitely not objective. Paragraph 4 also states that: "We are developing the new assessment in collaboration with a group of independent specialists in health, social care and disability, including disabled people." What 'independent' means is that a private company such as Atos will be contracted to run assessments. This will include meeting with an 'independent' healthcare professional – not necessarily qualified as doctors - working for the assessors. The objections to a private company using unqualified staff who know their jobs depend on keeping to strict targets aimed to reduce numbers qualifying for a particular benefit are too many to</p>

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		<p>list.</p> <p>**Paragraph 12 on page 13 of the consultation paper suggests that: “The criteria on which DLA is currently based, on care and mobility needs, are subjective and unclear.” It could be argued that this statement is subjective and unclear as there is no qualification of the statement, and no evidence is offered in support. The lack of a formalised set of criteria for DLA awards is due to the varying impact of disability, meaning that such a ‘tick-box’ test would not be objective either. The following paragraph in the paper suggests that ‘care’ and ‘mobility’ may not be the best proxies for the additional costs faced by disabled people. The paragraphs also state that “there is currently conflicting evidence on the factors that affect the extra costs that disabled people face in the 21st Century”. The very fact that the only two DWP research reports cited to support offer conflicting evidence raises questions about the DWP’s choice to accept one piece of evidence above the other.</p> <p>**Paragraph 14 of page 13 offers the example: “‘mobility’ as currently defined concentrates on an individual’s ability to walk, not their ability to get around more generally.” It is true, generally, that people with disabilities are more mobile as aids and access have improved. However, this additional mobility has come with extra financial costs, such as new mobility aids, adapted vehicles, taxis. Moreover, it is crucial to remember that additional mobility does not mean universal mobility. Paragraph 15 of page 13 suggests an intention to refocus the Personal Independence Payment (PIP) at those most impaired in their ability to carry out a range of activities, because: “There is some evidence to suggest that individuals whose impairments have the greatest impact are likely to experience higher costs.” This statement is bizarre, as this is exactly what DLA does. Paragraph 16 on page 14 discusses splitting PIP into a ‘mobility’ component and a ‘daily living’ component, with two rates for each component. This suggests that the change from DLA will be a vastly expensive re-branding exercise, as modifying DLA could achieve this..</p> <p>**Paragraphs 17 and 18 on page 14 argue that “The individual must have a long-term disability” in order to claim PIP, so that “an individual’s health condition or impairment must be expected to last a minimum of 12 months”. This will punish those who suffer debilitating short- and medium-term illnesses, but eventually recover their mobility and ability to care for themselves. Whilst people are ill over the short- or medium-term, they will have mobility and/or care needs and face the same extra costs as those with long-term conditions. They may even have to purchase mobility or care aids for their temporary conditions. Yet this consultation paper seems to ignore their needs. Long-term conditions are also targeted as paragraph 19 on page 15 suggests the end of automatic entitlement for certain conditions. The example of renal dialysis automatically entitling on to the medium-rate care component of DLA is given, and it is argued that: “As a result, eligibility for DLA is sometimes based on medical condition rather than the impact of that condition, meaning that support is not always appropriately targeted.” The meaning of this sentence and argument is completely opaque, unless it is to suggest that one should be denied support because they are too ill to use it; a thoroughly distasteful argument which I refuse to believe that the DWP countenanced.</p> <p>**Paragraph 21 of page 15 argues for the full removal of PIP from individuals in “hospitals or similar institutions or care homes”. As care homes take income and savings into account, this will mean that care home residents no longer have any independent income to pay for short journeys or other ways of retaining independence, and become entirely institutionalised.</p> <p>**Paragraph 24 on page 16 states that: “We remain committed to the social model of disability. The new assessment will not be based solely on the medical model of disability and focused entirely on an individual’s impairment, but will instead focus on the ability of an individual to carry out a range of key activities necessary for everyday life. “ The meaning of this statement is unclear. Paragraph 26 adds little clarification, stating: “Activities we assess could include, for example, planning and making a journey, and</p>

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		<p>understanding and communicating with others. The extent to which an individual could carry out these activities would determine their eligibility for Personal Independence Payment and the level of their award.” As I have argued above, such a tick-box approach to the impact of disability is counter-productive and not objective. A person able to complete the activities in your example may still need the same type of support as another who cannot and the ability to plan a journey is surely a matter of intelligence not physical ability.</p> <p>**Paragraphs 27 and 28 state that PIP will “take greater account of the successful use of aids and adaptations as part of the Personal Independence Payment assessment”. This means that successful use of aids – including wheelchairs – could mean that claimants are not eligible or eligible for a lower rate of PIP. This is a ridiculous suggestion. For example Tanni Grey-Thompson – one of the most successful athletes of all time – is a 6 times winner of the London marathon. She is obviously ‘successful’ in her navigation of London streets. Yet she will face the additional costs of her mobility needs just like any other person with a disability. The general truth is that successful use of an aid does not negate additional mobility costs.</p> <p>**The point that most concerns me is the focus on DLA as a disincentive to work, which is both false and disingenuous. People who receive DLA do often have lower work expectations as the reform consultation paper suggests, and rightly so as many conditions and impairments make work impossible. Disabled people are often unable to compete equally in the labour market, because of ignorance amongst employers and a lack of willingness to consider making adjustments that may well be relatively cheap and straightforward but are perceived as too onerous. People with high rate awards have the highest levels of impairment and are most likely to be unable to work, regardless of benefits, Those who do work are often only able to do so because of the aids, support or adaptations that DLA or Access to Work allows them to purchase. The focus on moving to work has no place in discussion about DLA other than to make the important clarification that DLA is not work related, and exists to assist with the additional cost incurred when living with an impairment or long-term health condition.</p> <p>**Other problems include the fact that the PIP proposals will see some current recipients of social care losing financial benefits now paid at least in part to the local authorities for receipt of that care. This will force the LAs to make up the shortfall in funding or, more likely, cut care packages. Another aberration in the recommendations made is the impact of these plans on independent living, making that harder to deliver. Removing DLA from those who receive care packages, and especially those in residential care, will not promote independence. Lastly, some people may lose money as the aids and adaptations they use to enable them to live with their impairment or long term health condition will be seen as negating the need for that financial support, ignoring the fact that the DLA Mobility Component may be the only way of paying for adaptations such as wheelchairs or taxis.</p> <p>**Although the caseload may be cut, PIP will still look very much like DLA. The current system allows for automatic entitlement to DLA for certain conditions. The new system will not allow for this, and will re-asses all claimants every few years. This would be costly as automatically entitled conditions are by nature the most severe and incurable. The only thing achieved will be the extra cost of unnecessary assessment, and hardship for severely ill people. Further waste comes from ignoring the fact that, unfortunately, some people will remain disabled and have impairment-related support needs even if they no longer meet the new thresholds under PIP. They will be ignored up to the point they become seriously ill and end up costing the NHS and local authorities more in terms of hospitals and residential care. Further, the proposed reforms don’t take into account the reality that some conditions are severe but acute. Not supporting people with acute illness and disability makes it more likely that this will become a costly long-term problem therefore increasing dependency.</p> <p>**There is a strong feeling amongst people with disabilities that the Coalition</p>

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		<p>Government have decided to target us. Announcements about 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 that was actually 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 of DLA Reform. Whilst there may be ways to improve and reform DLA, they should not involve replacing it with a new benefit that will be costly to implement, and neither do they involve removing anyone from the claimant caseload.</p> <p>*Whilst RR No. 648 gives evidence that DLA is complex and not understood by all claimants, as suggested in paragraph 19 on page 10, this is surely grounds for improving the current system rather than expensively replacing it with an entirely new one. The way the consultation paper is written makes it sound like all a claimant has to do is say they are disabled and they get a big fat handout. This is not the case. The vast majority of the paper states 'new' measures that are in fact already in place:</p> <p>**• 6 month qualifying period? Yes.</p> <p>*• Assessment of what you can and can't do? Yes.</p> <p>*• No process to check the award is correct? Yes there is, awards can be (and frequently are) fixed term (people can get better or learn to adjust- DLA is for needs arising from a disability, NOT from the disability itself)</p> <p>*• Scored on a proxy of care needs and mobility needs (the report on one hand criticises this and on the other confirms PIP will have the same approach!)</p> <p>*• Successful use of aids etc should be considered? Yes, DLA already does this.</p> <p>*• Individuals responsible for reporting changes of circumstances? Yes.</p> <p>*Any money saved from not reforming the whole benefit but refining it could be spent where it is most needed, on educating people (both disabled and non disabled) that being disabled doesn't make people useless or stupid; it just makes them approach tasks in a different way. So many people are amazed that a blind person can use a computer for example. Or that a blind person can navigate round a room or sit on their own without a sighted person following them round like they are made of glass. Or that a person like me, with MS isn't confined to a wheelchair and can (and does) work.</p> <p>*DLA means people like me CAN work. It supports us in work, and my being in work means I need more support than if I were sitting at home all day. In addition, because receiving DLA means that I can work, I pay lots of taxes and make a greater contribution to the economy than I could if it were removed and I couldn't work.</p> <p>**I am forwarding copies to the Secretary of State for Work and Pensions, and to the DLA Reform Team in your department. I am also forwarding this letter to Austin Mitchell MP who represents my constituency, and to Lady Tanni Grey-Thompson. I am sure my MP will read it with great interest, and I know that he will wish to raise a number of searching Parliamentary questions regarding the conduct of DWP during the compilation of the DLA reform consultation paper. I await your reply.</p>
EM113	20-Dec-10	<p>Re: Disability Living Allowance reform 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. **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 robustly questioned. Questions are also raised concerning</p>

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		<p>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> <p>**I am sending a copy of this by post, and expect your prompt personal reply with distinct reference to each and every point I have made. I am forwarding copies to the Secretary of State for Work and Pensions. I am also forwarding this letter to Mr James Clappison who represents my constituency. I am sure my MP will read it with great interest, and I know that he will wish to raise a number of searching Parliamentary questions regarding the conduct of DWP during the compilation of the DLA reform consultation paper. I await your reply.</p>
EM114	20-Dec-10	<p>I am responding as an Individual.*</p> <p>*I wish to respond to Question 7: Assessment of Variable and Fluctuating conditions*</p> <p>*I have Multiple Sclerosis, diagnosed 24 years ago.*</p> <p>*You will doubtless be receiving consultation responses from a number of groups representing people with multiple sclerosis, as well as from a number of individuals with multiple sclerosis.*</p> <p>*It is highly likely that a very frequent refrain in those responses will be that assessing people with multiple sclerosis on any on particular day and then basing the decision as to DLA award on the person's abilities on that specific day alone will not be 'fair'. That is because it will not take account of the variable and fluctuating nature of the disease. In many cases, that will be a valid objection.*</p> <p>*However, I wish to speak as one of a minority of people with multiple sclerosis, around 10% of the total, who do not have and have never had 'variable and fluctuating conditions'. I have been diagnosed with Primary Progressive Multiple Sclerosis. This describes my condition, and that of the 10%, as my symptoms never lessen either cyclically or with time, but always grow worse.*</p> <p>*Thus for people with such a diagnosis, their prognosis on the specific day of any assessment is not that they are likely to have periods when symptoms are less, but rather that for tomorrow and for all the tomorrows, our condition is deteriorating.*</p>

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		<p>*I ask that this is borne in mind if any uniform handling of people with multiple sclerosis is proposed, as this could possibly put me and others who share my condition at a disadvantage.*</p> <p>*Please contact me if I have not made myself clear.*</p> <p>*With thanks for your consideration, and for giving me the opportunity to respond</p>
EM115	20-Dec-10	<p>I would like to make a comment on question 8. *</p> <p>*As my answer to question 3 would be :-</p> <ul style="list-style-type: none"> * the salary of carers, * aids and adaptations, * transport <p>* and my answer to question 16 would be that "aids and adaptations" must currently be funded from dla*</p> <p>*this would make my answer to question 8 an emphatic "no", "aids and adaptations" being an integral part of the purpose of the benefit. * *If "aids and adaptations" were, illogically, to be taken into account, existing adaptations, and possibly obtainable adaptations, should be treated equally, for the sake of fairness. It would be unjust to penalize people who have already made the effort and expense to adapt their living conditions,</p>
EM116	21-Dec-10	<p>Dear Mr [REDACTED],</p> <p>*PUBLIC CONSULTATION INTO PROPOSED CHANGES TO DISABILITY LIVING ALLOWANCE (DLA)</p> <p>*As my local MP, I am writing to you with regard to the government's proposals to replace Disability Living Allowance (DLA) with Personal Independence Payments (PIP). Having reviewed the consultation documents and listened to various ministers discussing reforms to benefits for disabled people in the media, I have concerns as to the proposals and would like to ask for your assistance in raising those issues in the House.</p> <p>*I am a disabled person. I became disabled in 1991, at the age of 15, with a chronic neurological illness which means that my life is majorly restricted by mobility problems, fatigue and pain. I am dependant on a wheelchair for more than a very short distance (classed as 'virtually unable to walk' under DLA), although the 'invisible' elements of my condition cause an equal level of disability. I have been receiving DLA for 17 years, currently at higher rate mobility (HRM) & lower rate care (LRC) components. With the assistance that DLA has provided, I have managed to complete my education to degree level, and now live in my own flat and work 4 days a week (the maximum that I can). I also volunteer as a Trustee of my local Access Committee, to improve access to public facilities for disabled people within Birmingham.</p> <p>*With regards to the proposed benefit reforms, there seems to be a fundamental misunderstanding as to the purpose of DLA. It is not an 'out of work' benefit, but designed to be there precisely to cover the additional costs that we face as disabled people, to enable us to participate more fully in society. It is not, as has been represented in the press, a disincentive for disabled people to work, but provides the support that many people need to get out into society and hold down a job. In its most basic form, it is about equality of opportunity.</p> <p>*My main concerns relate to a number of different issues, which I will try to explain as concisely as possible. These concerns come from my personal perspective, but most of the points also relate to people with other disabilities, such as sensory impairments, learning difficulties, and mental health conditions:*</p> <p>*Mobility: Replacing 'Walking' With 'Mobilising'</p> <p>*I am concerned about proposals to replace the assessment of people's ability to walk with 'mobilising'. The premise being that if a person has the appropriate mobility aids, e.g. in my case crutches and a wheelchair, or strong painkillers to deal with pain, they are no longer disabled as they can now get about as they wish.</p> <p>*. Availability of Mobility Aids</p> <p>*The NHS has very restricted resources, and often cannot afford to supply the</p>

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		<p>level of mobility aid required for optimum independence. I have had 4 manual wheelchairs over the years, through 2 different PCTs, but am not</p> <ul style="list-style-type: none"> *eligible for an electric wheelchair as, even though fatigue means I can only push short distances, I can walk a little. I was last assessed a year ago, but Wheelchair Services were unable to provide a manual wheelchair that met all my assessed needs, as they only have a restricted range which they can prescribe. Instead, the NHS provided me with a 'voucher' contribution towards the wheelchair, and I was responsible for paying the remainder, plus covering all maintenance costs for its 5 year life. My new chair cost £2,100, of which the NHS *paid £1,500 - although NHS contributions for previous wheelchairs have been as low as £200 under different PCTs. My DLA Mobility Component has to be used to make up the difference in cost. *. Transport (Motability Scheme/adapted car) *As stated above, I am unable to push my wheelchair very far, especially as I live in a hilly location. Although advances have been made in accessible transport, there are still many inaccessible bus and train routes, or only infrequent services to selected destinations. Fatigue issues, travel distance to/from bus stops and inclement weather (including the current snow and ice) also make public transport difficult to access. I also need to have a car for work. *The mobility component of my DLA is used towards funding a car. Here again I have increased costs, above and beyond the average person, which my DLA pays for: <ul style="list-style-type: none"> *o hand control adaptations to allow me to drive, as well as a hoist for my wheelchair *o larger car to fit the wheelchair, automatic transmission and power steering *o Increased petrol costs mile for mile, as it is a larger car *o Increased petrol costs, as have to drive where other people can walk *o comprehensive breakdown cover, as I am very vulnerable if stranded *o specialist car insurance, to provide taxis if my car is damaged, as there are no adapted hire cars available. *. Accessibility of the Built Environment *Despite the advances made in recent years through the introduction of the Disability Discrimination Act, there are many places that are still not accessible. You only need to go to the average High Street to discover that many shops, hotel, pubs, etc. are still not accessible. Similarly, many workplaces are also not accessible and, with restrictions on the resources of Access to Work, this will not be easily overcome. My illness and fatigue issues also mean that I am often too unwell to leave the house so, even if the whole of the UK was flat and wheelchair accessible, I would still be restricted. This means that I have additional costs, which my DLA helps towards, such as: <ul style="list-style-type: none"> *o A laptop computer and home internet access to allow for buying items on line and working from home (lying down) on my days when pain and fatigue are too great *o Paying for delivery charges on internet shopping, on top of the cost of the items *o Having to shop at a more expensive supermarket chain, rather than the budget ones, as they don't do home delivery *o Staying in more expensive hotels when going away, rather than smaller B&Bs or hotels, as they are often not accessible *o Paying for carers to accompany me on holiday or days out, to help overcome access and fatigue problems. As it is, I can only afford this very occasionally. *o More expensive holidays, as I can't book accessible holidays as 'last minute' deals. Heat is especially helpful in reducing pain, so a break every year in a hot climate provides welcome respite from some of the worst of the pain. *. Pain Control *It is not the reality for me, or many other people, that my pain can be

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		<p>controlled by strong pain killers as the PIP proposals seem to suggest, thus removing any disability. I am under the care of a Consultant pain specialist, on strong opiates and cocktail of other painkillers, but these only take the edge off the pain. They also come with a raft of sideeffects, which must also be managed – it is often a judgement of which is the 'lesser evil' to contend with. I cannot take more painkillers without this compromising my ability to work and drive, so pain still continues to be a significant impairment. Without DLA to help cover the additional costs of daily living, and an amazingly understanding employer who allows me to work very flexibly, I wouldn't be able to work or participate in society. I have experienced much discrimination in the workplace, and know my employer to be the exception, rather than the rule.*</p> <p>*Care Component: number of levels of award</p> <p>*The proposals include plans to reduce the different levels of award for the Care Component from three to two, effectively eliminating the lower level to target help to 'those with greatest need.' Currently the 3 rates are awarded broadly for:</p> <p>*Lower (LRC) – inability to prepare a cooked meal</p> <p>*Middle (MRC) – significant daytime care needs</p> <p>*High (HRC) – significant day and night-time care needs</p> <p>*The proposals state that the new PIP will be more flexible and will adapt to suit the disabled person's situation better. However, I disagree that reducing the number of different levels of award will help. It is more likely that people to fall between the gaps, as the gulf is too great. As it is, there is a great difference between the level of care needs required to qualify for the Lower & Middle Care Rate. I am on LRC, but have more care needs than just help preparing a cooked meal. This is the position that many disabled people are in – with the little money we get, having to choose between spending it on eating properly or things such as having clean clothes to wear. For those of us that are trying to work as well as live independently, it is a difficult choice. Removal of the lower rate would severely reduce my ability to work, be an active part of society and ultimately lead a fulfilling life. I believe that the number of levels of Care Award should actually increase, to allow support to be better tailored to the individual. For example, these are some of the main issues I face:</p> <p>*. Cooking:</p> <p>*o I struggle to cook for myself, due to fatigue, so need meals prepared for me</p> <p>*o I have multiple food intolerances as part of my condition, so can't eat most supermarket 'ready meals.' I also need to buy specialist wheat and dairy free foods (bread, pasta, biscuits, etc.) which are very expensive.</p> <p>*o I end up having to get Chinese takeaways, etc. which can be specially prepared to meet my dietary requirements, as I can't afford a carer on the few pounds a week I get in LRC. This is the best solution I can see, however, it is difficult to eat healthily.</p> <p>*o If do buy fresh salad or pre-prepared vegetables, hoping I might have the energy to prepare/cook them, I often don't and they go off and have to be thrown away.</p> <p>*o I have had to pay for a new, more accessible kitchen to be installed, with an accessible oven, easy access hob, fridge freezer and a perching stool. Even so, I often burn myself or spill things trying to get food in and out of the oven & microwave.</p> <p>*o I often will eat food straight out of containers, or use the same plate and glass for 4 or 5 days, to minimise washing up/having to fill the dishwasher</p> <p>*o I spill food down myself often when eating, as my co-ordination is often not very good, so this creates more laundry.</p> <p>*. Dressing:</p> <p>*o When I wake up in the morning, all my joints are stiff and I can't bend or grip things easily.</p> <p>*o I often don't have the energy to get dressed or undressed, so end up sleeping in my clothes, not being able to go out with friends or having to work from home as I don't have the energy to get dressed.</p>

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		<p>*o I often don't have the energy to carry out basic hygiene tasks. I have to buy expensive mouthwashes to use in the evening, instead of brushing my teeth. I buy baby wipes and dry shampoo for when I am too unwell to wash.</p> <p>*o I use hot baths for pain relief but often fall asleep in the bath or end up sitting in water that has gone cold, as I don't have energy to get out. I have often been woken up when my head has gone underwater and I can't breathe.</p> <p>*Additional Costs of Living, as a Disabled Person*There are also many other additional costs that I have, as a result of my disability, that are not immediately obvious. If you choose to have a Motability car, then you surrender your Higher Rate Mobility component in exchange, which leaves you with only the Care Component remaining. I have listed some examples of additional costs I have below:</p> <p>*o Costs of paying for house cleaning, changing the bed and ironing clothes – but these are not considered as 'Care' needs.</p> <p>*o Extra clothing, such as 3 weeks' supply of underwear, as don't have energy to do laundry often, and it is physically a struggle.</p> <p>*o Wheelchair gloves and special clothing or shoes, as they are worn out by pushing the wheelchair and my unusual gait, even when walking the small distances I can.</p> <p>*o Pre-pay prescription card (over £100 a year), as I take 9 different medications</p> <p>*o Extra heating as I have poor circulation and feel the cold easily</p> <p>*o Extra electricity for cooling/fans in the summer, due to poor body temperature control</p> <p>*o Water & heating costs for deep baths and multiple hot water bottles for extra pain relief</p> <p>*o Higher phone and internet charges, as am unable to get out of the house very often</p> <p>*o Aids and adaptations, e.g. ramps, bath boards, grab rails, wheelchair bags, perching stools</p> <p>*o Memory foam mattress and pillows, due to back pain and problems with sleep.</p> <p>*o More expensive ground floor housing, with ramps, etc. As other housing is inaccessible.</p> <p>*o Expensive travel insurance due to pre-existing medical conditions</p> <p>*o Vitamins/supplements recommended by clinicians, but not available on prescription</p> <p>*o ... I could go on!</p> <p>*I am not eligible for additional help for a lot of these things because I work and don't claim any other benefits.</p> <p>*Distribution of Funding for Care</p> <p>*I am also concerned about reports in the press, suggesting that the government is considering cutting the amount of benefits given directly to disabled people and, instead, giving it to Social Services to provide support instead. For me this would be a detrimental change. It has been a struggle to achieve my independence, and DLA gives me full control of the money I receive, to spend exactly where I most need support. It has made a great difference to achieving independent living and being able to get out to work. My family live 100 miles away and, if I were reliant on 'Meals on Wheels,' Social Services Transport, or carers whose timetable suited the Council's schedule (rather than mine), then I can categorically say that I wouldn't be able work. Restricting support, and making it harder to access in this way, will only 'disable' people further.</p> <p>*In conclusion, to recap:</p> <p>*DLA is needed to cover the myriad of additional costs that being disabled entails. It is about giving</p> <p>*people a chance at equality - enabling people, not discouraging them from working.</p> <p>*. Mobility – the world we live in is still far from accessible and other issues, such as fatigue, pain and chronic illness restrict people's mobility. DLA is</p>

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		<p>needed to help fund mobility aids and adapted cars, although a wheelchair, etc. should not be seen to 'remove' a disability.</p> <p>*. Care – the number of levels of award should be increased, not reduced, to allow support to be better tailored to the individual.</p> <p>*. Support Services – the money needs to continue to be provided directly to disabled people, not given to over to Councils, so that we can tailor support to suit our own needs.</p> <p>*Thank you for reading this letter – I apologise that it is long, however I hope that has given you an insight into the role of DLA, and how it helps, rather than hinders disabled people such as myself. I am very concerned at the image that ministers are painting of disabled people as being 'benefit scroungers,' with plans intended to reduce the amount of DLA claimants by 20%, where the official DWP figures show the rate of DLA fraud as only approx 0.5%. The insistence that support needs to be targeted only towards 'the most severely disabled people' seems just to be trying to 'raise the bar' to save money, rather than based on a fair assessment of need. Based on that premise, I am concerned that I wouldn't fall under the government's classification of the most severely disabled. I understand fully that the current economic times means that hard choices must be made, however, I depend on the support to help me work and, because of that, I am able to contribute more in taxes and NI into the system than I claim back – which must surely be in the government's interest! However, this isn't just about work, but also about the right to a fair chance at life, rather than returning to the days where disabled people were marginalised and institutionalised. The most vulnerable – who generally find it hardest to make their voices heard – shouldn't suffer and be made out to be public scapegoats for the current state that the country is in. I hope that you will agree with the points I have made, and would be willing to raise them with the DWP and relevant ministers, and vote accordingly on the proposed reforms to DLA in the House. I, as many disabled people, are living with the very real fear of what the changes to PIP would mean to our lives, and would greatly appreciate your support in this matter.</p>
EM117	21-Dec-10	<p>Here is my response. I think it's a simple, straightforward and easy to maintain plan</p> <p>*Q1.</p> <p>*A. Societies perception of disabled peoples abilities.</p> <p>*B. Fear of appearing to be "less" than the others and letting themselves and others down.</p> <p>*C. Vulnerability, wide open to attack, ridicule and pity.</p> <p>*Q2. No response</p> <p>*Q3.</p> <p>*A. Costs to enable them to have an equal quality of life as the able bodied or as near as possible</p> <p>*B. Transport - either in terms of "Motability" or public transport.</p> <p>*C. Help - to pay for someone to clear snow while an able bodied person could do it themselves.</p> <p>* Help - to clean their environment, able bodied can do it themselves, but for some people a dusty house means ill health.</p> <p>*Help - to make a meal.</p> <p>*Help - to get to work without arriving like a limp lettuce because the effort has drained them.</p> <p>*Q4. No response</p> <p>*Q5.</p> <p>*Some conditions should automatically trigger payment. The "Diagnoser" is responsible for saying wether or not the persons condition is likely to improve and to monitor it.</p> <p>*Q6.</p> <p>*To be able to be clean, make yourself a meal, be safe in your main environment.</p> <p>*Q7.</p> <p>*By realising everybody has good days and bad. Some conditions may</p>

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		<p>fluctuate but unless you can foresee this you can't do anything about it. The Person isn't being fraudulent if they go on holiday - their condition goes too but getting away for a while may help them to cope better when they return.</p> <p>*Q8.</p> <p>*Yes. They are trying to be independent by using them. My issue would be that sometimes aids are given but are not used because the Person just can't manage to use them. I think that aids need to be tailored to the individual and if they are unable to cope with them then they shouldn't be issued.</p> <p>*Q9.</p> <p>*There doesn't need to be a form for the Person to fill in. At the point of diagnosis whoever diagnoses that there is a condition that's likely to have a long term impact on the Person they fill out a simple on line form with Name, Address, NINO and impact on the person, print off a copy and give it to the Person to keep. Form sent via email to PIP. NO payment made to diagnoser. Award made on basis of diagnosis with date that Person next sees diagnoser. Same process again. If the persons condition is maintained benefit maintained, all treatments, referrals etc relayed to PIP. If condition becomes worse or treatment hasn't helped this is noted. At each visit person is given "receipt" to show that update has been sent. PIP must confirm within 5 working days stating that they have received the updates and whether or not it has had an affect on their award. Some conditions may not worsen or improve and may not need to be maintained. This should be noted by diagnoser. Visits to GP re condition or other side affects need to be relayed to PIP - receipt given to Person. Receipts should be no bigger than a prescription and don't need reams of info on them, just that Person attended, date, presenting problem only relating to claim, action taken, signature of diagnoser. No payment to surgery or diagnoser.</p> <p>*Q10.</p> <p>*Diagnoser -> referrals -> OT/Physio etc. No payment made to them re filling in on line PIP</p> <p>*Q11.</p> <p>*This is compulsory. No one to get benefit unless they have been assessed. If they are not assessed they don't qualify. End Of.</p> <p>*Q12.</p> <p>*A review is done every time they see their GP/Consultant/Physio etc. They update the Persons info even if it's only to say something like "No change". They have reviewed the person. They note it, send to PIP and give receipt to the Person.</p> <p>*Q14.</p> <p>*At the outset they need to know that unless they are/have been diagnosed with a condition that qualifies them for a payment they won't be getting one. When diagnosed they will be reviewed each time they see a Health Professional re their condition. They should expect to have blood pressure/tests/weight and whatever else their condition requires to be done. At each visit the HP (Health Professional) will fill in an on line form regarding the visit which will be sent via email to PIP, they will get a copy of this on leaving. PIP will confirm to them either via email or post within 5 working days. There is no form to fill in. They are expected to attend all referrals and if they don't their benefit WILL be withdrawn immediately. Whereas the benefit is available to all who need it there are controls in place to ensure those who don't qualify won't get. They will be required to stop smoking if this is the cause/contributor to the condition. Failure to do so will ensure that benefit will stop. Support available if needed. Not targetted just at smokers but Person has to be encouraged to help themselves instead of accepting and succumbing to their condition.</p> <p>*Q15</p> <p>*As Above HPs diagnose/manage condition Person responsible for complying. Onus on HP to ensure Person understands what is being said and required of them. Some conditions require drugs that cause/exacerbate confusion and dampen ability to retain info.. Supporters to be available to ensure Person/Carer understands.</p>

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		<p>*Q16. *Aids should be available after a trial run with OT etc.. Not dished out willy nilly. If the aid doesn't work or Person can't use it then it's not needed.</p> <p>*Q17. *The needs of the child, their carers, schools etc.. A child has, we hope, a broader support base but they ALL need support to enable them to manage.</p> <p>*Q18. *One of problems with DLA is that the Persons claim is assessed by a decision maker with no medical training. They don't contact HPs for info and the awards or not are their assessment and could be withdrawn without any evidence that the claimant is at fault. It doesn't mean that you don't qualify if just means that that decision maker rejected your claim. However, DLA was a good passport to other benefits and this was beneficial.</p> <p>*Q19. *PIPs need to do this seamlessly. No more forms. At PIP HQ when cold weather payments are due everyone gets theirs automatically.</p> <p>*Q20. *The one assessment is enough. If they qualify for PIP they qualify for the rest.</p> <p>*Q21 *The benefits of the system I have outlined will be to:*</p> <ul style="list-style-type: none"> *Be more user friendly - no lengthy forms to be filled out or assessed. *Reduces waiting times for consultants etc to confirm need. *Less chance of fraud as it all starts with the diagnosis and is supported by info from blood tests etc.. *Person has a receipt from each HP they see and these are sent to PIP. *Email form kept simple. Name, address, NINO, diagnosis, Referrals, todays date, signature of HP. Hit "print", send to PIP. Simple.*No payments to HPs for filling in simple form. *Person given readable account of diagnosis and proof email form sent. *Person receives confirmation from PIP. *Payment awarded/not. *Ongoing updates on conditions only at each HP visit. Same process. *Time from diagnosis to award reduced dramatically. *Costs minimal. *Make it tight to protect budget. *"Supporters" required to assist people to comply with assessments eg, transportation to and from appointment. <p>*Q22 *Keep it simple, straightforward and going!*</p> <p>*Just my thoughts based on my experience with DLA. I haven't thought it all out so I'm happy to discuss any points you may have.*</p>
EM118	21-Dec-10	<p>I have tried in vain to register/log on to respond to the questions asked without success and after receiving contradictory instructions on email repeat, passwords etc I have given up trying to respond in this manner.*</p> <p>*However, what this document does not take into consideration is the disabled person who lives on their own and who has no relatives/family to assist them to lead an independent life. This means extra cost all round. For example one has to pay out for the simplest tasks to be done i.e. changing a light bulb. Where the person has to be totally independent having no financial support from family to install a low level kitchen for the wheelchair user this means one does without cooking a decent meal. In addition being unable to use a bath without any financial support one has to get washed the best way one can by getting washed at the basin because the installation of a wheel in shower is far too costly. *</p> <p>*Without the motability allowance this would mean total isolation from society when the cost of purchasing a car is beyond a disabled person's income.</p>
EM119	22-Dec-10	<p>am convinced this new benefit is designed to rob seriously ill people of their benefits and i would like that put on record. as far as re assessments go if somebody is suffering problems which can never be cured then any more</p>

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		<p>reassessments would be a complete waste of money to the tax payer as it can not reach a different conclusion than the incurable illnesses. as far as illness which is better on some days than others as well as prolapsed discs in back and shoulders and degeneration i also have diabetes ,ulcerated colitis which is incurable and hiatus hernia which because of my condition is inoperable and fibromyalgia. but on some days you would think i look normal and people say how well i look, if only they knew the truth. you must also take into account that because pain killers and anti inflammatories give me burning and stomach bleeds i have to take morphine for severe pain and gabapentin for severe diabetic nerve pain. so to undo my for life award and put me through hell and uncertainty whether the new benefit will rob me of much needed help and extra washing due to soiling and always feeling cold. i hope you are proud of yourselves and can sleep at night because some might forgive you but god wont and nether will my family. my son is a prison officer my daughter a nurse and my elder daughter a wife and mother so despite your depiction of us as lying thieving scum and cheats many of us are decent people who have had the temerity in your eyes to fall ill. i hope you are proud of yourselves . my father was a regimental sergeant major who nearly died at dunkirk and he would turn in his grave to see the unfair society you lot are trying to create i thought maggie was bad but not a patch on you lot.</p>
EM120	22-Dec-10	<p>Answered Easy Read Questions</p> <p>*1. Lack of transport is one of the biggest issues. Under the current scheme if people are entitled to the higher rate mobility they can use that money to get a motability car, if they choose to do so. However for those who don't qualify for the higher rate they have to use public transport or taxis. Some of the people I work with who are learning disabled find it very difficult, if not impossible to use public transport, which leaves taxis, which are expensive. Also if they live in rural areas, of which there are many in Hampshire, there is very little public transport anyway. If people cannot get around they cannot use leisure facilities, make new friends, or meet up with old ones.</p> <p>*2. Both care and mobility components, but consideration needs to be given to my point above about how the 2 are linked to modes of transport.</p> <p>*3. Higher than average laundry, transport, more water than the average household (because sometimes they require more baths), sometimes heating is higher because they can be less mobile and so can move around to keep warm, or they need air conditioning to control the temperature (because spikes in temperature can cause health issues, eg, seizures), specialist equipment, eg, baths, hoists, adapted vehicles, specialist diets, higher than average use of prescriptions.</p> <p>*4. i)It sounds like it should be easier; I would need more details, but anything that simplifies the system is always welcome.</p> <p>*4. ii)Please see above.</p> <p>*5.i) Yes some disabilities and health conditions are so profound or serious that people may need the allowance quickly or if they have a particular disability then certain conditions/symptoms can be predicted.</p> <p>*5.ii) Some people will need to be assessed on an individual basis, because you can have 2 people with the same diagnosis but one may have far more severe symptoms than the other, eg, epilepsy.</p> <p>*6.i) By listening to the individuals themselves or to people that know them really well, if they have limited communication, e.g, families, support staff, advocates, care managers etc.</p> <p>*6. ii) Anything that helps build relationships, accessing the community, transport, having the appropriate support (paid or informal), the general public having a positive view of people with disabilities.</p> <p>*7. Ask people on a regular basis (perhaps annually) to report any changes, but they can also report anything in between.</p> <p>*8. i)They could help indicate the level of disability a person has, and often if they use aids and adaptations their outgoings are higher than a non-disabled person (see question 1)</p> <p>*ii) I don't understand this question.</p> <p>*ii)</p>

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		<p>*9. i) Provide in different forms, eg, pictures, dvd's, people who can sit with individuals and help them complete the form.</p> <p>*ii) Provide the user friendly forms (see above) to professional cares, families, advocacy groups, partnership Boards, adult services, colleges, TV/radio adverts, etc.</p> <p>*10.i) Please see question 6</p> <p>*ii) What does an average day look like and what does a really bad day look like, bearing in mind that people do not know how often they will have a bad day.</p> <p>*11. I assume the independent person will have training into how to complete the form correctly, which will be good, as sometimes they can be confusing and so people don't give the correct information and so could loose out on some funds. The bad things are that some people may not be able to understand the person asking the questions and the questioner might not be able to understand the method of communication of the claimant; some people need to build relationships with people in order for them to share space with them; some people will need a supporter(s) to help them answer the questions.</p> <p>*ii) Some people, e.g, someone with autism would find it very difficult to have someone in their house who they are not familiar with; if someone was seriously ill there could be a possibility of cross infection.</p> <p>*12. i) See question 7</p> <p>*ii) Yes</p> <p>*13. Asking them using an accessible format</p> <p>*14.i) Signposting onto other services, e.g support groups, helplines; what other benefits they might be entitled to; how they can get adaptations</p> <p>*ii) Yes</p> <p>*15.i) Adult services will assess the needs of individuals and may help towards costs. Individuals are also financially assessed.</p> <p>*ii) Yes, if it means they don't lose out on a weekly income.</p> <p>*16. I can't comment on this; I haven't worked with children</p> <p>*17.i) Very useful, eg, motability</p> <p>*ii) Listen to people who have disabilities and realise how difficult it can be for them to live ordinary lives.</p> <p>*ii) Their lives would be a lot harder</p> <p>*18. Obviously you would need permission to do this, and some people would be unable to give consent to this, however, using the Mental Capacity Act you could then have a "best interest" decision on behalf of the person. Once you have this consent I think it should be asked of the individual which pieces of information they are happy to have shared and you need to specify exactly which departments this is going to.</p> <p>*19. If you assess everyone on an individual basis it shouldn't affect them negatively.</p> <p>*20. Is there a way you can allow individuals to choose to share a car under the motability scheme, so that they all have the same rights (the shared scheme currently does not do this)? If people are sharing a house in a supported living model this would sometimes be a preferable option to having a car each.</p>
EM121	22-Dec-10	<p>Disability Living Allowance Reform – Consultation Part 1*</p> <p>*The English Community Care Association (ECCA) is a leading representative body for community care in England. ECCA members provide a wide range of care and support services; residential and nursing settings, domiciliary care and housing support for adults, including those with physical and learning disabilities. *</p> <p>*Our members represent the diversity of the independent sector and include charitable and commercial, large and small providers. ECCA campaigns to ensure the optimum environment exists for independent care providers to give high quality care for those who wish and need it.*</p> <p>*ECCA intends to respond in full to the Disability Living Allowance (DLA) reforms and questions detailed in the Department of Work and Pension's consultation. We are still in the process of discussing the proposals with our</p>

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		<p>members to ensure that we deliver a comprehensive and evidence-based response. *</p> <p>*However ECCA has been informed that the Department wishes to gather before January as many opinions, and examples, of the impact on service users the removal of the DLA mobility component for individuals living in residential care will have. *</p> <p>*ECCA would therefore like to take this opportunity to respond specifically to the DLA reform proposal 21 – “payment will stop if the individual is in hospital or a care home”. ECCA believes that the reason for the mobility component removal is based on a flawed and mistaken understanding of the funding of mobility needs, and the ability to claim the mobility component should remain for individuals living in a residential care setting.*</p> <p>*We have included a case study written by one of our member’s residents, whose independence and ability to see his family restricted by the mobility component removal. *</p> <p>*Duplicated Spending</p> <p>*ECCA agrees that the care component of the DLA/Personal Independence Payment should cease once an individual moves into a residential or nursing home as their care needs are met by the care provider. *</p> <p>*ECCA understands that the removal of the mobility component for those in residential care is based upon the belief that local authority fees include a consideration of an individual’s assessed mobility needs.*</p> <p>*Minister for Disabled People Maria Miller has stated that:“Local authority contracts with care homes should cover services to meet all a resident’s assessed needs, including any assessed mobility need, so an individual’s care support and mobility needs should be met by residential care providers from social care funding. This measure will remove an overlap of public funds while ensuring that resources continue to be targeted at disabled people with the greatest needs.”[1]*</p> <p>*However, when the DLA and the mobility component were introduced in the early 1990s local authorities consciously decided to not to include transport costs in their fees. This enabled the service user to keep the mobility funding that was designed to allow them to pay for their own, personal transport needs. Local authorities were actively looking to avoid duplicate spending of public money. *</p> <p>*Consequently, local authorities have been negotiating their fees at a lower rate for nearly two decades. This means transport costs are now considered an ‘additional charge’ by service providers. The mobility component of the DLA allows the individual to not only meet these additional costs but maintain greater control over their transport and activity choices.*</p> <p>*Local authority contracts do not currently cover services to meet mobility needs, so there is no obvious overlap of public funds for adults in residential care settings. Unless local authorities match the average £33 weekly loss, this removal will severely curtail the independence of thousands of individuals across the country.*</p> <p>*Prioritising Support</p> <p>*How do we prioritise support to those people least able to live full and active lives? Which activities are most essential for everyday life?*</p> <p>*ECCA believes it is vital that residential and nursing homes are recognised as an individual’s home. If a person chooses, or is required, to move into a residential care setting this change should not make them a ‘lower priority’ for support from the new Personal Independence Payment.</p> <p>*If a care home resident qualifies for the benefit in all other respects, they should not be discriminated against because they have higher or more intensive care and support needs. They deserve exactly the same support to live as independently as possible as someone who can remain in their own home.*</p> <p>*ECCA believes that the Personal Independence Payment should take a fully personalised approach towards defining and funding essential activities for everyday life. This is illustrated by the situation of one of our member organisations, who provide residential services for young adults with severe</p>

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		<p>learning disabilities, autism and challenging behaviour.*</p> <p>*All of their residents are entitled to the DLA mobility component and the money is used to fund physical activities such as horse riding and swimming, as well as trips out. Their Director of Care believes these activities are "vital to keep them mobile and active". Once the mobility component is removed, the residents will receive only £21 per week, which is intended to be used for other essential needs such as toiletries. Under these new reforms, residents will also struggle to take part in more general activities, such as shopping or hospital appointments, as they need more assistance to do things other people can more easily do.*</p> <p>*Whilst horse riding may not be typically categorised as an 'essential activity', for one individual it could be the necessary activity that keeps them physically active, engaged with their wider community and able to meet new people. Being able to go horse riding once a week could be vital in preventing further institutionalisation and would contribute to improved health, fitness, behaviour and an overall better quality of life. Any consideration of 'essential activities' in the DLA reform should therefore prioritise individual needs, preferences and circumstances as much as possible.*</p> <p>*Efficient Support</p> <p>*The mobility component of the DLA is the most efficient and cost-effective way for public bodies to assist people living in residential care that find it difficult to or can no longer walk, or need extra help to get around.*</p> <p>*It is highly unlikely that individuals requiring funding from a local authority for residential care can afford the £33 shortfall the removal will enforce. The removal of the mobility component penalises an individual simply because they, through no fault of their own, require a higher level of care.*</p> <p>*ECCA is sceptical of local authorities being able to include an allowance for mobility needs as part of their fees to care providers. The majority of local authorities have already announced a nil increase or reductions to fees paid to independent care providers and, as you are aware, also face a 28% reduction in funding over the next four years.*</p> <p>*Without local authority funding, care service providers are also unable to fund their residents' mobility needs. The nil increase in local authority fees already equates to a 5% financial loss when increasing product, commodity and wage prices and inflation are taken into account. If providers must also fund transport and mobility-related personal assistants, this would be a further 5% cut on top of their initial losses for the next financial year.*</p> <p>*Case Study: [REDACTED]</p> <p>*Good morning. I am [REDACTED], age 60, and a resident in a nursing home. The proposed changes to mobility allowance would have a major impact on the quality of my life. *</p> <p>*As a result of the effects of multiple sclerosis diagnosed in 1982, my physical ability and mobility very gradually deteriorated, but I was able to remain in my own home with my wife. For a number of years I was provided with a package of home care which continued until October 2004, but was discontinued when the home care agency, "due to shortage of staff" withdrew weekend care. No other home care agency was able to provide the necessary weekend care and I took up residence in my current nursing home.*</p> <p>*The complete package in the nursing home is of exceptional quality. With the help of money from my mobility allowance my wife and I use a specially adapted Renault Kangoo in which I travel in my wheelchair.*</p> <p>*This vehicle is a necessity when attending dental and occasional hospital appointments. A major pleasure in life, requiring use of such a vehicle is visits to my grandchildren who are resident a 30 minute drive away. Regular day long pleasure excursions take place with this vehicle. I also privately finance my electric wheelchair from this allowance.*</p> <p>*I became very concerned, on reading an article in The Times newspaper indicating that the mobility component of the disability living allowance is to be withdrawn from recipients in residential care homes. Is that the intention of this government?*</p> <p>*Quote from The Times:</p>

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		<p>*"What he said: "We will align the rules for the mobility and care elements of disability living allowance paid to people in residential care, generating savings but enabling us to continue with this important benefit." *</p> <p>*What he meant: People on disability living allowance with an extra mobility premium to pay for wheelchairs and stair lifts will no longer get the payment if they move into residential homes."*</p> <p>*[REDACTED] *</p>
EM122	22-Dec-10	<p>My company manages 31 courts of privately owned extra care housing for older people across England and Wales and we provide accommodation for about 1600 people in all. Many of our owners (approximately 72%) claim AA but a few receive DLA having developed a care need before they retired. AA and DLA are a vital component of the benefit system for ensuring that service charges in retirement housing of this type are affordable for everyone with care needs.*</p> <p>*In your consultation you say at para 42:</p> <p>*42. We will consider whether the upper age limit for new claims to Personal Independence Payment should rise in line with State Pension age, once it has equalised for men and women in 2018.*</p> <p>*My response is this. It would appear sensible to raise the qualifying age for DLA in line with the state pension age and retain AA for people in receipt of the state pension. However, whatever decision is taken it is vital there is not a 'gap' between qualifying ages in which people cannot claim one benefit or the other.*</p> <p>*I have no comments on the remainder of the proposals as the 'principle' of a simpler benefit which is easier to claim and administer is a sensible one so long as people with real care needs and disabilities are not financially disadvantaged by the changes.*</p>
EM123	22-Dec-10	<p>As a father of a child of 16months ([REDACTED]) with Prader-Willi-Syndrome (PWS) I am most concerned with the expertise of the independent healthcare professional to make a fair assessment. I am also concerned the categories of mobility and ability to carry out daily tasks, are missing out greatly on behavioral problems as well as learning difficulties. These require additional support on all fronts.*</p> <p>*PWS is a rare disease and requires specialists knowledge.. It is only fair that when making an assessment the assessor has the required specialist knowledge themselves as not all disabilities are related to mobility or that required to carry out daily tasks. The paediatrician currently allocated to [REDACTED] for example is not a specialist in PWS and could not himself alone make a fair assessment. The PWSA have put us in touch with specialists and due to its rarity there are only a handful of them in the entire country.*</p> <p>*A major aspect of PWS not immediately obvious include an insatiable appetite, leading to obesity which requires constant monitoring to prevent them constantly seeking food. Healthcare professionals in the past have failed to diagnose such a disability. There are knock on effects in terms of learning disabilities and hypotonia also not visible from the outside. *</p> <p>*I do hope in the case of seeking savings in expenditure, shortcuts are not made, in fairly assessing the needs of the disabled person.</p>
EM124	23-Dec-10	<p>We are a medium sized charity providing residential and respite care services to people with profound and multiple disabilities.*</p> <p>*Following the government's announcement of its plans to cut DLA for people living in residential care, I wrote to Maria Miller citing examples of people in our care who receive DLA and for whom this benefit makes a vital difference to their ability to get out and about and be a part of their local community. The fee we receive from the local authority or PCTs in most cases does not include an allowance for mobility and this is something we can easily prove by way of contracts etc.*</p> <p>*One service user CS uses her DLA to be able to see her mum each week as her mum cannot afford the transport costs herself. Without this benefit CS would not be able to see her mum nearly as frequently. I know the government wishes to apply these changes fairly but as things stand it will</p>

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		<p>hurt some of the most vulnerable people in our society who cannot speak up for themselves.*</p> <p>*I will be happy to provide you with more information if required and hope that this brief submission coupled with the many others you will not doubt have received will allow you to rethink the proposals as they currently stand.*</p>
EM125	26-Dec-10	<p>I reject the consultation paper! I am contacting you on behalf of an existing claimant *</p> <p>*I reject/disagree/you fail to address the following points:</p> <p>*What does exactly happen for those you have already been awarded an indefinite award? You mention those who will need re-assessments i.e the benefit has been awarded for three or four years but not indefinite? Indefinite currently means that the award will change if circumstances change, what will be the new award periods under the new scheme as you fail to address it?</p> <p>*The consultation paper is not accessible by those who struggle to read or understand lengthy documents thus excluding the weak and vulnerable</p> <p>*the changes you propose sound exactly the same as the current DLA system i.e mobility and care</p> <p>*You don't talk about the forms being easier, more accessible the whole new system will create more unnecessary stress and confusion</p> <p>*Definitions and points within the document contradict each other and are more confusing than the current DLA process. If i am struggling to clarify points how is any one else when i am a Masters Level educated person??</p> <p>*How does people's entitlement to the motability car scheme differ? *What is the changes for children?</p> <p>*How do we know that the medical assessors fully understand the nature of every disability when disability is often unique and different in each case???</p> <p>How do we know they will be fair? How do we know they wont rip you off etc?</p> <p>*I have copied in my local MP in the hope that he can get me some answers to the above points?? - Steve can you?*</p> <p>*I do look forward to hearing from both of you ASAP</p>
EM126	26-Dec-10	<p>Here is my response to the proposed reforms to DLA. I am responding as a disabled individual and have addressed the points of interest to me as a blind person.</p> <p>*BARRIERS TO AN INDEPENDANT, FULL AND ACTIVE LIFE.</p> <p>*As a blind person, the barriers I encounter from moment to moment include:</p> <p>*Inaccessible information regarding time, such as being unable to read a conventional watch, set a conventional alarm clock or conventional cooker timer. Without specialist aids and adaptations, getting up on time in the morning, arriving at appointments on time and being able to cook independently are but a few activities that would be impossible to carry out.</p> <p>*Inaccessible information on labels, such as being unable to read labels on clothes, food, bathing and cleaning materials, laundry goods, medicines and/or paper files. Again, without a range of specialist aids and adaptations, bathing, getting dressed, cooking, household cleaning, doing laundry, taking appropriate medication and filing written materials would be impossible to carry out.</p> <p>*Inaccessible equipment, such as being unable to use conventional computers, cooking or laundry equipment,, televisions, radios and phones. Again, without specialist aids, adaptations, technology and/or the support of another person, shopping, cooking, doing the laundry, reading, writing, watching TV, listening to the radio and communicating with others would be impossible to do. *Inaccessible transport signage, such as being unable to read printed street, bus, underground, train or airport signs and information. Again, without specialist aids, adaptations and/or the support of another person, getting around by public transport would be impossible as well as dangerous.</p> <p>*Inadequately adapted streets, shops, sports venues, theatres, cinemas, museums, galleries and public transport. Again, without specialist aids, adaptations, and/or the support of another person, accessing what these venues have to offer is only partial at best and is dangerous at worst.*</p>

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		<p>*EXTRA COSTS THAT DISABLED PEOPLE FACE?</p> <p>*As a blind person, the extra costs I face are:</p> <p>*The cost of equipment to enable me to read, write, communicate, get around, tell the time, shop, bathe, dress, do my laundry, cook and monitor my health. These include a computer with speech to text software, a flat bed scanner with optical character recognition, a broad band internet connection, a mobile phone with OCR scanner, GPS and text to speech software, a large buttoned land line phone, a talking kitchen weighing scales, a talking kitchen thermometer, a talking kitchen timer, a talking label reader, a brail measuring jug. A brail dymo tape machine, a colour reader, a talking bathroom scales, a talking body temperature reader, a Braille watch and a white cane.</p> <p>*The cost of adapting conventional equipment to enable me to cook, do my laundry, cleaning, watch TV and listen to the radio. These include adapted knobs on my cooker, washing machine, dishwasher and radio, adapted buttons on my Hoover, blender, iron and toaster and a free view box to enable me to access audio description on my TV.</p> <p>*The cost of a range of personal assistants to enable me to shop for clothes, get round unfamiliar places, read handwritten materials, clean my home, do household maintenance and keep fit.</p> <p>*The cost of taxis to enable me to travel to and from unfamiliar, or difficult to access locations and venues.</p> <p>*The cost of altering my clothes because they are too long or large for me, repairing them because I damage them on sharp objects I cannot see and cleaning them more frequently because I soil them on dirty surfaces I am unaware of.*</p> <p>*WHICH ACTIVITIES ARE MOST ESSENTIAL FOR EVERY DAY LIFE?*As a blind person, the following activities are essential to enable me to function independently on a daily basis.</p> <p>*To be able to tell the time, which involves reading a watch or clock and/or setting an alarm clock or timer.</p> <p>*To be able to bathe myself, which involves distinguishing one bathing product from another and reading their usage and/or safety instructions .</p> <p>*To be able to dress myself, which involves distinguishing the colour of one garment from another and knowing which clothes are clean and which are not.</p> <p>*To be able to do my laundry, which involves distinguishing colours, reading labels and/or instructions and using a washing machine and/or iron.</p> <p>*To be able to cook for myself, which involves following a menu, identifying different foods , reading product labels and instructions, measuring, weighing and/or cutting ingredients, boiling, frying, baking, grilling, or toasting according to instructions, serving food and cleaning up dishes, cooking utensils and implements.</p> <p>*To be able to clean my home, which involves distinguishing one cleaning product from another, reading safety or cleaning instructions and using cleaning implements or machinery.</p> <p>*To be able to shop for food, clothes, household goods and furnishings, which involves walking independently, using public transport, navigating my way round on-line or in-house stores, distinguishing one product from another, identifying product sizes, prices, and/or colours, reading product labels and instructions and handling money and/or credit cards.</p> <p>*To be able to get around indoors and out-doors, which involves walking independently, negotiating public and/or private transport, navigating various in-door and out-door venues and reading signs and/or instructions.</p> <p>*To be able to communicate in writing, including filling in forms, signing my name, typing or brailing letters and writing e-mails or text messages.</p> <p>*To be able to read, including hand writing, letters, e-mails, books,, articles, news papers, magazines, web pages, text messages, instructions, signs, labels, bills and money.</p> <p>*To be able to work, which involves walking independently, using various forms of public and/or private transport, negotiating in-door and/or out-door venues, using a computer, printer, scanner, diary, telephone, and/or photo-</p>

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		<p>copier, writing letters, e-mails, reports and/or case records and reading letters, e-mails, text messages, reports, articles and/or books.</p> <p>*To be able to look after my health, which involves, participating in regular sporting/or fitness activities, monitoring my health, visiting my GP or medical consultant and taking medication.*</p> <p>*HOW SHOULD ACCOUNT BE TAKEN OF VARIABLE AND Fluctuating CONDITIONS?</p> <p>*I think the person with the disability should notify the benefit provider of any changes in their circumstances. If random reviews were also carried out, people who had not notified the benefit provider of such changes could be identified and appropriate action taken. I do not think regular reviews should be carried out as this would be too expensive.*</p> <p>*SHOULD THE ASSESSMENT TAKE INTO ACCOUNT ANY AIDS AND ADIPTATIONS?</p> <p>*I think the following questions should be addressed when considering this issue:</p> <p>*Given the wide range of aids and adaptations available to enable people with disabilities to live an independent, full and active life, should the new scheme only approve certain aids and adaptations? For example, would a personal assistant, guide dog, long cane and/or specialist satellite navigation system all be approved to enable blind people to negotiate their environment independently, or would the most cost effective option only be approved? If aids and adaptations are to be approved, then I think there should be a wide range of options available in order to meet the variable needs and abilities of different blind people. For example, an older blind person might feel a guide dog offers them security when getting around, while a younger blind person might feel a long cane and specialist navigation system offers them greater freedom of mobility. .</p> <p>*To what extent do aids and adaptations enable the person with the disability to live an independent, full and active life? Computers, flat bed scanners, text to speech software, optical character recognition software and broadband internet connections all contribute to the ability of blind people to shop, work, read, write and communicate with others. However, these needs cannot be fully met by the use of this equipment alone . Many blind people also have to pay someone to help them shop for clothes, hire cabs to go to work when public transport is not available and buy specialist software for their mobile phones to enable them to read, write and communicate with others when on the move.</p> <p>*Who pays for the aids and adaptations to enable people with disabilities to live an independent, full and active life? : While Access to work and employers pay for aids and adaptations to enable blind employees to undertake the same work as their sighted colleagues, they largely have to pay for the equipment they use at home to enable them to function independently. Who pays for the aids and adaptations and whether they can be used for both employment and personal purposes would therefore have to be taken into account when assessing the proportion of the new benefit which should be allocated to the purchase of aids and adaptations.</p> <p>*Will aids and adaptations need to be replaced or up-graded in order to enable disabled people to live an independent, full and active life? Over the life time of a disabled person the aids and adaptations they use will break down, become obsolete or be superseded by more efficient models. For example, Braille and Tape recording has been replaced by talking computers over time as a means of communication for blind people. This will therefore have to be taken into account when assessing the proportion of the new benefit which should be allocated to the replacement and/or up-grading of aids and adaptations. account when assessing the amount of money to be allocated to the replacement of aids and adaptations.*</p> <p>*IMPROVE THE PROCESS OF APPLYING FOR THE BENEFIT?</p> <p>*Will the application form for the new benefit be fully accessible? That is to say, will it be available in different formats for people with different disabilities, in a range of languages for people from different ethnic</p>

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		<p>backgrounds and clear enough so that people with different language skills will be able to understand and answer the questions fully.</p> <p>*How are the needs of people with different disabilities, let alone the needs of those within the same disability, going to be assessed? For example, some blind people can use a guide dog to get around while others cannot because they cannot accommodate a dog where they live. Again, some blind people are able to use text magnification software on a computer to read and write while others cannot because it is too slow a means of communication for their particular needs. Given this level of complexity within one disability, who is going to be sufficiently qualified and/or experienced to assess what people with different disabilities need to live an independent, full and active life?</p> <p>*What is meant by an independent, full and active life? For me as a blind person, it means being able to care for myself, negotiate public places, undertake a job and participate in leisure activities.</p> <p>*RACE</p> <p>*If the new scheme is administered equally across all those with a disability, the number of people from different ethnic groups claiming the new benefit should increase considerably. I can see no reason why there should be less people with physical, sensory and/or mental impairments amongst those from different ethnic backgrounds than amongst the white population. Indeed, because of their comparative socio/economic disadvantages, I would expect there to be more of them rather than less. I can see that the amount paid to white people is likely to decrease marginally under the new scheme, but is this going to be sufficient to cover the cost of the increased number of claimants from different ethnic groups?</p> <p>*If you want to discuss any of the above points further with me, please do not hesitate to get in touch.</p>
EM127	27/12.2010	<p>*Lack of access to public transport with little in the way of an investment plan for future improvements to the current system</p> <p>*unfair extra charges if people require personal assistance while travelling or for personal care whether at home or out and about</p> <p>*unnecessary and ridiculous bureaucracy</p> <p>*lack of information, misinformation or ignorance</p> <p>*lack of access to free, or at the very least affordable, personal care</p> <p>*a disregard for enforcing equality legislation in the real world, meaning even if something is legislated against nobody does anything to make things better for disabled and elderly people. I.e. why are new buildings still being built that are inaccessible and why when older properties are refurbished is there a lack of clarity regarding potential punishment if people do not retrofit (at the appropriate time and cost) accessibility improvements?</p> <p>*A staggering degree of complacency and lack of knowledge about the quality and consistency of care provided either within one's own home or within care home/NHS environments.*</p> <p>*Constantly reassessing individuals whose conditions ARE NOT going to alter or in any substantial way improve is a complete waste of time and money. Therefore, it seems sensible that a range of impairments or illnesses are identified that will not require consistent reassessment, there are no miracle cure is and modern medicine is not going to 'normalise' a large amount of disabled people.</p> <p>*What are the main extra costs that disabled people face?</p> <p>*Transport is a significant one, it can be broken down even further into other subsets (although this list is by no means exhaustive):</p> <p>*personal everyday mobility, such as wheelchair or other equipment needs;</p> <p>*subsistence travel, i.e. providing for food or utilities etc</p> <p>*significant distance travel, i.e. moving between home and work or visiting somewhere or someone</p> <p>*personal care, especially for those that require significant input and/or 24-hour cover (or least a large amount of input from others)</p> <p>*extra heating</p> <p>*extra power</p> <p>*Internet (especially for those who find travel or personal interaction for some</p>

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		<p>reason difficult)</p> <p>*specialist telecoms, for instance I can't answer the phone without having a very specific set of telephones or headsets in combination, without one part of the set nothing works!</p> <p>*specific medical assistance (for example occupational or physical therapy, this is very difficult or impossible to come by for most people after school age; which in itself costs significant amounts later on in treatments that could have been prevented by good physical care)</p> <p>*significant technical outlay on things such as speech recognition software, door openers or other forms of environmental control, essential for those unable to use more standard provision</p> <p>*• Will having two rates per component make the benefit easier to understand and administer, while ensuring appropriate levels of support?</p> <p>*It might, providing sufficient complexity can be covered using only four parameters, although it has to be said the odds aren't good are they?</p> <p>*• What, if any, disadvantages or problems could having two rates per component cause?</p> <p>*A significant number of people "fall through the cracks"</p> <p>*if "one size DOESN'T fit all" then the social turmoil caused will be significant</p> <p>*The Passporting structure is not sufficiently flexible to deal with the simplification and people are incorrectly assigned other benefits or advantages using this approach as a <i>raison d'être</i>.*</p> <p>*Yes, it's just ridiculous to assume that some things can vary enough to make a difference to this kind of scattergun qualification process.</p> <p>*It is expensive not to use this approach, it is also a waste of time (which I'm sure you know means a waste of money)*</p> <p>*This question is making an assumption that people on the scheme at the moment do not need the assistance and funding of the current DLA structure. To draw the line at any particular form of activity i.e. toiletry, dressing, moving around, communicating etc is ridiculous and merely one person's opinion of where you start this process, it is unique to every individual and if you understood the social model as more than a rationing tool you would understand that.*</p> <p>*Medicine, whilst not being a perfect system can give you pretty good ideas about anybody's pathology and what they're going to be going through although not when (with enough accuracy).</p> <p>*With that being the case, it should be possible for somebody with a modicum of knowledge, to make these assessments and, where necessary, make or require personal visits to accurately assess a level of need any one time if there is any doubt.</p> <p>*All of these assumptions about people ripping off the system is just going to cost far more money than you're ever going to save...*</p> <p>*This makes the assumption that people get all the aids that they require, or that they can get them if they are assessed as needing something (or even that they can try something out just in case?)</p> <p>*People don't have all the things they need and the state does not have the necessary funding or provision to allow everyone to have what they need (so we are told when we ask for the things that we need).</p> <p>*With the above being the case how would this be useful?</p> <p>*• What aids and adaptations should be included?</p> <p>*• Should the assessment only take into account aids and adaptations where the person already has them or should we consider those that the person might be eligible for and can easily obtain?*</p> <p>*Make it electronic and reusable so you don't have to fill in these things again and again.</p> <p>*• How can we improve information about the new benefit so that people are clear about what it is for and who is likely to qualify?</p> <p>*This makes the assumption that you will know who will qualify, I don't think you can or will know this to any large degree although there will be rough guidelines that you can use but they will inevitably be based on medical diagnosis.*</p>

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		<p>*Medical conditions should provide a reasonable gauge and where these are not sufficient a series of questions regarding ability to complete daily task should be used.</p> <p>*If this is not sufficient then personal visits and assessments can be provided*</p> <p>*Some healthcare professionals do not care to be used in such fashion and, workloads being such as they are, some professionals will sign anything just to get awkward customers out of the door.</p> <p>*Individual opinions differ, healthcare professionals are only useful up to a certain level and should have some kind of peer level body as a backup or part of the review process.</p> <p>*• Are there any circumstances in which it may be inappropriate to require a face-to-face meeting with a healthcare professional – either in an individual's own home or another location?</p> <p>*Yes, the list for this is rather endless, sometimes these questions need a little more thought and a little less asking.</p> <p>*How should the reviews be carried out? For example:</p> <p>*• What evidence and/or criteria should be used to set the frequency of reviews?</p> <p>*Why review people who will never get better on the highest rate? Proof of life should be sufficient.</p> <p>*• Should there be different types of review depending on the needs of the individual</p> <p>* and their impairment/condition?</p> <p>*As above</p> <p>*The system for Personal Independence Payment will be easier for individuals to understand, so we expect people to be able to identify and report changes in their needs. However, we know that some people do not currently keep the Department informed. How can we encourage people to report changes in circumstances?</p> <p>*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>*Could some form of requirement to access advice and support, where appropriate, help encourage the minority of claimants who might otherwise not take action?</p> <p>*If so, what would be the key features of such a system, and what would need to be avoided?</p> <p>*How do disabled people currently fund their aids and adaptations? Should there be an option to use Personal Independence Payment to meet a one-off cost?</p> <p>*Usually one off aids and adaptations are afforded through scrimping and saving or loans at high street banks etc, sometimes through making approaches to charities although this seems to be only viable for those who are children.</p> <p>*A one-off payment system would be a useful function providing it did not unduly impact on the amount of ongoing aid somebody could claim as things like wheelchairs and other equipment generally need to be maintained as well as initially purchased and this is expensive.</p> <p>*What are the key differences that we should take into account when assessing children?</p> <p>*How important or useful has DLA been at getting disabled people access to other services or entitlements? Are there things we can do to improve these passporting arrangements?</p> <p>*Unlike this paper, my assumption is that the current system is quite easy to work out and therefore the passporting implications quite easy to think about it, care component equal's access to care arrangements, transport component equal's access to transport related assistance.</p> <p>*What would be the implications for disabled people and service providers if it was not possible for Personal Independence Payment to be used as a passport to other benefits and services?</p> <p>*It would cost local authorities and other such services more money to</p>

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		<p>individually assess people all over again, in the long term it would be more expensive to disallow this function.</p> <p>*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>*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>*Is there anything else you would like to tell us about the proposals in this public consultation?</p> <p>*A significant number of the changes announced by the coalition government to date have significantly targeted services and funding specifically intended for disabled people.</p> <p>*There is a real danger that any potential good that could come from remodelling this benefit will be lost in the overwhelming drive to save money from the DWP budget which can only really be done by removing benefits and services from the most vulnerable in society.</p> <p>*It is to be assumed all systems can be improved, however, in implementing any public consultation on this kind of issue it is also to be hoped the overriding concern in doing so is not JUST to save money.</p> <p>*The shortsighted and, for me anyway, simply baffling announcement that the current DLA mobility component will be removed from those in residential care because they should already be getting all the services they require from other areas of funding shows that there is no real understanding of the need for DLA in the first place.</p> <p>*This has also highlighted a significant issue that should be obvious; has anybody actually asked anybody in residential care whether this is indeed the case?</p> <p>*Some clear understanding of the social model would also be useful instead of trying to use it as a tool to save money when it is clearly meant as a lever for social change.</p>
EM128	27-Dec-10	<p>1. Talking from the blindness side, its knowing where to start. To start with, most sighted people do not understand the problems. The world is built for sight. Take employment. I was working for many years till forced to stop by stress as my sight worsened. Most jobs these days proclaim, must have clean driving licence, even if driving is not part of a job. This means you never get an interview if you are honest. Many employers find their staff feel uncomfortable with blind people who cannot read body language or cope easily if the office etc, is re-arranged. Also, any computers need sound and specialist software in order to use them. This list goes on. I'd also suggest that people who have become blind are at a greater disadvantage with a given level of vision than those blind from birth. The latter will have had their brain moulded to cope a lot better than the older brain can. Transport. There is no driver in the cupboard to take one out on a whim, or to anywhere. Life has to be planned ahead with either paid helpers or volunteers, or taxis used. Busses are better than they used to be, but the problem is often getting to and from the stops with busy roads with no crossings. Subsidised transport is being cut to ribbons by the lack of investment by Government and hence this is a reducing resource. Reading mail is obviously a problem, and thus people can be out of touch with their local goings on.</p> <p>*One needs to spend money to get help. You need a bright person who can be the eyes for cleaning, clothes and appearance (no soup stains) Shopping, and often transport. There are issues over use by dates on packaging of food and cooking instructions. More and more appliances use menu driven systems totally inaccessible to a blind person. Bring back the knob and depressible button! Most adapted equipment needs a deep pocket to buy it too. If you have a family, it can make things easier, but as many are out at work in the day, it still means there are serious problems, particularly for women. Us men are known to live in squalor! Many clubs cannot accommodate blind people. I for one do not really want to just socialise with other blind people.</p>

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		<p>*2. Well, I do not like the new name, it gives me the PIP, and there is the pun that is going to make it not very nice. I'd suggest that automatic pass porting for blind below a certain sight level should be introduced with both quite a high level of care and mobility entitlement. Blindness is seldom actually cured. The sort of temporary blindness due to cataracts may be a special case, and I suppose as treatments improve, others will follow, but at the moment I personally feel we get a raw deal compared to other disabilities, and this may well be because we try to do the best we can as seldom does the disability give pain, like other physical disabilities do. There are also often severe sleep problems with blind people due to lack of synchronisation with daylight, and visual disturbances that occur randomly. This latter problem of course affects day to day ability to work as well. So yes, I think blind folk should be pass ported after initial investigations. This will save a lot of money of re evaluating people who will not have great changes in their condition.</p> <p>*3. See above. One cannot quantify this, as every case is going to be different. I deliberately wrote the forgoing so you can see the complications. Some with enough site may be able to cope with some magnification, others may need to employ people. The sad fact is that things usually get worse and in the end many of us have to go for the employed person. Even here of course, to employ someone means paperwork, and this has to be handled by someone as well!</p> <p>*4. The new benefit will have two rates for each component:</p> <p>*Will having two rates per component make the benefit easier to understand and administer, while ensuring appropriate levels of support?</p> <p>*NO, I personally do not accept it is confusing at all. The main problem is that the current rules were not originally written for anything but a physical disability. If it was a sliding scale of some sort it would be fairer, but then this might cost more to administer and I take the point that it should be simple.</p> <p>* My feelings here are that three levels are still best. It then does not leave the folk with the lowest needs outside the system and thus they can feel they can ask for an upgrade if things get worse. This avoids the problem of people having to start from scratch at a time when they are already stressed by a worsening condition.</p> <p>*What, if any, disadvantages or problems could having two rates per component cause?</p> <p>*Well covered as above really. Its too coarse and might in the end, if evaluation is needed make it more expensive as hopefully an appeal will grant an award and this might be at a higher level than was needed.</p> <p>*A great deal of work was done originally to come up with the current state of play, and I think they got it right. The only problem is the forms were not written for disability types very well.</p> <p>*5. I favour an automatic entitlement for the lower levels for blind people, but any extras based on the individual. Similar to above, I think its then a lot easier for people to approach the department if they are getting an award and their circumstances have changed, say death of a spouse for example, than it would be for someone refused and then having to come in anew.</p> <p>*6. How long is a piece of string. I really don't see that you can compromise on the hard things. Food, reading of mail, cleaning and safety, some social interaction, help to get a job if the person gains confidence and feels they can. We have not mentioned older people yet, but I do strongly feel that any entitlement to whichever arm of dla should continue through retirement until the person no longer can travel, if its mobility. It is in these years where more local social care may well be needed and I really think some joined up thinking is needed here, given the way the current government cuts are being interpreted by local government to mean social care only for the most critical, making others leave the system by monetary pressure.</p> <p>*7. Very difficult. I personally feel one has to bite the bullet and after investigation, treat that person as if they were the worst they can be. After all, it's a brave employer who will take on someone with ms or sight problems that vary as a good chunk of the time they will not be at work!</p> <p>*This of course is where many of us find voluntary work a real benefit. Its</p>

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		<p>easier to say, I can do X from home as long as you don't care when I do it. An employer would not be so flexible! For some people, like myself volunteering has kept me sane during long times of living alone with my sight loss. However, I think the decision of an award should not be made on whether the person can work or not. The key areas are still the same.</p> <p>*8. Well, I can only speak for blind people. I think not in the main. It is not a substitute for a reader, to have a reading machine. These are completely foxed by handwriting, and changes in font style etc, and cannot scan and read the important bits as humans do either.</p> <p>*One will often have to update technology though so in any award, care should be taken to allow for this aspect.*</p> <p>*What aids and adaptations should be included?</p> <p>*You would know if you had looked at the problem that these are far too varied to even guess at sometimes. It might well be that something is used that nobody had ever thought of. Hence my reply above.</p> <p>*Should the assessment only take into account aids and adaptations where the person already has them or should we consider those that the person might be eligible for and can easily obtain?</p> <p>*See my point about updating technology, also new devices are coming out all the time. See also my comments on domestic appliances being less blind friendly than they used to be.</p> <p>*9. It has to be said that for the blind this will always involve another party.</p> <p>*Its not much good expecting folk to do it on line as penetration of computers in blind circles is only in the young and very young unless like myself you are a gadget freak by nature. Most people tend to tell me life is complicated enough already.</p> <p>*So what would be good is a training course for people working for charities who could offer this form filling service. They would help to keep the blind person at ease and thinking about the true answers. At the moment many genuine claimants do not reply truthfully, often when presented, for example, with how far can you walk unaided, will say miles, when if they tried it they would bump into the nearest lamp post or bollard. People do not think of what you mean, so to speak.</p> <p>*How could we make the claim form easier to fill in?</p> <p>*By explaining how the questions will be seen by an adjudicator. That is, is it points based, or does one item outweigh another. It might be good also to try to make the forms in packs with one aimed at say, blindness, one at physical, one mental and one multi. Something similar. I'm sure the charities could help you here.</p> <p>*How can we improve information about the new benefit so that people are clear about what it is for and who is likely to qualify?</p> <p>*This is going to have to be education of the points at which people will start to enquire, charities, social services and please for once, health practitioners, not just a bundle of leaflets. You need audio and large text for the blind for example, and it should not be just on if you cannot read this ring for a cd basis. Kind of self defeating idea that one I always thought!</p> <p>*10. Well, For those where the award is mostly on the medical grounds, say registered blind or whatever, it has to be the person the claimant sees surely? The medical records. If there are other more subtle issues, normally I'd say the key worker in social services has a role to play here, but as mentioned above, with the increasingly low involvement of Councils with social care unless critical you will find a lot of people outside the system making claims, an it may well be that a change in the councils criteria so its not a postcode lottery might be the best plan, but that will cost more money in settlements to councils, which have been cut too much I feel.</p> <p>*11. An important part of the new process is likely to be a face-to-face discussion with a healthcare professional.</p> <p>*What benefits or difficulties might this bring?</p> <p>*Well, the problem is, as I have seen, well heard, most normal doctors have no clue about blindness. Thus I think it might be actually better for the person to be seen by the right sort of healthcare professional. What good is a person</p>

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		<p>who is good on amputees to a blind/deaf person. Also and this has to be said, there would be the suspicion that the doctor, if brought in by the department of work and pensions, would be biased toward no award for obvious reasons when you consider the cause of this review is costs. *</p> <p>*I'd prefer own home. Might also be nice to have OT Occupational Therapy help as well, though of course the council used to provide this on request. Some people are very nervous around new people, and from the blind perspective, I really do feel that if the documentation shows severe sight loss, no need for this part as the case should be proven, and it would save money for you too.</p> <p>*12. How should the reviews be carried out? For example:</p> <p>*What evidence and/or criteria should be used to set the frequency of reviews?</p> <p>*Should there be different types of review depending on the needs of the individual and their impairment/condition?</p> <p>*Yes, some disabilities are only going to get worse, and really I'd have thought it should be up to the individual to contact you if this occurs. However, for temporary conditions, then a yearly assessment is a good idea as there is no doubt in my mind that there are people out there who take advantage of the current situation</p> <p>* Also anyone who may be living independently but has a history of mental problems might benefit from a regular assessment to stop them dropping under the radar if things are going wrong. Memories of Care in the Community and the problems that showed up must be avoided.</p> <p>*13. Well, People are lazy and often only do something when its really affecting them. From the blind perspective, anything you do will involve paper which is a pain in the neck, but if those claimants have employed a reader, these people should be able to flag up any change I'd have thought. Otherwise, more liaison with council social services, which hopefully you will fund again, would seem to be the answer. These are the local people on the ground.</p> <p>* I do not like the idea of 'thou must make an appointment or your benefit will stop' big stick approach. Hopefully with those who had the temporary awards having frequent assessments fraud should be very low.</p> <p>*14. I'd have thought it was absolutely required that the claimant knows the rules and what is passed on and under what conditions of proof for a start, and available in the format of choice straight away.</p> <p>*15. I don't really understand the question. Most people come into thinking about claiming due to the funds dwindling due to funding their lives getting too expensive and eating into their savings, or fear for their health but a need to stay where they are. Staying where they are from a blind point of view makes sense as it stops someone needing to learn new routes and premises when blinded later in life.</p> <p>*If the info is out there and healthcare professionals and social workers and charities are taught to bring up claims if they see a need what more can be done?</p> <p>*16. And replacement costs as well. Of course. Also as times change other items will be needed. Read my comments on the problems with domestic appliances for the blind.</p> <p>*17. Well being a child at heart.. Sorry, I'd say that independence from the parents and fostering confidence is a very important aspect for those growing up with disability. Access to sport they can actually do for example, and sympathetic teaching staff or extra tuition where the impairment makes this important.</p> <p>*Also, from my blind aspect, I'd have benefited from being able to have some other sight impaired people of my age to talk to etc. Quite how one would cost this is hard to say, but obviously it will depend on the age of the child.</p> <p>*18. Yes, I think that the current arrangement on the abolition of Incapacity benefit for working age people is not good for blind people. As mentioned above many cannot find work, far more as a proportion than for other disabilities, so I'd suggest they should be able to have an extra payment for</p>

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		<p>themselves and much more help for finding work, not a big stick to go on income support if they cannot find it. This is the most negative message. Do you really think we don't want to work? Often we get burned out by our mid fifties due to having to be better than the sighted or we get the boot under these current short term contract employment rules many have these days. So yes, more carrot and less stick for those with long term conditions. I think it's a social need.</p> <p>*19. Security. The ability to plan a future. When I became unemployed after some time being self employed until stress made me give it up, I found the IB very much a comfort. I'm not rich, indeed I was in a negative cash flow as I lost my Mother and had to use savings, but it's a cushion. To have to really start all over again to justify what is blatantly obvious would seem to be a complete waste of time and money and very belittling at a time when your self esteem is on the wane as well.</p> <p>*20. I agree this is a constant problem, but one has to realise that dla is not means tested or taxed... I hope.. but other benefits are, including the care from local authorities. With personal budgets coming in, it might be handy if this aspect was centralised, not left to the individual councils who all seem to be going slightly different ways over this and thus the outcomes will be very different wherever you might live.</p> <p>* So, maybe looking at it as a one assessment for all possible benefits might be a better way, then if you change, you can ask for any top up, and those on the short term versions will be reviewed as usual. Surely this has to be cheaper?</p> <p>*21. Well having lost the will to live around page 20... no seriously, I do feel that the document is very long to absorb for an average person and I'm reading it by artificial speech, so it can be hard to understand what you are driving at.</p> <p>* I think if you read the forgoing, you will see my stance on this one. I personally do not like disability being combined with other equalities, as it's a totally different thing. Even sensory loss and physical disabilities are totally different unless one suffers from both, in which case its real bad news.</p> <p>*Could one ask that what might be very good is a campaign to educate employers about the various disabilities, and maybe, shock horror, bring back the disabled quota system for us? It was a bit old fashioned, but it did keep me paying tax well after I'd have been out on my ear otherwise.</p> <p>*Schools should have visits from blind people and people with other disabilities, and we should be di mystified and our problems explained in a non patronising way. The awareness is the main problem or rather the lack of it.</p> <p>*22. Yes. I think at the moment there are too many changes all happening at once. A rethink is needed. OK so dla is claimed a lot. Its very successful as a benefit and should stay. I think with all this talk of a big society, we need to remember the less able amongst us and realise too, that to keep us the society does need to spend more money than it might appear is advisable from an accountants point of view.</p> <p>* Not all disabled people are the same, but I do feel that as far as dla or whatever you decide to call it is concerned, this must be the same for all that decide to claim, though I do think that if you have half a million in the bank, it might be advisable not to allow claims till you reach say, the price of a reasonable house!</p> <p>*Most of the criteria that are being brought in at council level are designed to make us use our dla outside the social care departments of councils, as otherwise they would try grabbing all our dla for that care. This is wrong in my view and is brought on by some kind of feeling that we are spongers. No we are people and if we cannot look after those who fall on hard times, mostly due to no fault of their own, then I fear for society, big or otherwise. I think you have cut the grants to councils far too much without allowing them to raise funds in other ways.</p> <p>* Too much too soon. OK not in the document, but as it will change the financial landscape for disabled people for the worse, it has to be taken into</p>

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		<p>account in this consultation.</p> <p>*Blind person, blind later in life, partially sighted for most of life Current age 60. Not intending to do paid work again but want to not be useless so help with local blind and disabled charities as an when I am able to.</p>
EM129	28-Dec-10	<p>I advice you not to scrap DLA and no need to replace, Geroage obsone said "DLA has double expensive" I know how to saving DLA okay would like to explaining you.*</p> <p>*Jobcentre plus said "if you do not want a mobabilty car get more money" I need to keep my motabilty car because help me to getting around.*</p> <p>*Lots of disabled people who got receive lower rate or higher rate motabilty without a car but they shouldn't receiving motabilty allowance because got a free bus pass and taxi fares reduce. If disabled people who cannot walk and cannot drive then need someone got a car will help with disabled so rather than to keep the cash. My deaf friend got receiving lower rate motabilty and free bus pass but shouldn't to keep motabilty allowance. *</p> <p>*higher rate motabilty its only for a car or mini van used for a wheelchair is rights way. Govertment will saving lots of money. Its not fair for me for example deaf or disabled got receiving higher rate motabilty can keep the money in pocket but I have to paying my hire car and petrol. *</p> <p>*Please do not scrap DLA rates because i have to pay my friend for helping me shopping, clean my flat, windows cleaner,cooking. DO NOT FORGET THAT MENTAL HEALTH ETC CANNOT TRUST OR SCARED WITH OTHER PEOPLE BUT WOULD PREFER WITH FAMILY OR FRIEND. *</p> <p>*Medical assestment need to be reform for example deaf go to audioglogy professional and deaf social worker can send report to DLA, who having a walking problem need to see physiotherply or opthmpic doctor can full report then send to DLA. much cheaper than own private doctor because don't know about disabled background. *</p> <p>*Deaf people do not need medical assestment every 3 years because they will never become hearing and hearing aids is not helpfull really. Deaf should go to audioglogy for hearing test for example hearing level below 50% mean very deaf, over 80% hard of hearing. who are very poor speech meaning cannot hear properly. who are very good speak mean can hear very well. Lots of deaf have failed DLA because private medical don't believe that a person is deaf. DLA never ask deaf people for audioglogly report. What if hearing people can saying lies that Im deaf without audioglogy report. *</p> <p>*07.01.11 I was born carebal paisy walking problem and profound deaf. I got receiving middle care and higher motabilty rates for more than 13 years. *</p> <p>*Question 2 What parts of disability living allowance do you think we should keep</p> <p>* Lots of disabled want to keep DLA is very important for example mental health who do not want to meet with stranger to help but would prefer a family or friends.</p> <p>*I can ask my friend for help me to shopping etc.*</p> <p>*Question 3 What extra things to disabled people need to spend money on?*</p> <p>*1) wheelchair or walking problem cannot paint and decorating in any room but they cannot afford to pay decorating because very expensive. honest I never paint my flat for 13 years because no one will help me and very depressing over dirty walls.</p> <p>*2) Did you know that automatic car is very expensive petrol than manual car. I have spend too much petrol because my deaf and family live outside Edinburgh.</p> <p>*Lots of disabled people who do not want go to work or college because petrol are very expensive and extra cost about £30 a week total £60 a week, disabled should getting petrol allowance from the govertment. Its very important for disabled people need to get out the house and improve social life.</p> <p>*3) My pairs of boots is damaged every month and paying too much money for new boots. I do not want to ask my family to pay me for new shoes or boots because make me very embarrssing. govertment stopped give me new boots when i was under 16 but should carry on for life. Normal people can</p>

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		<p>buy a new boots only once a year but mine is more but not fair for me.</p> <p>*4) health spa or message for carebal paisy want to relax and feeling better. Im not happy with phsyotherply because they do not understand how do i feel but I need someone to message my back and legs make me feeling better. Im paying £80 for 1 hour and 30 mins*</p> <p>*I believe that carebal paisy should get more money because spend new pairs of boots, petrol, health spa and massage, painting and decorating, garden and much more.</p> <p>*Lots of deaf people have failed DLA becuause private medical do not believe that a person is not deaf. why not deaf with private doctor to visit audiology test to make sure a person is deaf or not before to calm DLA</p> <p>* I have no problem with DLA form but too much questions. Im very happy with DLA rates but need more money for petrol expense and painting decorating one off.*</p> <p>*Motabilty finance is no problem excellent.*</p> <p>*16.01.11 proforma:</p> <p>*I am writing to urge you, as Minister for Disabled People, to recall the Public Consultation on 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. In this letter I will begin by discussing the problem with your case for reform, and then address the consequences of reform.</p> <p>*First, the case for reform. The reasons given for DLA reform are not robust, with little evidence to support the case for reform and, importantly, no independent academic research. My use of the word 'little' in this context refers to the two pieces of internal DWP papers used as evidence to build the entire case for reform – a footnote for one reference appears twice on consecutive pages. Thus the case for reform falls apart upon even cursory examination.</p> <p>*The wildest claim to support reform is that 'evidence suggests that DLA can also act as a barrier to work'. This passage is footnoted, referring to "DLA and work: Exploratory research and evidence review, 2010, DWP Research Report No. 648" (RR No.648). This report also finds that "the main factor affecting the employment rates of disabled people is their disability or health condition" and that "a larger than average proportion of DLA recipients also appears to be affected by the specific types of impairment that carry the greatest employment disadvantage for disabled people" – yet these findings are not reported in the consultation paper, thus skewing discussion. *In fact, though the report claims that there exists a "perception of disability permanently precluding work is prevalent among individuals with disabilities not already in employment", there is no evidence cited in the report that suggests DLA could be a barrier to work. The section and all references to it in the consultation paper could be interpreted as an attempt to misdirect, and should be removed forthwith. Further, it should be noted that the consultation commits the statistical crime of confusing correlation with causation. Whilst RR No. 648 does provide evidence that low employment is correlated with claiming of DLA, this in no way implies that one causes the other.</p> <p>*It could be suggested that the lack of evidence pointing to a need for reform has meant that misdirection was used in an attempt to convince the public that DLA reform is necessary. In particular, the graphs presented as Figure 1 and 2, on page 8 of the consultation paper, used to show the DLA caseload increasing at an alarming rate, are flawed in many ways, not least in the fact that no baseline is established for when take-up of DLA by people with disabilities plateaued after its introduction in 1992/93. There are further issues regarding the number of Pensioners as the report ignores demographic trends to show that there is a dramatic increase in claims by people over State Pension age. This is particularly questionable since a Pensioners' eligibility for DLA would usually depend on their receipt of DLA prior to this – otherwise, they would be eligible for Attendance Allowance, as I am certain you are aware. *Figure 2 is also misleading as it could be read carelessly as showing</p>

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		<p>that 8% of the population claim DLA. I am loath to interpret this as intentional misdirection but it is, at the very least, a sloppy drawing of graphs. Another example of sloppiness is the first sentence of paragraph 15 of the first chapter, on page 7 of the consultation paper, reading "In just eight years, the numbers receiving DLA has increased by 30 per cent." This sentence is utterly meaningless and a misuse of statistics although, once again, I do not wish to interpret this negatively. Yet another example of the spurious use of statistics is Table 1 on Page 9 which presents the "Distribution of current caseload by rate combination". This table appears between two paragraphs – 16 and 17 – arguing that the current system is too complex and the benefit is not understood. This is an odd, and potentially misleading, place for this data to be displayed.</p> <p>*Beyond misuse of statistics, sloppy presentation of data and lack of evidence, there are further points to be queried. Whilst RR No. 648 does give evidence that DLA is complex and not understood by all claimants, as suggested in paragraph 19 on page 10, this is surely grounds for improving the current system rather than expensively replacing it with an entirely new one. Likewise the assertion, in paragraph 18 of page 9, that there is no system to check that rewards remain correct. The statement that "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" is a rhetorical tautology. Indefinite awards are given to claimants with conditions that will not improve. Whilst it is not unreasonable that medical advances in the treatment of a certain condition should prompt re-evaluation of those cases, this could be achieved by augmenting DLA rather than replacing it.</p> <p>*The core argument of the consultation paper is that DLA is a benefit not fit for purpose. Paragraph 9 on page 6 of the consultation paper states that: "DLA is a benefit that provides a cash contribution towards the extra costs of needs arising from an impairment or health condition." The arguments presented in paragraphs 14 and 15 of page 8, claiming that the benefit is not fit for purpose, do not touch upon the original purpose of DLA or offer any argument as to why it is failing to meet its original purpose. The information presented is that the DLA caseload and expenditure is a "lot more than was originally expected" and the aforementioned misuse of statistics on the increase in DLA claims. No arguments are presented as to why this means that DLA is not fit for purpose. The only way an argument can be construed is to look at the issue with a preconceived idea that there is an acceptable level of DLA claims prior to evaluating the health and impairment of claimants.</p> <p>*Finally, paragraph 2 betrays this preconception by stating: "We believe that now is the right time to reform DLA", yet offers no qualification or reasoning for this belief. Paragraph 3 continues by saying that: "We must ensure that our resources are focused on those with the greatest need", with no qualification or definition of the term "greatest need". This could be pointed to as a suggestion that those with "lesser needs" will have to struggle unsupported with their impairment, and that the definition of needs is at the whim of the Secretary of State for Work and Pensions.</p> <p>*The arguments above demolish the case for reform presented in the consultation paper, dealing with each point made in the consultation paper. I will now address the second part of the consultation paper, explaining why the reforms intended by the DWP will be harmful to disabled people.</p> <p>*Paragraph 4 of Page 11 begins by stating that: "Central to Personal Independence Payment will be a new, fairer, objective assessment, which will allow us to identify those who face the greatest need, in a more consistent and transparent manner." The previous section of the paper does not suggest that the current DLA assessment is unfair or that it is not objective, and neither is there evidence that it is inconsistent or lacking in transparency. The current system is assessment by a variety of resources; information from a carer or support worker, the person's GP, specialist consultant or physiotherapist. Trying to slim down this evidence base to on homogeneous assessment will mean that the impact of disability on the individual is ignored.</p>

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		<p>This is definitely not objective. Paragraph 4 also states that: "We are developing the new assessment in collaboration with a group of independent specialists in health, social care and disability, including disabled people." What 'independent' means is that a private company such as Atos will be contracted to run assessments. This will include meeting with an 'independent' healthcare professional – not necessarily qualified as doctors - working for the assessors. The objections to a private company using unqualified staff who know their jobs depend on keeping to strict targets aimed to reduce numbers qualifying for a particular benefit are too many to list.</p> <p>*Paragraph 12 on page 13 of the consultation paper suggests that: "The criteria on which DLA is currently based, on care and mobility needs, are subjective and unclear." It could be argued that this statement is subjective and unclear as there is no qualification of the statement, and no evidence is offered in support. As suggested in the previous paragraph, the lack of a formalized set of criteria for DLA awards is due to the varying impact of disability, meaning that such a 'tick-box' test would not be objective either. The following paragraph in the paper suggests that 'care' and 'mobility' may not be the best proxies for the additional costs faced by disabled people. The paragraphs also state that "there is currently conflicting evidence on the factors that affect the extra costs that disabled people face in the 21st Century". The very fact that the only two DWP research reports cited to support offer conflicting evidence raises questions about the DWP's choice to accept one piece of evidence above the other. *Paragraph 14 of page 13 offers the example: "'mobility' as currently defined concentrates on an individual's ability to walk, not their ability to get around more generally." It is true, generally, that people with disabilities are more mobile as aids and access have improved. However, this additional mobility has come with extra financial costs, such as new mobility aids, adapted vehicles, taxis. Moreover, it is crucial to remember that additional mobility does not mean universal mobility. Paragraph 15 of page 13 suggests an intention to refocus the Personal Independence Payment (PIP) at those most impaired in their ability to carry out a range of activities, because: "There is some evidence to suggest that individuals whose impairments have the greatest impact are likely to experience higher costs." This statement is bizarre, as this is exactly what DLA does. Paragraph 16 on page 14 discusses splitting PIP into a 'mobility' component and a 'daily living' component, with two rates for each component. This suggests that the change from DLA will be a vastly expensive rebranding exercise, as modifying DLA could achieve this.*Paragraphs 17 and 18 on page 14 argue that "The individual must have a long-term disability" in order to claim PIP, so that "an individual's health condition or impairment must be expected to last a minimum of 12 months". This will punish those who suffer debilitating short- and medium-term illnesses, but eventually recover their mobility and ability to care for themselves. Whilst people are ill over the short- or medium-term, they will have mobility and/or care needs and face the same extra costs as those with long-term conditions. They may even have to purchase mobility or care aids for their temporary conditions. Yet this consultation paper seems to ignore their needs. Long-term conditions are also targeted as paragraph 19 on page 15 suggests the end of automatic entitlement for certain conditions. The example of renal dialysis automatically entitling on to the medium-rate care component of DLA is given, and it is argued that: "As a result, eligibility for DLA is sometimes based on medical condition rather than the impact of that condition, meaning that support is not always appropriately targeted." The meaning of this sentence and argument is completely opaque, unless it is to suggest that one should be denied support because they are too ill to use it; a thoroughly distasteful argument which I refuse to believe that the DWP countenanced.</p> <p>*Paragraph 20 on page 15 of the paper confirms that PIP will continue to apply the same presence and residence criteria as DLA, but may consider a habitual residence test. This will impact on workers not born in this country</p>

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		<p>who develop a disability. This seems extremely harsh as, although it will make PIP consistent with other benefits, whatever one's attitude to immigration, I cannot believe that anyone would argue that a foreign-born individual living in this country should be denied support if unfortunate enough to become disabled.</p> <p>*Paragraph 21 of page 15 argues for the full removal of PIP from individuals in "hospitals or similar institutions or care homes". As care homes take income and savings into account, this will mean that care home residents no longer have any independent income to pay for short journeys or other ways of retaining independence, and become entirely institutionalized.</p> <p>*Paragraph 24 on page 16 states that: "We remain committed to the social model of disability. The new assessment will not be based solely on the medical model of disability and focused entirely on an individual's impairment, but will instead focus on the ability of an individual to carry out a range of key activities necessary for everyday life. " The meaning of this statement is unclear. Paragraph 26 adds little clarification, stating: "Activities we assess could include, for example, planning and making a journey, and understanding and communicating with others. The extent to which an individual could carry out these activities would determine their eligibility for Personal Independence Payment and the level of their award." As I have argued above, such a tick-box approach to the impact of disability is counter-productive and not objective. A person able to complete the activities in your example may still need the same type of support as another who cannot.</p> <p>*Paragraphs 27 and 28 state that PIP will "take greater account of the successful use of aids and adaptations as part of the Personal Independence Payment assessment". This means that successful use of aids – including wheelchairs – could mean that claimants are not eligible or eligible for a lower rate of PIP. This is a ridiculous suggestion. For example Tanni Grey-Thompson – one of the most successful athletes of all time – is a 6 times winner of the London marathon. She is obviously 'successful' in her navigation of London streets. Yet she will face the additional costs of her mobility needs just like any other person with a disability. The general truth is that successful use of an aid does not negate additional mobility costs.</p> <p>*There are other minor points that I could raise, and will do so if you proceed with the Public Consultation. For now I will turn to my conclusions.</p> <p>*The point that most angers me is the focus on DLA as a disincentive to work, which is both false and disingenuous. People who receive DLA do often have lower work expectations as the reform consultation paper suggests, and rightly so as many conditions and impairments make work impossible. Disabled people are often unable to compete equally in the labour market, because of ignorance and fear amongst employers and a lack of willingness to consider making adjustments that may well be relatively cheap and straightforward but are perceived as too onerous. People with high rate awards have the highest levels of impairment and are most likely to be unable to work, regardless of benefits. Those who do work are often only able to do so because of the aids, support or adaptations that DLA or Access to Work allows them to purchase. The focus on moving to work has no place in discussion about DLA other than to make the important clarification that DLA is not work related, and exists to assist with the additional cost incurred when living with an impairment or long-term health condition.</p> <p>*Other problems include the fact that the PIP proposals will see some current recipients of social care losing financial benefits now paid at least in part to the local authorities for receipt of that care. This will force the LAs to make up the shortfall in funding or, more likely, cut care packages. Another aberration in the recommendations made is the impact of these plans on independent living, making that harder to deliver. Removing DLA from those who receive care packages, and especially those in residential care, will not promote independence. Lastly, some people may lose money as the aids and adaptations they use to enable them to live with their impairment or long term health condition will be seen as negating the need for that financial support, ignoring the fact that the DLA Mobility Component may be the only way of</p>

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		<p>paying for adaptations such as wheelchairs or taxis.</p> <p>*Although the caseload may be cut, PIP will still look very much like DLA. The current system allows for automatic entitlement to DLA for certain conditions. The new system will not allow for this, and will re-asses all claimants every few years. This is not only foolish but also costly as automatically entitled conditions are by nature the most severe and incurable. The only things achieved are the extra cost of unnecessary assessment, and hardship for severely ill people. Further waste comes from ignoring the fact that, unfortunately, people will remain disabled and have impairment-related support needs even if they no longer meet the new thresholds under PIP. They will be ignored up to the point they become seriously ill and end up costing the NHS and local authorities more in terms of hospitals and residential care. Further, the proposed reforms don't take into account the reality that some conditions are severe but acute. Not supporting people with acute illness and disability makes it more likely that this will become a costly long-term problem therefore increasing dependency.</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>
EM130	28-Dec-10	<p>Need to keep the dla if we lose it will confuse the disabled people should be change if it is more money you must tell evrey disaled person regards [REDACTED] it hurts me to do this writeing *</p>
EM131	29-Dec-10	<p>I would just like to point out the Government may be committed to reform the DLA and get 'disabled' people back to work but unless the workforce is also as committed this will not work. I have been to several interviews and have always been honest about my mobility as soon as they see me walk they have decided that I am not employable. They do not even bother to say why I did not get the job. So it is not just the Government but the community that needs to accept that 'disabled' people can help and classed as employable.*</p> <p>*Along with DLA I also receive ESA this has been so far reviewed by face to face contact. I believe that all benefits should be reviewed this way so the person reviewing is able to see what limitations are and have a better idea as what part of the different components that make up the DLA, or any that replace this, should be claimed for.*</p> <p>*Blue badge is mentioned this should also be looked into as I have seen many people young and old walking away from their cars with no problems or need of support. *</p>
EM132	29-Dec-10	<p>Q 1 The young adult with learning difficult may only have the mental age of a young child, so would require significant help and funding for this help to live independently and integrate into the community, we would also suggest the most of these young adults would wish to undertake some form of paid work.</p> <p>*Q 3 Significant funding for help to live independently.</p> <p>*Q 5 All claims should be based on the needs and circumstances of the individual applying.</p> <p>*Q 8 The assessment should take into account the needs of the person and the health professional should suggest aids or adaptations that would aid the individual, and then include the funding in the assessment.</p> <p>*Q 10 In the case of young adults with learning difficulties coming up for an initial adult assessment after leaving special educational provision, could the provider of the pervious special educational provide information for the initial</p>

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		<p>assessment?</p> <p>* Q 11 What happens when the person involved in the process is a young adult with learning difficult, they may only have the mental age of a young child, so would a parent be able to sit in at the interview and tell the healthcare professional about the child's needs? Secondly would the health professional be required to have expertise in the field that the applicant was suffering from, i.e. mental health issues or an expert on integrating adults into the community and independent living?</p> <p>*Q 12 & Q 13 A review may well be needed for the DWP to assess if a young adult with learning difficult had any changes that needed to be reported, as they would be unable to do so.</p> <p>*Q 15 Allowing parents/ carers, siblings or other form of advocate to speak on the needs of the person attempting to access the payment if they have learning difficulties.</p> <p>*Q 17 As the support for children with special educational needs is becoming multi agency, then this may need to be repracated in the assessment, and of course the parents / carers, siblings or other form of advocate to speak on the needs of the person. *</p>
EM133	30-Dec-10	<p>I am the full-time carer of my profoundly and multiply disabled daughter who is 16 years old and who receives DLA at the highest rate for both care and mobility. I totally agree with the premise of the reform, to focus support on those with the greatest need, to simplify the process of application and to monitor and periodically review awards. I would like to comment on 2 areas, one to do with the mobility part of the benefit and one more general point about transparency and equity.*</p> <p>*Currently, the system is such that anyone in receipt of the higher level of the mobility component of DLA is automatically entitled to use that allowance to lease a Motability vehicle. I have two concerns about this:</p> <p>*First of all, there does need to be a tightening up of exactly who is eligible to the mobility allowance, as at the moment this is anything but clear - people can argue all sorts of reasons, some of which may have little to do with whether or not they need extra support to get around.</p> <p>*Secondly, there is a fundamental unfairness inherent within the Motability scheme - it actually favours those with the lowest levels of disability. Thus, someone who can use a perfectly ordinary car, with no need for any adaptations at all, is not only presented with a huge choice of vehicles, many of which require no contribution other than the mobility allowance, but they also get a new car every 3 years. By contrast, those who are unfortunate enough to be so significantly disabled that they require a vehicle to be adapted so that they can travel in their wheelchair, not only have a very restricted choice of vehicles, but they also have to contribute quite a lot of money up front (can be thousands), and only get a new car every five years. My point is simply the inequity of this situation, which urgently needs to be addressed and reformed.</p> <p>*The other area I want to comment on concerns the way in which the various pots of money from different departments overlap in such a way that, once again, those who receive the most tend not always to be those with the highest support needs. A single joint assessment by all relevant departments (eg health, social care, work and pensions, education, housing) would go some way towards a less fragmented system. And the total of public funds that each person receives, whether as a direct payment of money or as a service, should be openly stated - it is surely only by being really upfront and transparent like this that we could begin to see the inequities that exist. For example, young persons in residential schooling (up to age 19) still receive full DLA even though virtually all their costs are already being met (and in an extremely expensive, ?inequitable way) by the state. That doesn't seem quite right. *</p>
EM134	30-Dec-10	<p>1 From my perspective, what I do find very difficult is going anywhere new for the first time as I cannot find doors into the premises, don't know where the steps are, I wouldn't be able to find the rest rooms etc. In the world we live in,</p>

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		<p>there is so much “street furniture” that isn’t always a constant which makes mobility quite difficult. One of my major concerns right now is “shared surfaces” – where both traffic and pedestrians share the same space – for people with severe sight loss this is a potentially fatal situation. Not all buses and trains tell you what the next stop is, and without this resource you have to rely on others. Without the support of the DWP, I think it would be very difficult for a lot of disabled people to carry out their day to day work tasks.</p> <p>*2 Why the need for change? If it works well, why change it?</p> <p>*3 If you have to go to an unfamiliar area, inevitably I would use a black cab and they are expensive. I don’t shop on line; therefore if I want to do a big shop, I have to rely on taxis. If you do take someone else with you, you feel obliged to pay for them. You might need to change your glasses on a fairly regular basis. Assistive technology is expensive to buy i.e. speech for a computer or telephone.</p> <p>*4 Unless the individual understand exactly all the rules to Disability Living Allowance, then it might be slightly confusing. I would say there’s almost a “postcode lottery” about Disability Allowance and who gets what rates. We all know of people that are on rates that maybe would surprise us. There needs to be some consistency on who’s eligible and who’s not. I would also say that people who are partially sighted are still unable to drive, so why are they going to be penalised.</p> <p>*5 I think anybody who has a dual sensory loss should have an automatic entitlement.</p> <p>*6 To not be socially isolated is an integral part of someone’s mental health and well being. You don’t want the rates of depression to increase. Already, when someone is newly diagnosed with sight loss, there’s a lot to come to terms. Receiving DLA most definitely helps even if it might be you using assistive technology regularly and you have a slightly higher electricity bill as a result. Just knowing that the money is available to pay that bill puts your mind at rest. The RNIB do have a lot of environmental equipment to support people with sight loss, but it’s all an extra cost that sighted people would never require.</p> <p>*7 I don’t know that we can. My understanding is you have to have a “permanent” and “substantial” loss to qualify for DLA in the first place. *8 Aids and adaptations do not take away from the fact that you have little or no vision. I don’t think that it would necessarily help to take into consideration environmental equipment that you use. You can’t replace another human being, a computer can’t think for you. The use of a guide dog might be a fairly good indication that people aren’t able to move around easily. A guide dog is a clear indication that people are struggling but people shouldn’t automatically assume that just because someone has a guide dog everything is fine. The guide dog cannot read a train time table for example or a menu in a restaurant and cannot speak to other people for you, a guide dog cannot tell what coinage or money you are using.</p> <p>*9 Have a conversation over the phone rather than relying on people with a severe sight loss to deal with necessary paperwork. Give people the option to do it electronically as again, we have to rely on someone else to fill the form in.</p> <p>*10 The Ophthalmic Consultant who lives out the CVI would be a good person. Maybe an Audiologist for those who have a dual sensory loss.</p> <p>*11 I think it’s fair to say that some people feel nervous about meeting professionals and may not be at ease, as they think they are trying to be caught out rather than giving a true and accurate account of their life and how difficult it can be. Personally I don’t have problem with it but I don’t lack confidence.</p> <p>*12 If you know you have a long term condition, that isn’t likely to change throughout somebody’s lifetime, why is there a need for a review? Obviously, if someone has a fluctuating condition, then yes, maybe a review could be helpful. Why waste time and money if it’s a long term condition, why not have a lifetime benefit? If anything, the older we become our health fails more i.e. hearing loss, arthritis, unable to take lids of jars and bottles. Things aren’t</p>

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		<p>going to improve. Consultants only register a very small percentage of people per year who are considered to have severe sight loss. It's miniscule in comparison to the number of people who attend eye clinics every year.</p> <p>*13 Give people easier access to you, let them do it on line, on Facebook, allow them to send text messages. Reiterate that if there is a change of circumstances, to inform the Department</p> <p>*14 They need to fully understand what the eligibility criteria is.</p> <p>*15 Local authority staff need to be well informed. I also think that you need some experts within places like Age UK, Citizens Advice Bureaus as well as local charities that may support people with benefit checks. It's difficult to keep up to date with the changes that come in on a yearly basis, the benefits system constantly changes so you need to be constantly taught about the changes.</p> <p>*16 They spend their DLA on purchasing whatever it is they need to meet their needs. I do think, yes, it would be very helpful to people to help them buy assisted technology that's expensive but also it's not just a one off payment. Things need to be serviced on a regular basis to make sure they are in good working order. Computer technology is almost out dated the minute you get it home, new upgrades come out constantly. Machines need to be serviced regularly. These are not one off payments</p> <p>*17 Obviously if they have long term condition, they also need to have assisted technology from a very young age to support them with their studies. The education department does not have enough resources to provide this type of equipment for every child who needs it at home. They may have it at school but if they have access to a computer that speaks or has large print, that's going to give them a better opportunity to become gainfully employed in the long term. Parents are struggling enough and it is more expensive to have a disabled child, so why not make everyone's life easier and do it as quickly as possible. If a child has a permanent and substantial sight loss, they need to react as promptly as they can for the sake of the child. It is fair to say that we are living in an age now of assisted technology and you see computers in classroom from 4 or 5 onwards. As soon as children are diagnosed and provided for the better. It pays for some additional tuition the child needs if it falls behind. The money can be used for extra maths and English lessons.</p> <p>*18 There are things like the Blue Badge Scheme, taxi card allowance and some local authorities provide or issue the Talking Book Service for people who have severe sight loss. The Freedom Pass is also given to people.</p> <p>*19 How can they be so blinkered? A person is a person and you have to look at the whole person. If they want to take a person centred approach then you don't just take a bit of somebody. For example, vision impaired people cannot cut their own toe and finger nails safely, when you stop relying on your parents to do those tasks for you, you might have to pay a chiropodist and there is an additional cost involved.</p> <p>*20 Why combine it? Why not leave it as it is, why the need to complicated things, does that not just blur the edges?</p> <p>*21 You might be penalising people who are partially sighted that don't have any additional health needs.</p> <p>*22 I would reiterate they really need to educate an awful lot more people about these benefits and they need to make it available on line at the very least. They need to bring themselves into the 20th century. The forms are repetitive, long, give it to people in a format they can access for themselves rather than having to rely on someone else.</p> <p>*Why don't you support more people in completing forms themselves as an organisation. Why rely on others as heavily as you do?</p>
EM135	30-Dec-10	<p>I do agree with what you are doing, as it hurts me to see people who have walking sticks and walk as if they are missing but or something, they use electric scooters park it up then walk round shop carrying goods no problem, it's disgraceful, Now we can't say that person is disabled as we don't know the Circumstances of that person, i.e a Haemophiliac who in my eyes have been disgracefully treated, through no fault of their own, I hope the</p>

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		<p>whisper I hear is true and they do Sue If any action any way shape or form is against or asking them questions..But from what Ive read they will be fine as it is still terminal illness.*</p> <p>*Then there is DEAF those that have NO hearing at all, no hearing Aids, No Nothing, they are trying to come to terms with their loss, i.e they are ACQUIRED DEAF, I ve seen Acquired Deaf people who dont seem to be part of the real world, it must be hard for them, no BSL, No lip reading, Ive seen Divorces in that area, I know Of a guy in London who is 60-61 Im unsure, but he has been trying for work for YEARS, and no luck, how can you question people like that..If they lose any DLA or P.I.P Then that is most unfair. *</p> <p>*I do understand cutbacks and also those I KNOW who claim and in my eyes SHOULDNT, I DO KNOW OF A FEW, but me being me wouldnt shoot them, thats not my job..Getting back to Deaf people, Do you think a person with Hearing aids is DEAF, well it might surprise you, but I think NO, the hearing Aid is to help with sensoneural hearing they have, so theyb can hear, people who have none cant hear at all..I would even think that Cochlear Implant is middle rates P.I.P, as from what ive seen it takes years for people to communicate properly, some sadly it hasnt worked for at all.. Back to Acquired Deaf, they are in never never land not knowing whats going on around them, Im not moaning, just giving you food for thought, I BELIEVE that ACQUIRED DEAFNESS is worse thing in the world, surfing net even a Blind woman preferred to talk and communicate and talk and listen, she said her husband is Deaf and she gets nowhere with him!! *</p> <p>*Then I read this what you have put 6. under Executive summary>>></p> <p>*(considering the impact of the impairment) The only way to see or understand an Acquired deaf person is to be Deaf (totally) Otherwise you will never understand, Its different from being born Deaf, you kind of lose everything, some of them are even losing their normal speech. I hope you take care when considering Deaf people as for many many many many years they have been treated very unfairly, (ACQUIRED DEAF IM ON ABOUT) Sorry if it does sound if Im moaning, but its something that really annoys me, people with hearing aids saying Im deaf NO they are not, they are hard of hearing. Born Deaf YES they are DEAF, but its easier for them to adjust they are brought up in world of DEAF 1ST THEN MIX WITH HEARING.....</p> <p>*I find losing all hearing is like losing life, grandchildren :-(cant hear them, family :-(cant hear them, wife very hard work :-(outside if they get outside, as they get reclusive :-(my wife is my ears, Independence GONE..No matter how hard we try people take over, was what someone said to me..</p> <p>*Another question, how does acquired Deaf communicate? Speech to text reporter, very expensive and not many about, as again I surf and find a guy who asked for speech to text at job centre plus, the reply he got was " we dont do that" Wow how unfair an Acquired Deaf person trying, that is usual for DEAF or Acquired Deaf.</p> <p>*I think that there is 2 , yes TWO types that should get middle rate even higher come to that, as its hard very hard, 1 is Acquired Deaf, 2 Deaf..Deaf should mean D E A F, not hard of hearing until they are Deaf, Im sure Hospital would confirm a persons deafness?</p> <p>*10. Executive summary you said >>we could signpost individuals to other support, or ensure they have the opportunity to discuss their health condition or impairment with an appropriate professional.</p> <p>*Some of us have been to Link in Eastbourne for a week under labour gvt, so nothing new, and most of Acquired Deaf are still reclusive no confidence.</p> <p>*Well im sorry if I sounded Angry, But Im only angry with Acquired Deaf seem to be FORGOTTEN ones, always Deaf, hard of hearing..never much about Acquired Deaf from say youth or 20's, 40's, Try Imagine what its like to lose all hearing with the World. Food for thought?</p> <p>*Acquired DEAF who has troubles with the whole world, family included. Who loses voice because he cant hear his own voice, obviously Im Loud, 1 whos speech gets slurred.</p> <p>*AND IM SPEAKING FOR ALL ACQUIRED DEAF NOT JUST ME. P.S Sorry about size of text my vision isnt good at moment.many thanks anyway..</p>

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		please take note fo what Ive said please please....
EM136	30-Dec-10	<p>Q1 Discrimination, feeling inferior, failure to come to terms with their disability after amputation or severe injuries.</p> <p>*Q2 All of it</p> <p>*Q3 Heating, if you are at home all day and unable to get out it is very expensive to keep the house warm. Clothes, people with prosthetic limbs spend more on jeans, trousers etc that wear through at the knees or hips also footwear can wear unevenly. Carers, transport, adaptations for the home, transport costs, special diets.</p> <p>*Q 4 There are only 5 parts to the benefit now (3 care components, 2 mobility) going to 4 will not make much difference.</p> <p>*Do you think just having the 2 amounts....? Yes, there are many combinations of mental and physical disability.</p> <p>*Q5 Do you think some health conditions ...? Yes.</p> <p>* Or do you think that all claims should be based ...?Yes.</p> <p>*Q6 How can we make sure...? Make the application forms much shorter than the current ones.*</p> <p>*What activities or actions ...? Being able to live without constantly worrying about benefit changes.</p> <p>*Q 7 By asking claimants to let you know if there health changes and by asking there GP.</p> <p>*Q8 When a person makes a claim...? Yes.</p> <p>*What aids and adaptations...? All aids or adaptations that a disabled person uses to live an independent life, walking aids, bathing aids, etc,</p> <p>*Should we only take aids and adaptations...? Yes</p> <p>*Or should we take aids and adaptations...? If they need them they should be taken into account.*</p> <p>*Q9 Make it much more concise.</p> <p>* • How could we tell people...? Write to all people on benefits to see if they are claiming everything that they are entitled to.</p> <p>*Q10 Their GP, Carer, Healthcare Professional, spouse or close relative not an independent third party that knows nothing about the person and has only spoken to them briefly.*</p> <p>* Q11 An independent person may not be fully aware of a persons condition unless they are a GP, Carer or Healthcare Professional. People have good days and bad days an independent person may not see them on a bad day.</p> <p>* Is there any time when it would not be right...? Some Disabled people suffer from physiological problems and may not be confident enough to talk to an independent person sent by the DWP.</p> <p>*Q12 You should look at the type of disability the person has, amputated limbs do not grow back and many illnesses are incurable.</p> <p>* Should the way we look at a claim again...? Of course if they have a disability that may improve with time.</p> <p>*Q13 Providing contact number or email addresses or forms and prepaid envelopes that people can use.</p> <p>*Q14 What types of help...? Help to fill int he undoubtedly long and complex forms that we will receive.</p> <p>*Would it help if we told people...? Yes.</p> <p>*Q15 There should be no restrictions on what the payments can be used for as now.</p> <p>*Q17 How important or useful ...? I was not aware DLA could be used to get other benefits</p> <p>* What can we do to make things better? Clearly more information should be given to claimants,</p> <p>* At the moment people who get...? It would make a massive difference and increase costs to disabled people. The Blue Badge scheme in particular is invaluable to people who attend hospitals regular and have their own transport.</p> <p>*Q18 You should respect peoples privacy and not share information with</p>

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		<p>other government departments unless the claimant specifically requests that you do so.</p> <p>* Q20 Disabled people who rely on benefits because they cannot work are suffering from great stress at the present time with the benefit changes and the possibility of losing some or all of the money they currently receive. Changes should apply to new claimants and not those who currently receive DLA.</p>
EM137	30-Dec-10	<p>Following the government proposal to withdraw the D.L.A. Mobility Component from service users living in residential care homes who are funded by Local Authorities, I felt the need to write a response. *</p> <p>*I very much hope that, after reading my response, it will become obvious that the government has not properly understood the financial implications that a withdrawal of the D.L.A. Mobility Component would have for those affected, should an adequate income level not be maintained. I also hope that the government will change the wording of the proposal on the DWP website, so that it no longer implies that Local Authority funding covers all costs incurred by those who live in residential care homes.*</p> <p>*It cannot be acceptable to subject those on low incomes to such a large reduction in their finances. I, therefore, ask you and the government to reconsider this potentially incredibly damaging proposal.*</p> <p>*I look forward to hearing from you. Yours Sincerely, [REDACTED]. Residential Care Home Service User (Local Authority Funded).*</p> <p>*Introduction - This is a response to the summary of the government proposal (see attached), to withdraw the payment of the Mobility Component of Disability Living Allowance (D.L.A.) from residential care home service users who are Local Authority (L.A.) funded. The planned implementation date for this measure is October 2012. *</p> <p>*Before giving my views on the proposal, some background information is required, which, I hope, will add more clarity to my arguments. The information may lead you to question the government's attempts to justify their intentions.*</p> <p>*Disability Living Allowance and Continuing Care - Disability Living Allowance (D.L.A.) is a welfare benefit comprising of two components, the Mobility Component and the Care Component. Claimants are entitled to either or both components, provided they meet the eligibility criteria for the component or components for which they apply. Knowledge of the eligibility criteria for D.L.A. is not necessary for the understanding of this response. However, it is important to understand the differing ways in which Continuing Care is funded, and how this affects whether or not D.L.A. can be paid to the service user.*</p> <p>*From this point onwards, whenever D.L.A. is mentioned without a component being named, I shall be referring to both the Mobility Component and the Care Component.*</p> <p>*Continuing Care is a general term describing care provided over an extended length of time to those over 18 to meet physical and/or mental health needs caused by an accident, disability or illness. It may require services from the NHS and/or social services.*</p> <p>*There are four forms of Continuing Care. These are: NHS Continuing Healthcare, Intermediate Care, Continuing Health and Social Care and NHS Funded Nursing Care. *</p> <p>*NHS Continuing Healthcare is a package of ongoing care fully funded and arranged by the NHS.</p> <p>*Eligibility is primarily based on health care needs. It can be provided in most settings, care home, hospice or the service user's own home. Anyone receiving this funding can only be paid D.L.A. if they continue to live in their own home.*</p> <p>*Intermediate Care is short term (up to six weeks) and D.L.A. payments are not affected.*</p> <p>*Continuing Health and Social Care is primarily Local Authority funded and may be provided either in a residential care home or an individual's own home. Eligibility is primarily based on social care needs. Where a service user</p>

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		<p>requires additional minimal care from a registered nurse, the extra cost for this is met through NHS Funded Nursing Care.*</p> <p>*Service users in residential care homes are generally funded through Continuing Health and Social Care. This funding is means-tested. Where a service user has an income or savings above the upper threshold, they are deemed 'self-funding' and pay the total cost of their placement. Self-funding service users are also entitled to NHS-Funded Nursing Care, should this be required.*</p> <p>*Self-funding service users, whether or not they receive NHS Funded Nursing Care, are paid any D.L.A. for which they are eligible.*</p> <p>*Service users in residential care homes, who are L.A. funded, cannot be paid the D.L.A. Care Component, even if they are eligible. Where a service user is eligible to receive the D.L.A. Mobility Component, this is paid. D.L.A. Mobility Component is counted as Disregarded Income for L.A. means-test purposes and is kept by the service user.*</p> <p>*Finally, if a D.L.A. recipient is admitted to an NHS hospital or 'similar institution' (definition of 'hospital or similar institution' can be found in D.M.G. chapter 18, 18033 (see 'Sources')), and remains there for 29 days or longer, D.L.A. payments cease after 28 days. Upon discharge, payments will restart in accordance with the rules of D.L.A. pay-ability for the particular form of care and funding scenario into which the person is placed.*</p> <p>*It is not necessary to know the three rates of D.L.A. Care Component for this response. The Mobility Component has two rates. The lower rate is £18.95 per week and the higher rate is £49.85 per week. These rates are for the financial year 2010-2011.*</p> <p>*Personal Expenses Allowance - The Personal Expenses Allowance (P.E.A.) is money to which all L.A. funded service users are entitled. This includes care home service users, whether or not the home provides nursing care and regardless of who runs them (council, private or voluntary sector). *</p> <p>*The P.E.A. is set by the government each year at the same time that Benefit rates are adjusted. However, the P.E.A is not a Benefit. The P.E.A. is the amount of money which the government says the service user must be left with, in addition to any Disregarded Income. I will call this amount (Disregarded Income plus P.E.A.) Service User Income (S.U.I.), as it is purely for their use. The P.E.A. is £22.30 per week for the financial year 2010-2011.*</p> <p>*The Assessed Charge (the total amount of weekly benefit received by the service user minus their S.U.I.) is paid to the service provider by the service user.*</p> <p>*I have not, as yet, been able to establish whether a P.E.A. type payment exists for service users funded through NHS Continuing Healthcare. I will therefore assume that these service users do receive some money to cover personal expenses and that it is equivalent to the P.E.A. received by L.A. funded service users, thus giving a service user funded through NHS Continuing Healthcare, a S.U.I. of £22.30 per week.*</p> <p>*Personal Response - Having read the government proposal to withdraw payment of the D.L.A. Mobility Component from L.A. funded service users in residential care homes, I feel that it will be difficult for those being affected (myself included) to articulate the probable consequences of such a measure. The risk for those who are affected by the measure and willing to voice their concerns, is in giving the impression that they should, somehow, be exempt from being part of the hardship caused by the Comprehensive Spending Review 2010. Without being seen to offer some sort of compromise, gaining the support needed to alter government thinking on this issue may be impossible. Let me explain why.*</p> <p>*To simplify matters, the following section will be based on a L.A. funded residential care home service user receiving a weekly Disregarded Income of £49.85 (higher rate D.L.A. Mobility Component) along with the weekly P.E.A of £22.30. This will, therefore, give the service user a S.U.I. of £72.15 per week.*</p> <p>*I am quite sure that many individuals, couples and families in Britain, would very much appreciate having £72.15 each week to spend on, what some may</p>

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		<p>term, "non-essential items". Although most people would, probably, consider such things as personal hygiene products (shower gel, shampoo, toothpaste, etc) to be 'essential', an average weekly outlay of around £5.00 for such items could not really be considered a substantial fraction of £72.15 per week. *</p> <p>*The fees charged by service providers of residential care homes, are inclusive of food (excluding take-away meals or very specific foodstuffs unconnected with medical need) and the essential utilities (electric, gas, water). As none of these costs are met from the S.U.I., many members of the public, particularly those who have very low incomes, could, quite legitimately, argue that it is unfair for those living in residential care homes to receive as much as £72.15 per week. The sense of unfairness may be further compounded by the knowledge that residential care home fees, which are ultimately funded by the tax payer, can range between £700 and £1000 per week for those service users who have high levels of care need. *</p> <p>*Before concluding my response, it is necessary for me to comment on some of the specific justification, given by the government, for the withdrawal of D.L.A. Mobility Component from L.A. funded service users in residential care homes. These comments should be read alongside the copy of the section of the 'Spending Review 2010: Summary – Disabled people', which I have attached.*</p> <p>*The government seems to assume that service users spend their D.L.A. Mobility Component solely on mobility expenses. Although the name suggests this, and I am sure that most recipients do, at times, use at least some of the money for 'getting around', there are no restrictions on what the payment can be used for. I certainly do not set aside £49.85 each week specifically for travel and I can't imagine many recipients do so. My £49.85 (D.L.A. Mobility Component) is simply the majority of my S.U.I.*</p> <p>*When I do require transport, I, quite rightly, have to pay for it using my S.U.I. This could either mean using a private vehicle and paying for the fuel, hiring a taxi and paying the fare or purchasing two train tickets (one ticket for me, the other for the person accompanying me). On the occasions when I am able to use the home's transport, I still have to pay a tariff in accordance with distance travelled. None of my travel costs are met by L.A. funding.*</p> <p>*The third bullet point in the attached summary states that "Local Authorities and residential care homes have a duty to meet the needs of the local population and those they provide services to". This, along with the second bullet point, would suggest that L.A. funding covers all of a service user's requirements. The question then is, apart from the very obvious, what constitutes a need?*</p> <p>*For many service users who live in residential care homes, particularly those who have very limited physical ability, access to a computer and internet (and therefore a phone line) would be seen as a need. Neither the L.A. nor the care home pays for this equipment, nor do they pay for a private phone line or for internet access. A service user wanting these facilities has to purchase them using their S.U.I. For a service user who has severe physical limitations, life without a computer and internet access could be incredibly dull, were they unable to afford it. *</p> <p>*Similarly, a service user's quality of life may be enhanced by having subscription television. Again, this would only be paid for by the service user with their S.U.I.*</p> <p>*From purchasing clothing to paying for occasional time away, from buying CD's and DVD's to adequately insuring possessions, the list of items and services which L.A. funding does not pay for is obviously endless. Any attempts by the government to justify their intentions by pretending these costs are met by L.A. funding are grossly dishonest and misleading.*</p> <p>*The government further attempts to justify the withdrawal of D.L.A. Mobility Component from service users in residential care homes, in the fourth bullet point, and it was this which prompted my research, leading to the writing of the first part of this document. The government states that the change will "end the anomaly whereby two state funded residents placed in the same care home, with similar needs, can be treated differently according to whether</p>

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		<p>they are funded through the NHS or Local Authority". In my opinion, the statement deliberately misleads readers with insufficient knowledge of the subject.*</p> <p>*This attempt in justifying the withdrawal of money from L.A. funded service users relies upon the financial needs of L.A. funded service users being similar to those who are funded by NHS Continuing Healthcare.*</p> <p>*In order to receive funding for NHS Continuing Healthcare, the service user must require care of a nature which is too specialised and/or too intense for it to be funded by the L.A., even if supplemented by NHS Funded Nursing Care.*</p> <p>*It would be wrong to assume that those requiring a high level of nursing input were unable to enjoy a similar quality of life to those with high level social care need, and that the latter should therefore receive the greater S.U.I. But, presumably, the reason D.L.A. Mobility Component is not paid to those funded by NHS Continuing Healthcare, is because these service users are much less likely to be able to venture from where their care is provided, whereas those receiving social care tend to, and are encouraged to, be more active.*</p> <p>*Conclusion - In the absence of any indication to the contrary, it must be assumed that, should this proposal go through, L.A. funded service users in residential care homes will, from October 2012, only receive the P.E.A. It can also be assumed that any increase in the P.E.A. will, almost certainly, be in line with inflation (currently 3.2%). Therefore, by October 2012, the P.E.A. will be around £24.10 (a 4% increase for two years).*</p> <p>*The withdrawal of D.L.A. Mobility Component would mean S.U.I. would drop by 46% and 69% for those who had been receiving the lower and higher rates respectively;*</p> <p>*As a service user who currently receives the higher rate of D.L.A. Mobility Component, I would grudgingly accept a £10.00 or even £20.00 drop in my weekly income, as a way of taking my fair share of the drastic cuts which this government feels is necessary to make. However, losing 69% of my S.U.I. is definitely not acceptable.*</p> <p>*I acknowledge that there is unfairness in the differing S.U.I. depending on the funding source, but, with the P.E.A. being an insultingly low £22.30 per week, reducing S.U.I. to that level for L.A. funded service users, will create a greater sense of injustice among more people. The proposal, as it appears to stand, will result in many severely disabled people having their already limited independence, as well as their sense of well-being and dignity, further reduced.*</p> <p>*If this proposal is designed to create fairness and is not simply about saving £135 million a year by 2014-15 (omitted from the attached proposal, but tucked away in the Spending Review (see Sources)), the government would state that, as well as withdrawing the D.L.A. Mobility Component from L.A. funded service users in residential care homes, they would increase the P.E.A. for all state funded service users. *</p> <p>*The government must ensure that service users of state funded care receive a level of S.U.I. which is meaningful and not simply token. I suggest a minimum S.U.I. of £45.00 per week, which is linked to inflation, can be the only fair compensation for the loss of D.L.A.*</p> <p>* Written By :- [REDACTED].</p> <p>* Status :- Local Authority funded service user (residential care home).*</p> <p>Written :- December, 2010.*</p>
EM138	31-Dec-10	<p>Discrimination against disabled people and hate crime. The disability itself causes limitations that may not be possible to accommodate. For example wheelchair users cannot go to a first floor restaurant if there is not an accessible lift.</p> <p>*Poor street lighting is hazardous for many with disabilities particularly those with sight and hearing problems I have been prevented from social clubs due to my disability not because I could not participate but because I was considered a social outcast in having a disability. Society show little empathy with disabled people on public transport and if bus drivers for example are not</p>

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		<p>seen to support a disabled traveller then other passengers on the bus behave likewise. This creates disempowerment and threat to disabled passenger just simply by being on that bus, fortunately railway staff set a good example so travelling on trains is less threatening.</p> <p>*Due to society's behaviour this impacts in the employment field. This means that many disabled people are unemployed and once made redundant are less likely to find employment quickly. The older the disabled person is the less likely they are to be re-employed. This means that disabled people are retired far longer than non disabled people. In view of the government's latest statistics where it had been acknowledged that people are living longer there is a high possibility that disabled people will be retired for most of their lives due to society's discrimination.</p> <p>*DLA should remain as it is.</p> <p>*Disabled people are in the lower income group if employed, less likely to be offered career progression or promotion and have higher costs if not employed. For example disabled people are encouraged to purchase their own equipment to manage their disability as state equipment is so old fashioned that it can be embarrassing .Due to my disability I choose to travel in good daylight. This means that I am travelling during peak times which cost more. I need magnifiers, good lighting (higher costs in electricity bills).I am safer in travelling by taxi, which costs more and purchase furniture and equipment for my home that are safe rather than economical. I am limited (as are many other disabled people) in the choice of home that I can live in. This could be more costly in the long term as I would rent or purchase a property to meet my needs rather than the practicality of the location. *Shopping is only possible within the proximity of my home. This is due to limitations in travel and inability to carry; therefore I cannot shop for bargains or cut priced products unless this is offered by my local supermarket.</p> <p>*Perks in employment such as car loans is not possible for some disabled people especially those with a visual impairment which means that no alternative is ever offered and travelling around is more costly and stressful.</p> <p>*Not sure but I am happy with the present system.*Circumstances change which means that needs will change also. The disabled person has enough to cope with on a daily level already and if they are going to be judged on needs and circumstances periodically this is going to cause further stress and disempowerment. This will lead to mental health problems and inability to plan anything for the future, I believe that some health conditions and impairments should be an automatic entitlement as degenerative illnesses mean that the person is going to get worse anyway.</p> <p>*Preventing isolation is essential and this can only be achieved if local government is aware of those needing support. Social services presently do a good job in ensuring people that they live as independently as possible but some disabled people like myself; wish to retain their privacy and dignity by just depending on their DLA.</p> <p>*Reviewed every two years.</p> <p>*Should the assessment of a disabled person's ability take into account...? No.</p> <p>*• What aids and adaptations should be included?Aids and adaptations only assist; they do not resolve the problem. All disabled people I feel should have access to aids and adaptations to enable them to live as independently as possible. However disabled people cannot be forced into having these as many believe there is a stigma attached to being seen as disabled and are fearful of the consequences.</p> <p>*How could we improve the process...? For example:</p> <p>*• How could we make the claim form easier to fill in? Yes.</p> <p>*• How can we improve information about the new benefit so that people are clear about what it is for and who is likely to qualify? Too much information for disabled people is not always helpful. Therefore short and simple questions are advisable, giving the claimant an opportunity to describe their disability in the best possible way.</p> <p>*Doctors, Consultants and Opticians.</p>

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		<p>*An important part</p> <p>*• What benefits or difficulties might this bring? I see this as a positive thing; however what confidence can the claimant have that the interviewer is not biased?</p> <p>*• Are there any circumstances ...? I believe that interviewers could be judgemental of peoples own homes and therefore would only support interviews in another location. This may present a problem for many disabled people due to their disability of getting to the venue.</p> <p>*How should the reviews...? • What evidence and/or criteria ...? If the client is receiving the highest rate and has a degenerative condition they should not be reviewed for some conditions five yearly reviews would be appropriate but for others two yearly reviews are more appropriate.</p> <p>*• Should there be different types of review ...? See above.</p> <p>* Presently we have a system where welfare benefit fraud is a crime. This should remain as such and with the increase of CCTVs this should make it easier to prosecute.</p> <p>*Not sure.*In cases where clients cannot read for whatever reason (including brain injury) clients will need personal support, i.e. One to one discussions.</p> <p>*Presently clients apply for aids and adaptations via the state or charities, which are often old fashioned. I believe that clients would be better off being given a one off payment to purchase their preferred model of aid and adaptation.</p> <p>*Social background and peer groups should be taken into account when assessing children. For example a visually impaired 14 year old male does not feel 'cool' in being seen with a white cane. This of course has a dangerous impact on his physical ability however the need to know that he is attractive to girls may be an essential aspect for his mental health wellbeing.</p> <p>*I have found that DLA has been very useful as a recognised confirmation of disability access to other opportunities such as reduced theatre tickets, blue badge and a free carer's support cinema ticket. I believe that more organisations should offer subsidies. *Isolation, non engagement, further discrimination and mental health problems.</p> <p>*Not sure.</p> <p>*Not sure.</p> <p>*DLA should remain as it is.</p>
EM139	31-Dec-10	<p>I have read the questions and booklet downloaded from York Carers Forum. Which my husband is a member. It is a group of unpaid carers fighting for carers rights, paid caring for those they care for etc., I suffered a severe stroke in 2002 and was stunned at how hard it was to get DLA. Prior to the stroke I worked in a Post Office, of which 85% of my day was paying OUT benefits. Having worked all my life I thought the system paid out when needed, how wrong I found it, I was left on my own once I had left hospital. I had been in hospital about 8 weeks when I realized that I would not be able to work. I have short term memory loss. Partially sighted and my handwriting is that of a five year old child. We had a mortgage to pay, still have. I had to go to appeal twice to get what I thought I had worked for all my life. So my answers to the questions are as follows:-*</p> <p>Question 1. When people become disabled, the public attitude changes towards you. No longer can you pop on a bus, you are trapped in a body, still with a brain, but helpless, as you now have to depend on loved ones, family etc., to wash/bath you. Dress you, feed you then get you into the car, then into a wheelchair, before you can begin any sort of normal day. What you took for granted has gone. Eye sight affected by first stroke so that's why this is in large font size 18. Worst offenders for supplying material in large print. Pension Department. DLA from Blackpool wonderful, always in large print. Pension, winter fuel letters etc., NO</p> <p>*Question 2. Both parts of the DDA should be kept.</p> <p>*Question 3. I have to buy my incontinence products, I do get VAT exemption on them. I am permanently cold, so my heating is on 365 days of the year. If I require carers to come to me I have £25. an hour to find. If I had that amount of money to spend I could think of a lot of other things to spend it on. So I</p>

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		<p>cannot afford to pay or carers. Extra washing powders etc. for all the extra laundry that is required when I have an accident in bed, or clothes that need washing. The list is endless.</p> <p>*Question 4. Why change the two parts, they go together. Mobility and care are needed in my circumstance anyway.</p> <p>*Question 5. All claims should be based on the needs of each individual. Every stroke is different. Every heart attack patient, is different. I could quite easily give up, stay in bed all day and let my carers look after me. I was not brought up that way, so I have fought very hard to get some degree of life back.</p> <p>*Question 6. Try and consider what it must be like to*lose ones independence, ones eye sight, ones logical thinking, then try to see who needs this new benefit. I am dreading being re-assessed. I do not have the option of living an independent life, so cannot really answer that one.</p> <p>*Question 7 Try to get a more professional assessor, one who can understand how it feels to lose ones dignity. Life in a wheelchair makes you invisible. I could write a book about that experience.</p> <p>*Question 8. You should take into account what aids a person will need, I have found the system unfair. If one is on a means tested benefit, then that is the gate way to additional money. As my husband still at the age of 68 years old has to work to pay the mortgage and other household bills, we cannot be means tested as he salary is added to my DLA and pension. So we get no other help financially.</p> <p>*Question 9. My social worker in hospital completed the first set of forms for claiming DLA. When I eventually left hospital (you are on your own). I had no access to a social worker. My doctor had to complete the second set of forms, then I was assessed by a man, found it very embarrassing having to discuss hygiene problems with a young man. Trust the doctors report, usually they have known the person prior to the illness, so they should be able to give an honest report.</p> <p>*Question 11. Carries on from question 10. I would have preferred a lady to talk to. Some-one who understands what a lady would like to do, be it with*difficulty. I would recommend visiting the claimant in their own home environment. See how difficult or easy they can do simple tasks, to get them through the day. Then assess their needs.</p> <p>*Question 12. Each claimant has to be re-assessed/visited as and when they ask to be. I am a lot worse now, I have so far suffered four strokes and each one adds and makes the symptoms I have worse, but I do not think I can claim any extra money. I am on the highest rate for both parts, it really is not enough, some times I do think can we eat or heat? Make Carers Allowance to All that need it, not means tested.</p> <p>*Question 13. Make DWP more aware of persons*requirements. I now watch fraudster on television programmes, they are not made to pay back money,*its makes me very bitter. Some claimants, may not feel comfortable talking to strangers from DWP, I was made very uncomfortable.</p> <p>*Question 14. You should have some-one who understands long term illnesses and life long disabilities, as I get older I am unable to do what I did in 2002, ones age has to be taken into account. As we get older we slow down even more. I think it would have helped me to get advice from The Stroke Association, The RNIB, other organizations, one gets home from hospital and you feel you are on your own. You have to find out about other care facilities yourself, no one seems to offer a complete package of other agencies/services that you may find useful. Give contact details out.</p> <p>*Question 15. I eventually got help from the occupational therapist at the hospital who arranged for me to have aids to help me in the kitchen. Aids to help my husband when I require bathing etc., again we had to find this information out ourselves. Some*people can afford one off costs, I cannot anymore.</p> <p>*Question 16 I cannot imagine how distressing it must be to have a disabled child, so feel I cannot answer this question.</p> <p>*Question 17. In my experience I have not found getting DLA has given me</p>

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		<p>other benefits, apart from vat free goods. But I have just had to purchase a new gas boiler (£2500) why could I not get that item vat free, when some-one can get adaptations to a boat vat free? Surely that cannot be right. Make the system work for everyone. I am most grateful for my blue badge. Cannot say Warm Front Scheme has been of any use to me, (my husbands small part-time salary to pay mortgage) means I am not entitled to any help. Ridiculous! My life would be very difficult without my DLA allowance, I really would be in trouble financially.</p> <p>*Question 18. I think ALL DWP departments should be allowed to share information, also make them*comply to The Equality Act. Supply material in large print. Some claimants do not speak English, no doubt they would be offered a linguist. I have written to*Iain Duncan-Smith M.P.,3 times regarding the changes to DLA, not one reply back. Understand that every person is an individual.*Best wishes [REDACTED]. [REDACTED] * *</p>
EM140	01-Jan-11	<p>Thank you for asking the AOHNP (UK) to respond to the DLA reform consultation document. I have been asked to respond on behalf of the Association and my responses to the questions posed are as follows:*</p> <p>*The impact of their condition on their mobility, stamina and cognition, The access arrangements of society. If the person has physical mobility restrictions or a permanent underlying health problem, a great deal of stamina is expended to undertake activities just to exist day to day. It requires an immense amount of organisation and planning to eg travel, access areas other than home. Despite best intentions, eg lifts being out of order, lack of toilet facilities, delays in obtaining assistance eg on and off trains, impact immensely on a disabled person and are a huge barrier both to work and living an independent life.</p> <p>*The additional cost of having a physical mobility problem is also prohibitive – eg have to physically go to the train station in person to book assistance (unable to do by phone) which costs time (fuel & carer) and further impacts on time and stamina.</p> <p>*Even small things, fighting to open doors (just get in a wheelchair or mobility scooter and try to open the average fire door) are huge barriers to life and work. Slopes are great, but it is very hard to self propel a wheelchair up them – so cannot be independent.</p> <p>*Most 'disabled access' including Motability scheme, makes the assumption that the disabled person has a 'carer' with them (eg who actually pushes the wheelchair up the ramp? Who gets the ramp down?). An independent single disabled person faces huge additional costs to make the adaptations necessary for independent living, driving etc</p> <p>*Public transport (trains excepting) does not allow electric scooters on, so unless one can self propel in a wheelchair, one cannot travel independently on them. The bus service cannot guarantee that even their allocated 'wheelchair access' vehicles are functioning, or will run on a particular service. Therefore the bus pass that is available for the independent wheelchair user is functionally useless on the bus service - thus they incur the higher transport cost of running a car or getting a disabled access taxi</p> <p>*It should remain as a benefit that is not means tested. It should look at different aspects of disability (ie the care and mobility)</p> <p>*Equipment to facilitate both activities of daily living and mobility (please note that any equipment designed for 'disability or mobility' attracts a higher price tag).</p> <p>*Adapting the home/car – parking, very few disabled parking spaces are free or concessionary. It takes a physically impaired person longer to get out of the car (electric hoists, chairs etc) undertake task, meeting etc and so they incur higher parking charges than physically able.</p> <p>*Transport – running or access to a car is usually essential eg cannot even walk to local shop, post box etc, has to be a car journey. *Maintaining health and function – eg regular GP, Physio etc appointments (car, transport), prescription charges (pre paid now over £100 per annum), costs of eg swimming or exercise to maximise and maintain physical function.</p> <p>*Care/assistance.</p>

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		<p>*Heating/electric – as usually at home for greater part of the day than those that work full time, physically disabled individuals consume more energy costs. Individual often requires more heat etc due to nature of condition. Specialised equipment usually needs electric to run it (eg bath hoist, electric aids etc) and charging of medical aids</p> <p>*Insurance = higher for any travel, higher for adapted car</p> <p>*All consumables = extra cost as have to add transport cost</p> <p>*You have not given enough information in the consultation document regarding the 2 components, or how they are assessed to enable a valid response to this question</p> <p>*• What, if any, disadvantages or problems? Again, not enough information is given in the document to enable a valid response to this question. Thought needs to be given to any weighting of the 2 compoments.</p> <p>*Terminally ill (that is a firm diagnosis of less than 12 months of life expectancy) should be automatically entitled.</p> <p>*However, all claims should be based on the needs and circumstances of the individual rather than the 'diagnosis label' given them.</p> <p>*Being able to get services (including food) into the home that is a safe and adequate environment for the individual to sustain life.</p> <p>*Being able to wash, dress, move from sleeping area to living/social area. Being able to obtain (including supply of) food and nutrition in a format that can be consumed by the individual. Having adequate arrangements for toileting needs. Having activities to mentally stimulate or meet social needs of individual. Being kept safe from harm (including from self) without restraint.</p> <p>*By evaluating how much effort it costs the individual to undertake the assessed task and how long for recover. At what cost to the individual is the task undertaken?</p> <p>*If they undertake the assessed task, how sustainable is it? EG can they do it once a day, a week, a month or only eg in exceptional circumstances eg escaping a fire or life threatening event?</p> <p>*Has the assessor taken into account the effort or impact on the individual's stamina of everyday life in addition to the task assessed?</p> <p>*Has the assessor any understanding of the variability of different medical conditions? Eg can have good days and bad days.</p> <p>*Yes, if without the aids and adaptations, they individual would not be able to do the task</p> <p>*• What aids and adaptations should be included? Any that allow the person to undertake the task – the key question should be if the person had not got the aid or adaptation, would they be able to undertake the task?</p> <p>*• Should the assessment only take into account aids and adaptations where the person already has them or should we consider those that the person might be eligible for and can easily obtain? Should take into account both – and then decide whether realistic, pragmatic for the person to obtain any additional equipment. Ability to use additional equipment, storage and cost should be considered.</p> <p>*• How could we make the claim form easier to fill in? You could obtain the information you require in less than half the questions – at present the form is repetitive, relies on very subjective data. It also does not include information that should be considered as part of a valid and reliable assessment</p> <p>*• How can we improve information about the new benefit so that people are clear about what it is for and who is likely to qualify? Being consistent with the information produced and ensuring that this is accurate and reflects the reality of the benefit. Ensuring that staff give the public the same information (at present can obtain several different answers to same query!)</p> <p>*Primary health care team, eg GP, OT, Physio, medical report from treating consultant etc.</p> <p>*If individual has mobility or care needs, they will have had input from one of these sources and so information should be forthcoming</p> <p>*• What benefits or difficulties might this bring? Depends on the assessing and interpersonal skills of the health care professional in question. They need to engage with the individual and have the necessary clinical skills to look up</p>

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		<p>from their computer screen and OBSERVE the individual concerned. From this a good basic assessment of basic physical and psychological function can be made.</p> <p>*• Are there any circumstances in which it may be inappropriate to require a face-to-face meeting with a healthcare professional – either in an individual's own home or another location? If the individual is too unwell to undertake such a meeting. If the healthcare professional has not the adequate clinical or interpersonal skills to undertake the assessment.</p> <p>*The information on the application form plus and additional supporting evidence (eg from Primary Health Care Team, other health care professionals) should be assessed. From this it should be apparent if further assessment is required.</p> <p>*When the annual notification of payment is sent to individuals, a non threatening statement reminding individual to report changes in their needs with contact details should be clearly displayed</p> <p>*Being in contact with your other agencies eg the Shaw Trust, who do not appear to inform you when circumstances have changed in a person's abilities.</p> <p>*Clear information – can it be kept to one page? What it is for, who can claim it, how to claim.*</p> <p>*Could some form of requirement to access advice and support, where appropriate,</p> <p>*help encourage the minority of claimants who might otherwise not take action?</p> <p>*If so, what would be the key features of such a system, and what would need to</p> <p>*be avoided?</p> <p>*Self financed or by applying for grants. Limited availability through local authority for eg one wheelchair or assistance towards eg ramp.</p> <p>*Any additional impact /cost that the disability causes when compared to an able bodied child. Also the comparable speed with which changes in children occur (eg growth and impact on equipment size)</p> <p>*How important or useful has DLA been at getting disabled people access to other services</p> <p>*or entitlements? Are there things we can do to improve these passporting arrangements?</p> <p>*A lot less confusing and much less paperwork! It might also enable service providers to ensure that by using PIP as a passport, that they are directing their services to those most in need (assuming that the PIP assessment is going to be valid, reliable and effective)</p> <p>*When applying for Blue Badge, when applying to Local Authorities for services etc</p> <p>*If a person is disabled, the impact is shared across the equality groups, as long as the person is assessed and treated as an individual then there should be no other impact on the equality groups. Disability is a great leveller!</p> <p>*It is essential that stamina is taken into consideration, along with sustainability of task when conducting the assessment. Undertaking a task as a 'one off' is not an indicator that it can be repeated unless the true cost of undertaking the task on that individual can be effectively assessed.*</p> <p>*You do need to ensure you have assessment staff who are clinically competent and that the process allows them to use their clinical skills rather than being unable to observe the individual due to the demands of the IT system employed. If the initial assessment is undertaken in a thorough and effective manner, then it will be far more reliable. Then there will be far less appeals (and at present many appeals are successful due to the ineptitude of initial assessment) and the original decision should be more frequently upheld on appeal as the assessment will be effective, valid and reliable. This will save time, money and ensure that the system gains respect – which at the moment is sadly lacking.*</p>

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EM141	02-Jan-11	<p>i as many disabled people are very unhappy with this news of dla to pip as with incapacity benefit to esa it was always stated in the beginning no one would lose out? and what has happened as is seen on many disability web sites many people now being denied benefit and being told they are fit to work when clearly they are not fit. So how can we trust the dwp condemn or the last gov with dla reform,as said on the blind web site that dla is a great benefit and is going to the right people? how can we trust you when the gov is saying they want to cut the number of people on it. It is deeply disturbing to many of us that have been at work for many years and have retired medically and are in our 50s and have had the medicals with dwp and been given life or indefinite awards only to be told you have got to go through the stress of more medicals,as with many disabled we would all love to go back to work but to do so would not be safe or in detriment to our health if my health suffers because of any of your reforms including incapacity to esa i will not be happy. The dla and mobility are a great help to us and we do not want it to go?</p>
EM142	03-Jan-11	<p>Q 1 - Even with medication many disabled people are affected by pain and fatigue that limits their activities. This may mean that they can only engage in e.g. social activity once a week/month and only for a limited time, as activity worsens symptoms. Some disabled people are bedbound and so need activities to come to them. In my own case I am very restricted to a few activities during a day. So I have to prioritise which are the most important e.g. showering, access to the internet (to shop for food, maintain contact with friends/family), small domestic tasks e.g. loading the washing machine. Trips out are only on 'good' days, for short periods to do essential shopping/bank business etc... I use a wheelchair and need a carer with me. My social life is none existent!!</p> <p>*So many disabled people need a carer to help them to have access to a fuller life and to gain more independence. I rely at present on my teenage daughter, who is unpaid. Access to proper and appropriate equipment, and access to reassessment. So many disabled people are assessed once and left to get on with it.*</p> <p>*Q 2 - I think the tier system for mobility and care is fair at present. There are significantly different levels of need across the disability spectrum and the Allowance should reflect this.*</p> <p>*Q 3 - Paying for others to do tasks they cannot do for themselves: washing, ironing, shopping, cleaning etc... Paying for carers to wash & dress, and then to enable them to go out. Equipment: adapted equipment in the home e.g. to help with bathing; stairlifts, raised chairs, wheeled trolleys, hoists, oxygen etc.... Adapted computer equipment e.g. voice activated. The extra cost of travelling. Without access to public transport the person may need access to a car to make journeys outside the home possible.*</p> <p>*Q 4 - I think the present system is more suitable to cope with the range of disability.*</p> <p>*Q 5 - This would simplify and so reduce the cost of administering the benefit. But this would not reflect the severity of the disability accurately, from statistical studies someone with CFS may be far more restricted than someone with cancer who may receive the benefit automatically, and may go on to recover and no longer need to receive the benefit.*</p> <p>*Q 6 - The only way to ensure this is full medical examinations including detailed medical reports from Medical professionals involved in a individuals care and a detailed report from the person. With sufficient space on the form to give full explanations and an understanding of the variability of symptoms day to day. The Benefit needs to be clearly advertised in Clinics and details given when people are diagnosed.*</p> <p>*What activities or actions.... ?</p> <p>*Access to proper, well designed adaptations and mobility equipment. Proper provision of paid, trained carers. Access to appropriate transport.*</p> <p>*Q 7 - An understanding within the system that health conditions cause variable symptoms. But make self reporting the accepted 'norm' and impose sanctions if people don't report changes.</p> <p>*Question 8**Aids and adaptations that a person could use should be taken into</p>

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		<p>account. So many disabled people do not have access to all the aids/adaptions that could help them.*</p> <p>*Q 9 - Via Hosptial Clinics/Gp surgeries. Especially when a person is first diagnosed. The form needs to be long and detailed but places to give advice and guidance could be highlighted.*</p> <p>*Q 10 - The person themselves, their carers/family. The Medical professionals who see them regularly.</p> <p>*Daily living information from the individual/carer/family. Medical professionals do not see this.*</p> <p>*Q 11 - This in an important part of the assessment but it should not be the sole decider. The assessor needs to be impartial and not dismissive or derogatory.*</p> <p>*Q 12 - Reassessment should occur if the claimant reports a significant change. Otherwise 5 years would be a fair interval and better to administrate.*</p> <p>*Q 13 - Make self reporting the accepted norm. Impose sanctions if not complied with but make the system of assessment fair in the first place.*</p> <p>*Q 14 - Advice from trained advocates, e.g. Welfare Rights Advisors. These would need to be independant and impartial.</p> <p>*Yes - The help available would need to be well advertised by Clinic, local Support Groups. National Support organisations etc..*</p> <p>*Q 15 - Some come via the local NHS but they are supplied and then no follow up is offered. Many are paid for by individuals because of long waiting lists or they are not available via NHS.</p> <p>*Should disabled people be allowed to use the new benefit to pay for a one-off cost?</p> <p>*No, one off costs should be paid for by a different benefit. DLA should be for ongoing daily living.*</p> <p>*Q 16 - I have no experience in this area*</p> <p>*Q 17 - 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>*All Benefits should flag up possible entitlement to other Benefits. I didn't know about the Warm Front Scheme until now. I have received DLA and have a Blue Badge since 2005!*</p> <p>*Q 18 - Please bring in an integrated administration. Surely one assessment could be used for ICB/ESA and DLA rather than having to tell the same details over and over. *</p> <p>*Q 19- I can't see how there would be discrimination.*</p> <p>*Q 20 - DLA has allowed me to have an increased quality of life. Without it I would be housebound. I am very grateful for the help I receive.**</p>
EM143	03-Jan-11	<p>Re: Disability Living Allowance reform*</p> <p>*As a totally blind person, currently in receipt of DLA, I am writing to urge you, as Minister for Disabled People, to recall the Public Consultation on 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. In this letter I will begin by discussing the problem with your case for reform, and then address the consequences of reform.*</p> <p>*First, the case for reform. The reasons given for DLA reform are not robust, with little evidence to support the case for reform and, importantly, no independent academic research. My use of the word 'little' in this context refers to the two pieces of internal DWP papers used as evidence to build the entire case for reform – a footnote for one reference appears twice on consecutive pages. Thus the case for reform falls apart upon even cursory examination.*</p> <p>*The wildest claim to support reform is that 'evidence suggests that DLA can also act as a barrier to work' (chapter 1, paragraph 19). This passage is footnoted, referring to "DLA and work: Exploratory research and evidence</p>

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		<p>review, 2010, DWP Research Report No. 648" (RR No.648). This report also finds that "The main factor affecting the employment rates of disabled people is their disability or health condition" and that "a larger than average proportion of DLA recipients also appears to be affected by the specific types of impairment that carry the greatest employment disadvantage for disabled people" – yet these findings are not reported in the consultation paper, thus skewing discussion.*</p> <p>*In fact, though the report claims that a "perception of disability permanently precluding work is prevalent among individuals with disabilities not already in employment", there is no evidence cited in the report that suggests DLA could be a barrier to work. The section and all references to it in the consultation paper could be interpreted as an attempt to misdirect, and should be removed forthwith. Further, it should be noted that the consultation commits the statistical crime of confusing correlation with causation. Whilst RR No. 648 does provide evidence that low employment is correlated with claiming of DLA, this in no way implies that one causes the other.*</p> <p>*It could be suggested that the lack of evidence pointing to a need for reform has meant that misdirection was used in an attempt to convince the public that DLA reform is necessary. In particular, the graphs presented as Figures 1 and 2 in chapter 1 of the consultation paper, used to show the DLA caseload increasing at an alarming rate, are flawed in many ways, not least in the fact that no baseline is established for when take-up of DLA by people with disabilities plateaued after its introduction in 1992/93. There are further issues regarding the number of Pensioners as the report ignores demographic trends to show that there is a dramatic increase in claims by people over State Pension age. This is particularly questionable since a Pensioners' eligibility for DLA would usually depend on their receipt of DLA prior to this – otherwise, they would be eligible for Attendance Allowance, as I am certain you are aware.*</p> <p>*Figure 2 is also misleading as it could be read carelessly as showing that 8% of the population claim DLA. I am loath to interpret this as intentional misdirection but it is, at the very least, a sloppy drawing of graphs. Another example of sloppiness is the first sentence of paragraph 15 of the first chapter, reading "In just eight years, the numbers receiving DLA has increased by 30 per cent." This sentence is utterly meaningless and a misuse of statistics although, once again, I do not wish to interpret this negatively. Yet another example of the spurious use of statistics is Table 1, which presents the "Distribution of current caseload by rate combination". This table appears between two paragraphs – 16 and 17 – arguing that the current system is too complex and the benefit is not understood. This is an odd, and potentially misleading, place for this data to be displayed. More seriously, the figures in this table do not add up to the total quoted below it. The individual figures add up to a case load of 3,160,000 and the total case load quoted is 3,200,000, a very serious and misleading discrepancy.*</p> <p>*Beyond misuse of statistics, sloppy presentation of data and lack of evidence, there are further points to be queried. Whilst RR No. 648 does give evidence that DLA is complex and not understood by all claimants, as suggested in chapter 1, paragraph 19, this is surely grounds for improving the current system rather than expensively replacing it with an entirely new one. Likewise the assertion, in chapter 1, paragraph 18, that there is no system to check that rewards remain correct. The statement that "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" is a rhetorical tautology. Indefinite awards are given to claimants with conditions that will not improve. Whilst it is not unreasonable that medical advances in the treatment of a certain condition should prompt re-evaluation of those cases, this could be achieved by augmenting DLA rather than replacing it.*</p> <p>*The core argument of the consultation paper is that DLA is a benefit not fit for purpose. Chapter 1, paragraph 9 states that: "DLA is a benefit that provides a cash contribution towards the extra costs of needs arising from an impairment</p>

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		<p>or health condition.” The arguments presented in chapter 1, paragraphs 14 and 15, claiming that the benefit is not fit for purpose, do not touch upon the original purpose of DLA or offer any argument as to why it is failing to meet its original purpose. The information presented is that the DLA caseload and expenditure is a “lot more than was originally expected” and the aforementioned misuse of statistics on the increase in DLA claims. No arguments are presented as to why this means that DLA is not fit for purpose. The only way an argument can be construed is to look at the issue with a preconceived idea that there is an acceptable level of DLA claims prior to evaluating the health and impairment of claimants.*</p> <p>*Finally, chapter 1, paragraph 2 betrays this preconception by stating: “We believe that now is the right time to reform DLA”, yet offers no qualification or reasoning for this belief. Paragraph 3 continues by saying that: “We must ensure that our resources are focused on those with the greatest need”, with no qualification or definition of the term “greatest need”. This could be pointed to as a suggestion that those with “lesser needs” will have to struggle unsupported with their impairment, and that the definition of needs is at the whim of the Secretary of State for Work and Pensions.*</p> <p>*The arguments above demolish the case for reform presented in the consultation paper. I will now address the second part of the consultation paper, explaining why the reforms intended by the DWP will be harmful to disabled people.*</p> <p>*Chapter 2, paragraph 4 begins by stating that: “Central to Personal Independence Payment will be a new, fairer, objective assessment, which will allow us to identify those who face the greatest need, in a more consistent and transparent manner.” The previous sections of the paper do not suggest that the current DLA assessment is unfair or that it is not objective, and neither is there evidence that it is inconsistent or lacking in transparency. The current system is assessment by a variety of resources; information from a carer or support worker, the person’s GP, specialist consultant or physiotherapist. Trying to slim down this evidence base to a homogeneous assessment will mean that the impact of disability on the individual is ignored. This is definitely not objective. Paragraph 4 also states that: “We are developing the new assessment in collaboration with a group of independent specialists in health, social care and disability, including disabled people.” What ‘independent’ means is that a private company such as Atos will be contracted to run assessments. This will include meeting with an ‘independent’ healthcare professional - not necessarily qualified as a doctor - working for the assessors. The objections to a private company, using unqualified staff who know their jobs depend on keeping to strict targets aimed at reducing numbers qualifying for a particular benefit, are too many to list.*</p> <p>*Chapter 2, paragraph 12 of the consultation paper suggests that: “The criteria on which DLA is currently based, on care and mobility needs, are subjective and unclear.” It could be argued that this statement is subjective and unclear as there is no qualification of the statement, and no evidence is offered in support. As suggested in the previous paragraph, the lack of a formalized set of criteria for DLA awards is due to the varying impact of disability, meaning that such a ‘tick-box’ test would not be objective either. The following paragraph in the paper suggests that ‘care’ and ‘mobility’ may not be the best proxies for the additional costs faced by disabled people. The paragraphs also state that “there is currently conflicting evidence on the factors that affect the extra costs that disabled people face in the 21st Century”. The very fact that the only two DWP research reports cited to support offer conflicting evidence raises questions about the DWP’s choice to accept one piece of evidence above the other.*</p> <p>*Chapter 2, paragraph 14 offers the example: “‘mobility’ as currently defined concentrates on an individual’s ability to walk, not their ability to get around more generally.” It is true, generally, that people with disabilities are more mobile as aids and access have improved. However, this additional mobility has come with extra financial costs, such as new mobility aids, adapted</p>

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		<p>vehicles, taxis. Moreover, it is crucial to remember that additional mobility does not mean universal mobility. Chapter 2, paragraph 15 suggests an intention to refocus the Personal Independence Payment (PIP) at those most impaired in their ability to carry out a range of activities, because: "There is some evidence to suggest that individuals whose impairments have the greatest impact are likely to experience higher costs." This statement is bizarre, as this is exactly what DLA does. Chapter 2, paragraph 16 discusses splitting PIP into a 'mobility' component and a 'daily living' component, with two rates for each component. This suggests that the change from DLA will be a vastly expensive rebranding exercise, as modifying DLA could achieve this.*</p> <p>*Chapter 2, paragraphs 17 and 18 argue that "The individual must have a long-term disability" in order to claim PIP, so that "an individual's health condition or impairment must be expected to last a minimum of 12 months". This will punish those who suffer debilitating short- and medium-term illnesses, but eventually recover their mobility and ability to care for themselves. Whilst people are ill over the short- or medium-term, they will have mobility and/or care needs and face the same extra costs as those with long-term conditions. They may even have to purchase mobility or care aids for their temporary conditions. Yet this consultation paper seems to ignore their needs. Long-term conditions are also targeted as chapter 2, paragraph 19 suggests the end of automatic entitlement for certain conditions. The example of renal dialysis automatically entitling one to the medium-rate care component of DLA is given, and it is argued that: "As a result, eligibility for DLA is sometimes based on the medical condition rather than the impact of that condition, meaning that support is not always appropriately targeted." This implies that financial support would be withdrawn from those seen as being able to cope with a condition better than others, even though they may face exactly the same barriers, which they may be overcoming by making use of the financial support provided by DLA. This is actually a real disincentive for people to make an effort to improve their situation*</p> <p>*Chapter 2, paragraph 21 argues for the full removal of PIP from individuals in "hospitals or similar institutions or care homes". As care homes take income and savings into account, this will mean that care home residents no longer have any independent income to pay for short journeys or other ways of retaining independence, and become entirely institutionalized.*</p> <p>*Chapter 2, paragraph 24 states that: "We remain committed to the social model of disability. The new assessment will not be based solely on the medical model of disability and focused entirely on an individual's impairment, but will instead focus on the ability of an individual to carry out a range of key activities necessary for everyday life. " The meaning of this statement is unclear. Paragraph 26 adds little clarification, stating: "Activities we assess could include, for example, planning and making a journey, and understanding and communicating with others. The extent to which an individual could carry out these activities would determine their eligibility for PIP and the level of their award." As I have argued above, such a tick-box approach to the impact of disability is counter-productive and not objective. A person able to complete the activities in your example may still need the same type of support as another who cannot. There is also a huge assumption being made here, that the key activities identified will be an accurate guide to the full range of possible scenarios where a person might require assistance and that they will make allowances for the myriad ways in which a person may require assistance. I do not believe that any tick list could begin to come close to achieving this. *</p> <p>*Paragraphs 27 and 28 state that PIP will "take greater account of the successful use of aids and adaptations as part of the PIP assessment". This means that successful use of aids – including wheelchairs – could mean that claimants are not eligible or eligible for a lower rate of PIP. This is a ridiculous suggestion. For example Tanni Grey-Thompson – one of the most successful athletes of all time – is a 6 times winner of the London marathon. She is obviously 'successful' in her navigation of London streets. Yet she will face</p>

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		<p>the additional costs of her mobility needs just like any other person with a disability. The general truth is that successful use of an aid does not negate additional mobility costs, but may in fact be one of the reasons for them, in that these aids will need replacing periodically and are often expensive items.*</p> <p>*I will now turn to my conclusions.*</p> <p>*The point that most angers me is the focus on DLA as a disincentive to work, which is both false and disingenuous. People who receive DLA do often have lower work expectations as the reform consultation paper suggests, and rightly so as many conditions and impairments make work impossible. Disabled people are often unable to compete equally in the labour market, because of ignorance and fear amongst employers and a lack of willingness to consider making adjustments that may well be relatively cheap and straightforward but are perceived as too onerous. People with high rate awards have the highest levels of impairment and are most likely to be unable to work, regardless of benefits. Those who do work are often only able to do so because of the aids, support or adaptations that DLA or Access to Work allows them to purchase. The focus on moving to work has no place in discussion about DLA other than to make the important clarification that DLA is not work related, and exists to assist with the additional cost incurred when living with an impairment or long-term health condition.*</p> <p>*Other problems include the fact that the PIP proposals will see some current recipients of social care losing financial benefits now paid at least in part to the local authorities for receipt of that care. This will force the LAs to make up the shortfall in funding or, more likely, cut care packages. Another aberration in the recommendations made is the impact of these plans on independent living, making that harder to deliver. Removing DLA from those who receive care packages, and especially those in residential care, will not promote independence. Lastly, some people may lose money as the aids and adaptations they use to enable them to live with their impairment or long term health condition will be seen as negating the need for that financial support, ignoring the fact that the DLA Mobility Component may be the only way of paying for adaptations such as wheelchairs or taxis.*</p> <p>*Although the caseload may be cut, PIP will still look very much like DLA. The current system allows for automatic entitlement to DLA for certain conditions. The new system will not allow for this, and will re-assess all claimants every few years. This is not only foolish but also costly as automatically entitled conditions are by nature the most severe and incurable. The only things achieved are the extra cost of unnecessary assessment, and hardship for severely ill people. Further waste comes from ignoring the fact that, unfortunately, people will remain disabled and have impairment-related support needs even if they no longer meet the new thresholds under PIP. They will be ignored up to the point they become seriously ill and end up costing the NHS and local authorities more in terms of hospitals and residential care. Further, the proposed reforms don't take into account the reality that some conditions are severe but acute. Not supporting people with acute illness and disability makes it more likely that this will become a costly long-term problem therefore increasing dependency.*</p> <p>*There is a strong feeling amongst people with disabilities that the Coalition Government have declared war on us, with a continual ratcheting since the Emergency Budget in June 2010. Announcements on ESA, IB, and DLA 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 DLA Reform process. 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> <p>*I am sending a copy of this by post, and expect your prompt personal reply</p>

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		<p>with distinct reference to each and every point I have made. I am forwarding copies to the Secretary of State for Work and Pensions, and to the DLA Reform Team in your department. I am also forwarding this letter to Gordon Henderson MP who represents my constituency. I am sure my MP will read it with great interest, and that he will wish to raise a number of searching Parliamentary questions regarding the conduct of DWP during the compilation of the DLA reform consultation paper. I await your reply with interest.*</p> <p>*Yours sincerely, [REDACTED] *</p> <p>*cc: GORDON HENDERSON MP (Sittingbourne and Sheppey); The Rt. Hon. Iain Duncan Smith MP , Secretary of State for Work and Pensions; DLA Reform Team*</p>
EM144	04-Jan-11	<p>Q1 Attitudes of people around them towards their disabilities. Inaccessible buildings. Lack of finances and a lack of support from the health and social care system.</p> <p>*Q2 All of it apart from the form which is used for assessment. This should be changed so that it is less patronising.</p> <p>*Q3 Wheelchairs, extra money for Personal Assistants during social activities, such as providing for their meals etc. equipment and adaptations in the home, and anything else that anyone would reasonably spend money on that they had earned from employment. *Q4 I think the benefit should be kept exactly the same as it is now. If it is changed then this will cause much confusion and worry for many disabled people who already have enough worries in their lives. Especially when they are subject to the barriers mentioned in Q1. *Q5 All claims should be based on the needs of the person. We are all individuals and all have different financial priorities, just as able bodied people do.</p> <p>*Q6 The ability to pay for basic amenities such as food, gas and electric bills, council tax etc. The only way to make sure people get what they need is to ask them about what they think they need and provide appropriate support to manage money.</p> <p>*Q7 Ask them about it and remind them regularly to contact the agency about any changes. However if the person thinks that their condition is unlikely to ever change, this should be respected and they should not be pestered unduly by the agency.</p> <p>*Q8 No you should not take into account aids and adaptations they already have. People do not necessarily want to spend their benefit on equipment to do with their disability and this should not automatically be assumed. Adaptations should only be considered if on discussion with the person concerned it is clear that adaptations have a financial priority. However most disabled people I know use the benefit for basic amenities such as those mentioned above.</p> <p>*Q9 Pass information on to social services etc so that all people who may be interested can be made aware of the benefit. Claim forms need to be more open and generalised, asking people to give general information about their disability and the help they need, instead of asking people silly questions such as how many times day they use the toilet and how long it takes them to do this. Most able bodied people don't monitor this so why should any disabled person be expected to. It also invades the persons privacy. I find the current forms very upsetting and intrusive.</p> <p>*Q10 The person themselves is the person to ask. I understand that medical professional may need to be involved but it is up to the person themselves to provide contact details if they wish for anyone else to be involved with their application. The person that knows their body and needs best is the claimant and no one else should be authorised to make assumptions, unless the claimant says it is ok for them to do so.</p> <p>*Q11 As above getting other people involved is only a good thing if the claimant feel it is appropriate to. It may be useful when someone has communication difficulties or other such needs but I do not understand why anyone else should be involved at all without consent. The forms are very personal and people find them hard enough to fill in without professionals who are sometimes considered to be interfering involved in the process as well. So therefore unless the claimant gives consent I think information should only be</p>

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		<p>shared between them and the correct department of work and pensions. *Q12 Claims should only be looked at again if a claimant feels that their needs have changed and if reassessment is required. If not then the claimant should be guaranteed the benefit for life as their disability is highly likely to affect them for life.</p> <p>*Q13 Most disabled people find it difficult to keep on top of everyday tasks due to their disabilities and health conditions. Therefore something as simple as remembering to report changes to the agency is more difficult than people sometimes imagine. Particularly is someone is unable to physically operate a phone or computer. Staff needs to be more aware of this and regularly remind claimants by phoning them and asking them if they feel a reassessment is required and why. A system similar to the reminder systems at a dentist or doctors would be beneficial.</p> <p>*Q14 Yes people need to have the benefit explained to them in a form that they can understand. In some case face to face contact would be more beneficial to aid claimants understanding and signposting to relevant advise agencies, such as the CAB would be useful.</p> <p>*Q15 At the moment most adaptations are available through the social care and health system therefore in most cases the benefit shouldn't need to be used to fund adaptations. A one off cost would be of use in a limited number of cases but to most it would be of little use as buying equipment is okay but where do people find the money to maintain, renew or repair it etc.</p> <p>*Q16 Bare in mind the different circumstances and social situations they may be in. For example benefit may be put towards family days out to cover the extra cost incurred by provision for the disabled child during the day, or parents may want to spend the benefit on behalf of the child on toys, clothes or specialist equipment needed. Whereas adults are more likely to need to spend money on basic means of living, and extra care that sometimes isn't provided by social care and health.</p> <p>*Q17 The way DLA works is very important for most disabled people as it has enabled them to not only fund care but also mobility and other services such as the blue badge scheme. If this changes it will mean more separate assessments and even more stress for many disabled people who already experience more stress and anxiety in their lives than the average able bodied person.</p> <p>*Keep the system the same as it is currently.</p> <p>*Q18 Only information that the disabled person wishes the agency to share with which ever professional is necessary.</p> <p>*Q19 I don't think it would affect any equality groups apart from those with disabilities as unfortunately there is very little awareness of the issues disabled people face by other groups fighting for equality.</p> <p>*Q20 I think that the system is always changing and this needs to stop as although in theory this is supposed to help it actually makes a lot of situation worse for most of the disabled people. *</p>
EM145	04-Jan-11	<p>1. 1. Society is ignorant and creates barriers which hearing people take for granted for example, if i need to see a GP, then i have the problem of making an appointment, and then the problem of travelling due communication as bus driver wont understand me and i cant ask for directions, and then problem of communicating with receptionist and then problem talking with GP. i could try and ask them to book interperter but that is a problem in itself and cannot have interpreter at short notice need one month notice to book interperter due to national shortage of interpreters. its not just confined to gps too but if my alarm clock is broken, other people can quickly buy a cheap alarm clock from boots in the short term or whaetver, but i have to order it specifically which means i have to go without for a while and the special alarm clock costs more and takes longer to obtain lots of attitudes really that means i cant partake in society on equal basis to hearing counterparts and also have to travel more to meet with deaf so no friends locally, so i feel isolated and deaf have high mental health issues</p> <p>*2. 2. some deaf get differnt rates, should have deaf living allowance to make it easier for everyone and should continue being not means tested.</p>

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		<p>happy with current allowance and system, getting money direct will help me</p> <p>*3. 3. travel, interpreting, equipment, phone line because we use telephone longer to convey conversation and we pay more than hearing</p> <p>*4. 4. i dont understand this i know we have high, middle and low component. should be easy for deaf people and also need to think about deaf people with additional needs</p> <p>*5. 5. deaf should be automatic but should have evidence that person is deaf because if person is slightly hard of hearing they can live every day normally</p> <p>*6. 6. we should be able to access everyday life same as hearing but hearing always take for granted, we always struggle all the time even if fill car up with petrol have problem communicate with cashier say which number and also how much should be able to access everyday as we are restricted.</p> <p>*7. 7. whats wrong with the current system?</p> <p>*8. 8. some local authorities provide some or one equipment, some authorities dont. we got free smoke alarm from west midlands fire service but that is it. we have to pay for the rest so that we can live equal to others for example baby alarm has to be vibrate.</p> <p>*9. 9. simple, ask "are you deaf" then that is the eligibility questionnaire, then second stage is questions and ask doctor to write note proof that deaf but it cannot be called 'sick note' because doctors are funny about it, should be 'disability note'</p> <p>*10. 10. see answer to q9.</p> <p>*11. 11. see answer to q9. but need interpreter to help communicate.</p> <p>*12. 12. once you are deaf you are deaf for life. if person born deaf, then deaf for life. or become deaf later then deaf for life.</p> <p>*13. 13. same with child tax credit and any other benefits how you get people to report changes? but the child tax credit is awful for deaf, as difficult to understand on form and letter and also when phone, it is difficult we struggle with that one. should be easy online form, and for people fill in form yes or no change make it compulsory and if no reply, then dla stop.</p> <p>*14. 14. basic information fact sheet</p> <p>*15. possible</p> <p>*16. cant do one off cost as equipment break down or get old, so need update every now and then maybe every year,</p> <p>*17. 17. the number of special needs statements are declining even though there are loads deaf children. parents have to pay extra for the deaf child e.g. social events, transport to special school long way away, pay for communication support etc.</p> <p>*18. 18. dla is like compensation for me because i suffer and the money helps make up for it</p> <p>*19. 19. our quality of lives would be back to the stone ages</p> <p>*20. 20. dont know</p> <p>*21. 21. dont know</p> <p>*22. please dont cut dla we need it.</p>
EM146	04-Jan-11	<p>I have real concerns with the changes the government has set out for the DLA. After reading the white paper and as a disabled person myself I am concerned that the government is more concerned about saving money than helping the disabled people of this country. I have mobility problems and I rely on the money I receive to help me get to work and help me when I have to go shopping etc.</p> <p>*I am also Bi-Polar and need someone to keep an eye on me as I can be a danger to myself or others when unwell. *</p> <p>*I feel that the new medicals are an insult to disabled people, how can you say someone is not in need of DLA mobility if they can use an imagined wheelchair. Some people me included would rather struggle with trying to walk with a stick than give up and go in a wheelchair. Plus if you are in a wheel chair it is so hard to get around. The paths are uneven, the kerbs are high. Have you tried to get on public transport in a wheelchair?. Try it and then come back and say they don't need help. *</p> <p>*As for not giving the benefits people who can lift things with their stumps</p>

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		<p>what is that about. They may be able to life something a few inches but it does not mean they can do everything else. For example hold things, open things, move things it just means they can lift something a couple of inches with their stumps. I would like to know who thinks these things up. Able people who do not have any problems and who do not need extra few pounds to help them out when they need help. What about the men and women of this country who has lost limbs in wars suffered for their country and they come back to be treated this way. It is a disgrace. *</p> <p>*I find it hard to believe that rich able bodied people can sit there and dare make up things for disabled people when they know nothing of their situation. The government what to save money so they do what they always do pick on the people who can do least damage to them. If they really wanted to get money why don't they close all these tax loop holes. Oh sorry they can't do that as they all use them. Why do they not make the companies who do not pay taxes pay. Oh sorry they are friends with them. *</p> <p>*I think it wrong that you are trying to punish the very people who are trying to help themselves. DLA is not for work shy lazy people. I work because of my DLA if I lose it then maybe I will not be able to work. What then another person on long term sick or unemployed as how many companies out there will take a chance on a physically and mentally ill person. I am not stupid and will not work for minimum wage working for a company that takes advantage doing some mundane job when I can and do, do a responsible job working at help others less fortunate then myself. I may have a bad sick record but the charity I work for understand my needs and work with me to help when I am unwell. It is a shame my government does not do the same thing. I have been told that my problems will never get better and over time will only get worse so I have been told I would get DLA for life. Now I am being told that this is not the case as the government are changing the benefits and the rules to suit them and not the people they are meant to be helping. I am not a scrounger and nor do I want to be one. I just want help to cope with my disability without being judged and made to attend medicals which are hard to get to and will not show any different from what my Hospital consultants and GP says. After all they have been treating me for years and can tell you more than a half hour medical from someone who does not know me at all. *</p> <p>*I hope that when people try to change things they know nothing about they speak to the people to whom they are messing with before they make the changes rather than making the changes and pretending to listen to what people think afterwards. *</p> <p>*This government has already loss the votes from every child and their family who was going or was thinking of going to University and every public worker who has had their pay frozen now they are going to lose the vote of every disabled person too. *</p> <p>*I know you will not take any notice of this email or any other feedback you get as you have already made your mind up, but I think you should understand the damage you are doing.</p>
EM147	05-Jan-11	<p>I have worked as a CAB adviser for seven years, helping a large number of people with DLA applications and appeals. I also have a sister with MS to whom DLA has made a big difference. I offer my personal comments on the proposed reforms.</p> <p>*1.</p> <p>*2.</p> <p>*3. Transport – eg may have to use taxis when others would walk short distances</p> <p>*Communication- eg many people with disabilities make increased use of the phone both to maintain social contact and to organise their daily activities</p> <p>*Food eg may need to buy ready made meals, and may have dietary restrictions which involve extra expenditure</p> <p>*Fuel – Physical inactivity and being home all day are both factors which drastically increase heating requirements, and there are also issues such as laundry and bathing costs which may be higher for individuals with disabilities.</p> <p>*4. Reducing components from 5 to 4 will not make it any easier to</p>

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		<p>understand. The division between care and mobility needs is itself confusing.</p> <p>*• What, if any, disadvantages or problems could having two rates per component cause?</p> <p>*Removing the lowest band for care may deter many from claiming.</p> <p>*5. Automatic entitlement simplifies the system and seems to be perceived as fair by most people.</p> <p>*6. We are all individuals with differing needs and priorities eg socialising is essential to some, less important to others.</p> <p>*7. The fear of the return of symptoms may be just as disabling as the symptoms themselves. Assessment of fluctuating conditions need to take severity of symptoms into consideration. Eg an epileptic or diabetic may still limit their activities after several symptom-free months because they never know when they may collapse again.</p> <p>*8. Need to guard against a situation where people feel obliged to use aids and adaptations which are not actually appropriate to their personal needs and preferences.</p> <p>*9. More financial and training support is needed for voluntary agencies such as CAB which help people with the completion of the forms. Many people, especially those with certain mental health difficulties, will never be able to complete a form without help however it is simplified.</p> <p>*Giving GPs and other health professionals training would enable them to signpost people to the benefit. Currently many health professionals do not understand that DLA is based on personal needs rather than diagnosed condition.</p> <p>*10. There is a difficulty here, in that it is usually those who know the patient who are best placed to assess them, but there is also a need for objective and independent assessment. We also need to avoid an assessment process which will place additional stress on vulnerable claimants, especially those with mental health issues. A three way discussion between the claimant, a professional or carer and an independent assessor would provide the clearest assessment.</p> <p>*11. As above, the presence of someone the claimant already knows and trusts will facilitate fair & accurate assessment, especially as people with disabilities often underestimate the impact of their disability on their lives, becoming used to depending on help or managing without.</p> <p>*12. The current system allows some variation in periodicity of reviews. In many cases frequent reviews would be totally inappropriate. The main criterion should be the likelihood of any change in symptoms/disability.</p> <p>*13. Individuals could be sent forms annually or quarterly which require them to tick boxes stating that their condition is unchanged, better or worse.</p> <p>*14. Clear advice and information can be provided in writing at the time of claiming, but there is also a need for personal advice from independent agencies such as the CAB, and funding should be allocated for this.</p> <p>*15. Advice and support is unlikely to be of value when it is imposed. *16. Additional payments for special equipment can be very useful to some individuals, but ideally these should be provided through the health and social care services rather than the benefits system.</p> <p>*17.</p> <p>*18. Current arrangements work quite well, though claimants are still often ignorant of other services and entitlements. It would be helpful if claimants could apply for a range of additional services and entitlements by completing one form with tick boxes.</p> <p>*19. The passporting system is effective in targeting services at those who need them without the need for repeated assessments.</p> <p>*20. There could be links with ESA claims and social services assessments.</p> <p>*21.</p> <p>*22. Is there anything else you would like to tell us about the proposals in this public consultation?</p> <p>*The current system is basically effective. Problems include failure to claim, sometimes through ignorance or because the claiming and assessment process is stressful and embarrassing. This is particularly true for those who</p>

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		suffer with mental health conditions and feel that their condition is not properly recognised and understood.*
EM148	05-Jan-11	<p>Thank you for the opportunity to consult on the DLA reform. I manage the Blue Badge service at this Council and am responding to the request to provide feedback about the consultation document.*</p> <p>*One third (5,000) of our current blue badge holders are automatically entitled to a badge by being on the higher rate mobility component of DLA and we rely on the applicant providing evidence to prove this (showing letter of entitlement at time of application). If we had better collaborative information sharing abilities between LA's and DLA (PIP) records we could confirm that entitlement ourselves as often the applicant does not have the full information with them thus having to return with or submit the proof at a later time before badge can be issued.*</p> <p>*Could DWP notification letters be proactive to highlight that the award of higher rate mobility (PIP) automatically entitles the person to a Blue Badge where it is a permanent condition and does passport them to this service?*</p> <p>*Two thirds (10,000) of our Blue Badge holders fall under the discretionary criteria. Could the outcome of medical assessments undertaken to determine entitlement for DLA (PIP) be shared with Local Authorities to obviate/reduce the need for LA's to also have their own means of assessing discretionary eligibility and therefore avoid duplication of effort? There is currently a heavy reliance on the applicants own G.P. to provide this information but the independent assessment undertaken for PIP would ensure no conflict of interest in doctor/patient relationship (currently 95% of applications are approved). This process is also inefficient and costly but if the silo mentality and separation of responsibilities was removed, greater collaboration and better use of public funds would be hopefully possible. I hope that you find this information helpful*</p>
EM149	05-Jan-11	<p>I am writing in response to your consultation on the reform of DLA. I have Spinal Muscular Atrophy Type II, which is a genetic disability that causes severe muscle weakness. I use an electric wheelchair at all times for mobility and I am reliant on 24 hour personal care support to help me accomplish any physical tasks. I am a graduate and after joining one of the top graduate recruitment schemes, I have a full-time professional job. Currently, I receive high level DLA for both care and mobility components, and this along with social care funding from my local authority and the Independent Living Fund, has allowed me to live independently. *</p> <p>*I was dismayed to read the DLA consultation document, as it demonstrates little or no understanding of what it is like to live as a disabled person in the UK. It also instils me with no confidence in your knowledge of the importance of DLA. You state that you are intending to "replace DLA with a new cash benefit – Personal Independence Payment – which will contribute to the extra costs of overcoming the barriers faced by disabled people to lead full and active lives". That is the exact intention of DLA, thus, it appears that you are actually attempting a rebranding exercise not a revolutionary change in the support available to disabled people. You state that the benefit is not fit for purpose, but actually you are arguing that it is too expensive. Whilst I understand that the current economic situation and the Coalition Government's plans to reduce the deficit means restricted budgets, removing essential support from vulnerable groups is not conducive to a fair society where everyone can fulfil their potential. You state that there is no review system, when actually you are concerned with reducing the number of claimants, as you are unhappy with the rise in eligible people. Yet common sense dictates that as medical treatments improve, the number of disabled people surviving longer will rise, and as such you are seeking to punish individuals for being part of a growing minority. Finally, DLA is no disincentive to work, as its non-means tested, thus, if that is a real issue, I suggest that you start an information campaign not scrapping the benefit. The correlation between unemployment and high rate DLA is because these people are the most severely disabled, and so working is hardest for them. It</p>

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		<p>is ridiculous to interpret that correlation for causation. Therefore, overall, what you are attempting to create is a rebranded DLA that is cheaper with fewer claimants. In scrapping DLA and replacing it with a lesser version, you risk ruining many disabled people's opportunity to lead a full and active life because you have removed a vital part of the support that makes it possible.*</p> <p>*In answer to your specific questions:</p> <p>*Quantifying the barriers that prevent disabled people from participating in society is extremely difficult because having a severe physical disability affects every aspect of my life. You have cited the Disability Discrimination Act and Equalities Act as examples of how life has improved over the last 10 years. However, in a practical sense very little has changed and any progress is slow. Many buildings are still inaccessible, public transport is still poor, and attitudes are changing most slowly. I cannot take a train without booking 48 hours in advance and I have to use main stations as smaller ones are not accessible at all. I cannot use meeting rooms in my own office building because they are down 3 steps and I cannot enter any professional meeting without colleagues who do not know me staring in surprise. The barriers I face go even deeper than that, as I cannot even get out of bed in the morning or turn over without my Personal Assistant. The DLA helps with some of these issues. My mobility component is surrendered so I can have a car from the Motability Scheme, without which I could not travel. Half of the care component is used as my contribution towards the cost of my care, without which I cannot live. When you are disabled, life is very different, everything is that much harder and more complex.</p> <p>* The rates of funding should not be reduced</p> <p>*The motability scheme</p> <p>*Lifetime awards – there is no point reassessing people whose conditions do not change</p> <p>*Its use as a passport to other services</p> <p>*Purchasing equipment e.g. wheelchairs, hoists etc as these are not always available from the NHS</p> <p>*Having a PA means everything costs double e.g. a two bedroom house not a one bedroom, additional utilities bills, food, insurance, tickets for events</p> <p>*Cars – they are expensive to buy and adapt, cannot be easily purchased second hand, insurance is costly because it is an open policy to cover my PAs and very few companies cover the adaptations</p> <p>*This seems contradictory, you say you want flexibility, but in removing the middle rate, you are removing the ability to tailor the support package to the individual as closely. I do not think that having 2 rates rather than 3 will make the system any less complex, particularly as it is the assessment form that people find difficult.</p> <p>*Some conditions should be automatic – there is no need to assess people to find out what you already know.</p> <p>*Disabled people should have the same opportunities as everyone else, thus prioritising activities is pointless. In prioritising activities you are making a value judgement about what disabled people should and should not be able to do – that is very unfair.</p> <p>*Individuals should be assessed by their own doctors and specialists and that should carry more weight than an independent assessor. Whilst there will always be dishonest claimants, there should be the assumption that the individual is telling the truth about what they can and cannot do.</p> <p>*Many of the aids and adaptations you mention are funded by DLA, so if you didn't have the money you would not have the equipment. For example, the NHS will only fund a basic powered wheelchair, whereas in order to do the things I need to, I need a more robust and reliable chair. Thus I have to buy the chair, pay for servicing and repairs, buy the appropriate seating cushions and pay for insurance. This is an initial outlay of around £5000 plus around £300 each year if no major repairs are needed.</p> <p>*Make the assessment form easy and quick to complete</p> <p>*Ensure any assessment appointments are flexible according to the claimant's needs e.g. outside office hours</p>

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		<p>*Do not treat claimants like criminals or scroungers</p> <p>*Supporting evidence should be accepted by anyone the claimant deems relevant. This could include doctors, therapists, social workers etc. In addition, advice from non-professionals must also be considered.</p> <p>*This will be costly to implement. It will be necessary to ensure all meeting locations are accessible and at convenient times for the claimant who may need to be at work or have other responsibilities. The training and attitude of the healthcare professional will be vital, as it's difficult to understand someone's situation in one short meeting. These types of meeting are also very stressful, which could make it hard for claimants to argue articulately. In general, these types of meetings an assessment processes favour those who are able to act as their own advocate, thus, disadvantaged people may find it harder.</p> <p>*Reviews should not be automatic. I will be lucky if my condition remains stable and does not get any worse, but a reassessment would be pointless as I already have the highest rate. Thus, it would not be cost effective to keep doing reassessments.</p> <p>*Make it straight forward and simple; it's the probability of lots of bureaucracy that puts off lots of honest people.</p> <p>*It should be widely and accurately publicised. It should be mentioned as part of benefit claiming, but not exclusively so. Hospital clinics may be a good place.</p> <p>*There should be no automatic requirement to get advice. I've been disabled for 28 years, I know more about managing my condition than most professionals and if I do need help I would ask my specialist.</p> <p>*See question 8.</p> <p>*Parents / guardians should be heavily involved. Assessments should also take a long-term view so the child does not need to get reassessed every time something changes</p> <p>*This service is vital, as its one of the few ways to prove disability. An electronic copy of the letter would help when needing lots of copies to send off for things like carers allowance for my parents when I lived with them, cinema ticket discounts for PAs and blue badges.</p> <p>*More assessments would be necessary, thus it would mean more time spent applying for things. Being disabled is time consuming enough without adding more burdens.</p> <p>*It may have helped me if my DLA entitlement had helped prove my need for social care funding.</p> <p>*I think it will affect all groups equally.</p> <p>*I think here it is important to refer back to my opening statement. DLA is so crucial to enable me to live independently and to be able to afford the equipment and support that I need to live and work. My life is difficult to keep balanced between arranging my support, working full time and just trying to live and abolishing DLA will only make that harder. *</p> <p>*I hope that my responses have been helpful, but I would urge you to change your minds, recall the consultation and leave DLA alone.</p>
EM150	06-Jan-11	<p>Prejudice and ignorance are the main barriers to disabled people leading full and active lives. A lot of progress has been made for physically disabled people, mainly through having to think about access, but people still have negative views about none visual disabilities such as people on the autistic spectrum and speech and language disorders. Employers, like the public only see the difficulties. They fail to appreciate the positives, adherence to routine, will always turn up for work and be on time, those with aspergers are excruciatingly honest. If your vision is that 'work sets you free' (which is an iffy theme to identify the govt. with) then you will have to incentivise every employer to take on and train a disabled person. Without more support these vulnerable people will be living on minimum wage trapped in the poverty you claim to want to end.</p> <p>*The new benefit should still cover the range of disability from severe to mild. Continuing to help the most severe should not be used as an excuse to remove help from the less obviously disabled.</p>

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		<p>*Extra costs are normally incurred through the need for constant supervision, meaning one parent cannot work. Unpredictable behaviour or mobility aides mean own transport is needed necessitating the need for a car. Special diets often cost more. computers may be needed for special education. Cotton only clothing for eczema is expensive, and if your child is already man size clothing is no longer vat free. Adult size 12 shoes with velcro fasteners are almost non existant and cost upwards of £50.00. Trips have to be preplanned and destinations have to be notified of special needs and requirements, these often cost more. The world is designed for right handed able bodied people, any deviation from this norm has a surcharge!</p> <p>*Only two rates will give less flexibility. People are not either severe or mildly disabled, even medicine allows for three levels, mild, moderate and chronic! For families of children with unpredictable behaviour even the lowest rate care component is of benefit, as it can pay for attendance at special clubs where a high adult: child ratio is provided, giving families much needed respite time, this is not insignificant if it is your life.</p> <p>* Yes, some conditions will always require a minimum level of care and support and therefore should qualify automatically, with the level rising dependant on severity. i.e Autism, Neuro Developemental Delay, Cerebral palsy, Downs Syndrome etc.</p> <p>*Activities that are essential to everyday life include; being able to tell the time and relate it to the part of the day it represents. Being able to travel saftely and unaided, to cope with unexpected changes, such as a bus failing to arrive. Being able to go to a shop and cope with the choices and uncertainties you will find within. Understanding money. Being able to prepare food. Remembering to wash and change your clothes each day (to be fair most teenagers struggle with this!) Some severely disabled will never achieve these things no matter how much is spent, however moderately disabled can achieve full and active lives with supported independant living, work place training and or apprenticeships.</p> <p>*Ensure you ask people to describe their worst day. With this as a base line you can extrapolate.</p> <p>*Aides and adaptiones will help people to differing degrees depending on their particular disability. It would therefore be unfair to assume parity for all wheelchair users, as the wheelchair does not make them equally mobile. As people often use their DLA to buy better quality aides to further improve their quality of life the aides should not be taken into account when assessing disability.</p> <p>*To make the claim form easier, avoid the pages of repetition. Make Consultants, Camhs, OT, SALT, GPs, Senco's, or any professional you are likely to meet with regard to disability, obliged to advise you of DLA/ PIP. In the beginning I was involved with all these people but it was another parent who told me of DLA. Write an eligibility guide with case studies as examples</p> <p>*In the case of children, Senco's or class teacher from school, Children with a statement of special educational needs have usually been assessed by Ed psych, speech and language, occupational therapy, Camhs and others during the assessment process, statements are reviewed annually so would be a reliable source of assessment.</p> <p>*For children face to face may not be appropriate. Children with ASD would find meeting a stranger and being asked questions extremely traumatic as they cannot cope with the unknown or change of routine. Other children with impulsiveness and slow processing may not acknowledge any difference to their peers. In these cases confronting them with their disabilities could damage their self esteem and confidence.</p> <p>*Children an adults with fixed or permanent disabilities such as paralysis, downs syndrome, brain damage, autism etc are unlikely to see any major changes in their circumstances so could be reviewed every five years with a questionnaire which could trigger a more in depth review if needed.</p> <p>*People might report changes if they understood the award criteria and were not afraid of losing their support.</p> <p>*People need to know what other benefits and support are linked to DLA/PIP</p>

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		<p>and who to contact. Local support groups and organisations would also be useful.</p> <p>*Claimants may not be able to cope with too much social interaction however well meaning. Support, however necessary or useful would have to be done through a trusted third party.</p> <p>*Yes anything that improves quality of life.</p> <p>*Children don't like to acknowledge their differences/ disabilities. They will say they can do all sorts of things they cannot manage in order to appear the same as their peers. You must tread carefully about confronting them with their disabilities, as this can be damaging to their self esteem.</p> <p>*Just communicate your knowledge about services available. Benefits, their names and entitlements change all the time. It is worth advising people in communications to check their entitlement if their circumstances would seem to fit a criteria.</p> <p>*Your application forms are a nightmare! Disabled people have all sorts of problems, including literacy (as many are failed by the education system) that make form filling very difficult. If PIP is not made a passport benefit many of the least able will just not apply for the related benefits that could make a real difference in their lives. *Maybe information could be used by social services to assess for support (although Kent offer no support anyway), disabled parking badges, Additional education support, Disabled learning grants for higher education, supported living accomodation (more of these facilities are needed), supported work placements, apprenticeships for the disabled.</p> <p>*Changes will affect all groups equally. Disability is blind to culture or race, it is the able bodied who are judgemental.</p> <p>*It is a good aim to want to help those who are in the greatest need with the worst disability. However you should be wary about removing support from the least disabled as this group are likely to achieve a full and active life with the help of a minimal amount of support.</p> <p>*I am responding to the consultation as an individual who is a carer for a disabled teenager.</p>
EM151	07-Jan-11	<p>I would implore the Government not to target the most vulnerable members of society in its efforts to reduce public spending. I can assure you that in modern Britain disabled people have to compete on an unequal basis in all areas of life, and we rely on this benefit to give us some degree of independence. By announcing this review the government has spread fear in this community and it would be cruel not to give some reassurance that the disabled are not being sacrificed to allow Bankers to maintain their inflated standard of living. *</p>
EM152	07-Jan-11	<p>Disability Living Allowance reform Consultation response by the Disability Benefits Consortium January 2011</p> <p>*The Disability Benefits Consortium (DBC) is a national coalition of over 30 charities and other organisations committed to working towards a fair benefits system. Using our combined knowledge, experience and direct contact with disabled individuals and carers, we seek to ensure that Government policy reflects and meets the needs of all disabled people.</p> <p>*Executive summary</p> <p>*The DBC welcomes the opportunity for considered debate on the future of DLA. However, despite the significance of the consultation and its potential impact on disabled people, we are very disappointed that the DWP decided to run such a short – 9 week – consultation period, which was also spread over the Christmas holiday. This is 3 weeks short of the recommended time frame outlined in Government guidance[2] and will significantly reduce opportunities for individuals to add their views to the consultation. The communication needs of many of the disabled people potentially affected by the outcome of the consultation may mean the timeframe prevents adequate and effective engagement of a significant number of the people it will directly affect. It is also disappointing that the Welfare Reform Bill will have been debated in the Commons, and potentially will have reached the Lords, before the consultation period has ended. It will therefore not be possible for the</p>

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		<p>Government to take consultation responses into account as the Bill progresses through the Commons, further reducing the impact and value of the consultation process.*</p> <p>*While the consultation document outlines some positive proposals about simplification of the benefit, reducing bureaucracy and a better understanding of the extra costs faced by disabled people, we seek further clarification on certain aspects of the proposed reforms to DLA. We have significant concerns about the impact the changes will have on disabled people, particularly in the context of the wider reforms to the benefits system and as a result of the announcements made in the June Budget and the October Comprehensive Spending Review. It has been estimated that disabled benefit claimants will lose £9 billion in support over the course of this Parliament[3]. Despite the Government's stated commitment to supporting disabled people to lead independent and active lives, we believe the changes risk having the opposite effect for a significant number of disabled people and their families.*</p> <p>*Disabled people are amongst the most disadvantaged groups in the UK and are twice as likely as other citizens to live in poverty. Nearly a quarter of individuals in families with at least one disabled member live in relative income poverty and over 50% of working age disabled adults are not in paid employment.[4] A third of working age disabled people are estimated to live in poverty – and disabled people's higher living costs are unaccounted for in most tests of poverty, meaning actual poverty levels are likely to be higher.*</p> <p>*Millions of disabled people also rely on financial and other support from the state to help meet their basic social care needs and the extra living costs associated with their impairment. Reductions to, or withdrawal of, DLA is likely to have a devastating impact on disabled people. Although the proposed changes would not take place until 2013/14, the proposals have raised an enormous amount of distress and anxiety among disabled people and their families and carers, many of whom have contacted our respective organisations. In the context of wider benefit reforms, disabled people and their families are becoming increasingly anxious about losing some or all of the benefits they receive and how they will cope as a result. *</p> <p>*The following quotes from a survey on DLA reform being run by the Disability Alliance[5] are typical responses from disabled people and their families:</p> <p>***"My DLA has already been reviewed, however I went through 5 months of extreme anxiety and worry during the review...My health condition is chronic and there is no cure, if my DLA was reviewed again I don't think I would have the will to live anymore...I already struggle to get through the day and night...I would consider either to stop taking my medication or suicide as I cannot cope with anymore of the anxiety and stress such reviews entail."</p> <p>***"I would be in serious trouble."</p> <p>***"It has increased the quality of life for our family and reduced stress and other health problems, significantly saving money for the NHS."</p> <p>***In particular, the DBC's response seeks to highlight the following key issues:</p> <p>*Approach to DLA reform – Consideration of the current assessment and eligibility for DLA are not wrong in principle. However, we do not support the overall objective of a 'reduction target' of 20% as set out in the Budget report in June 2010. Although the Government has stated its commitment to supporting disabled people, we are concerned that the approach being taken is primarily concerned with reducing costs.</p> <p>*Numbers affected – There is a general lack of clarity about the numbers likely to lose or receive a reduced rate of DLA as a result of the proposed changes. However, based on a reduction of 20% 'expenditure and caseload', this will potentially impact 360,000 disabled people across the UK, as well as an, as yet, unquantified number of carers.</p> <p>*Focus on those with 'greatest need' – A focus on those disabled people with the greatest need will exclude many disabled people who still face additional costs associated with their disability or condition. The people accessing the lowest rates of DLA are often unlikely to be able to access support elsewhere and cuts to these groups could lead to unsustainable pressure on social care or NHS budgets. In the context of council budget cuts and the NHS being</p>

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		<p>under considerable pressure, people's needs could remain unmet elsewhere. This is especially relevant given the Government's announced changes to time-limiting contributory ESA and increasing sanctions and conditions on the disabled people who receive this out-of-work benefit.</p> <p>*Mobility component of DLA – We are opposed to the removal of the mobility component of DLA for people living in residential care. This is a regressive step which will deny 80,000 people[6] their independence and limit their participation in community life. This undermines the Government's commitment to promoting social justice for disabled people.</p> <p>*Increase in qualifying period – The Government propose that the new benefit will only be available to people with a long-term health condition or impairment which has lasted for at least six months. This will exclude a large number of people - for example, denying access to people seeking rehabilitation support following accidents – and will prove problematic in relation to some conditions where future need can be difficult to predict.</p> <p>*Concerns with the assessment process – Lessons must be learned from the Work Capability Assessment, which has shown to disadvantage certain conditions, including those with less apparent, 'hidden' disabilities and those with fluctuating needs. The impact of such conditions on day-to-day living can be much harder to effectively determine in a relatively short assessment process.</p> <p>*Impact on children and those over 65 – The DLA reforms set out in the consultation document apply to those claimants of working age. However, it also states that Government are considering whether to apply the new eligibility and assessment criteria to children and adults over 65. We seek clarity about who the reforms will affect.</p> <p>*Impact on carers – We are concerned about the removal or reduction in disabled people's benefits on carers. Families could be doubly affected as DLA is reduced or removed and Carer's Allowance is lost as a result. This could undermine unpaid care by making caring financially untenable for some families. *</p> <p>*Consultation response *</p> <p>*Impact on disabled people</p> <p>*Approach to reform There is no mention in the DLA consultation document of the savings the DWP is seeking to make from reform. The June Budget first announced DLA reform and predicted savings to government of over £1 billion a year by 2014-15. The Minister for Disabled People, Maria Miller MP, has confirmed that the government is "looking at saving 20% of the DLA in line with the Chancellor's commitment in the Emergency Budget"[7] yet the document gives no details as how this reduction is likely to be achieved, and provides no detail on levels of awards for the Personal Independence Payment (PIP). However, based on 'saving 20%', this will potentially impact 360,000 disabled people across the UK. *</p> <p>*The DBC welcome the fact that the consultation document recognises that "disabled people can face additional challenges to leading independent lives and...are committed to maintaining an extra-costs, non-means tested disability benefit to support disabled people". However, it also refers to supporting those disabled people who "face the greatest challenges to remaining independent and living full and active lives". A focus on those disabled people with higher needs will exclude many disabled people – who will still face considerable additional costs as a result of their disability or condition – from participating in society. Meeting lower level need is important in terms of preventative benefits as well as providing essential support. If the Government's aim is to create a "sustainable system" this approach risks allowing unmet needs to develop into crisis situations, which have higher costs to individuals, families and public resource – for example, through reduced work hours or hospitalisation. *</p> <p>*Tightening social care eligibility criteria mean that many disabled people who currently claim DLA receive no support from their local social services department – a situation that is worsening[8]. As a result, many people use their DLA allowance to access care and support. Consideration must be given</p>

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		<p>to the potential impact of a reduction in DLA on already stretched social care budgets. Many people who are not deemed 'disabled enough' will be hit twice, potentially losing both their DLA and not meeting the threshold for social care. It is misleading to suggest, as the document does, that DLA is "part of a wider range of support and services available to disabled people... including in the form of services or direct payments from Local Authorities to meet social care needs". In reality, large numbers of disabled people are not eligible for other services. For these people, DLA is an absolute lifeline. *</p> <p>*The Disability Alliance survey[9] on the Government plans to reform DLA has received the following statements from disabled people and their families expressing this sentiment in everyday terms:*</p> <p>**"It has contributed to my staying alive."</p> <p>**"Claiming DLA has given me back a little self-respect and self-worth."</p> <p>**"DLA lets me live an independent life.. I still can't afford most things.. but my life is still better with it.. than it would be without it... my mobility car gets me out .. which I would never do if I didn't have it.. it gives me choice.. please don't take that away from me."</p> <p>**"To restrict access to a benefit...will exclude and marginalise disabled people, reinforce negative stereotypes and incur significant costs when dealing with legal challenges not to mention the costs to the NHS and other public bodies....withdrawing support makes people who are already ill worse and so they cost the NHS more... these proposals will not save the tax payer money though they may save on the DWP's budget and they will cause real physical and emotional harm to those who are forced through the re-assessment process and could prove lethal to those who fail to make it through....vulnerable people will die because of this especially coming at a time of other welfare reforms and cuts".*</p> <p>*"The Way Ahead' (which led to the legislation which introduced DLA in 1990) focused specifically on people with additional costs, but lower needs who were unable to access alternative support. DLA was intended to benefit many of the people we now fear could lose access through restricted eligibility.*</p> <p>*Purpose of DLA We believe there needs to be a careful consideration of the original purpose of DLA and a more thorough understanding as to how it supports a range of disabled people. It has been described by the Department for Work and Pensions as providing: "a financial contribution towards the generality of extra costs experienced by... disabled people as a direct result of their disabilities... [DLA was] introduced as a policy response to the evidence that disabled people and their families suffered greater disadvantage and poverty than their non-disabled peers and preceded the opening up of the disability rights framework, including the introduction of measures to tackle discrimination against disabled people."[10] *</p> <p>*DLA is described by the Department as an "extra costs" benefit: it is paid not on the basis of a medical diagnosis, but to compensate disabled people for the extra costs incurred by the effect their condition has on their ability to get around or look after themselves. The consultation, however, offers little detail about how the new PIP will help ascertain or meet disabled people's higher costs of living. *</p> <p>*DLA also recognises the additional costs incurred by families with disabled children, and by disabled parents (as a consequence of the combination of both their disability and their parental responsibilities). It is vital that the Government ensure that any changes to DLA are not based on meeting arbitrary targets, but on better supporting disabled people and their families to overcome the additional costs and barriers that can drive them into poverty.*</p> <p>*The assessment</p> <p>*Focus of new assessment We welcome the focus of the new PIP on participation and the impact an individual's impairment or health condition has on their daily life. We also welcome the newly named 'daily living' component to replace the existing care component of DLA – however, we are very concerned that the new 'daily living' component will only have two rates of payments. *</p> <p>*It will be essential that any new assessment reflects the broad range of</p>

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		<p>'everyday activities' that an individual needs to undertake in order to fully participate in society. The DBC is very concerned that the assessment be made robust enough to reflect the wide range of disabilities and conditions or whether the 'impact on everyday life' proxy (as opposed to 'care' and 'support' used in DLA) will effectively measure the multi-dimensional drivers that impact on the costs that disabled people incur. It is difficult to imagine how an assessment looking at 'everyday activities' such as "planning and making a journey" and "communicating with others" will take into account some of the ways in which DLA is currently spent – for example, to help with increased electricity bills associated with doing laundry more often or for more expensive specialist clothing. *</p> <p>*Learning from the WCA Given the proposed introduction of an 'objective assessment' for PIP, there is clearly much to be learnt from the development of the Work Capability Assessment (WCA) which the recent independent review[11] has concluded is "not working as well as it should". In particular, the review notes that some conditions are more difficult to assess than others – for example, mental health and other fluctuating conditions. The review states that some of the descriptors used in the assessment may not adequately reflect the full impact of that condition on individuals. In addition, many of our organisations have expressed concerns about the limited knowledge of some healthcare professionals – another issue which was acknowledged in the independent review. Clearly, it will be essential that all independent health care professionals have the skills and awareness about a range of disabilities and conditions in order to make accurate assessments. *</p> <p>*We are also concerned that, at a time of considerable national belt-tightening, the Government is proposing to re-assess all current working age DLA recipients (as well as possibly all children and people over 65). The costs of introducing and implementing a new assessment (which will include regular reviews for all claimants) as well as appeals under the new process may outweigh savings and we seek clarity on the budget being provided for this purpose. The WCA has seen an increasingly high appeals rate – and many appeals are successful. To adopt a similar model for reassessing DLA claimants may further undermine the Tribunals' Service's ability to meet demand. *</p> <p>*The DBC is aware that, under the current DLA system, individuals and the DWP can initiate a review of a DLA award – including by a DWP-appointed Medical Examiner. We are keen to explore why the potentially more affordable option available within the existing system has not been fully considered, with the consultation document misleadingly stating that 'there is no process to check that awards remain correct'. Since 2000 a change in the DLA legislation has made all awards subject to review after appropriate periods of time (based on the individuals' circumstances). *</p> <p>*Medical or social model We welcome the increased focus on 'use of evidence' as part of the assessment process in order to consider thoroughly the impact of an individual's disability on their day-to-day life. However, while there is a commitment to the social model of disability, the Budget referred to an "objective medical assessment" for DLA. The policy costings document for the June Budget published by the Treasury states that: "This measure will introduce an objective medical assessment and revised eligibility criteria for both new and existing working-age claims for Disability Living Allowance, to be rolled out from 2013/14. The assessment will follow a similar process to the Work Capability Assessment (WCA) used for claims to Employment and Support Allowance"[12]. *</p> <p>*Maria Miller MP has since stated there is "no intention to introduce a medical assessment for DLA" and the consultation document itself refers to an objective assessment of individual need. However, as noted above, the involvement of a "face-to-face meeting with an independent healthcare professional" appears to be very similar to the WCA. Given the current problems with the assessment and surrounding processes, this is causing increased anxiety to many disabled people and has associated cost implications for Government. *</p>

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		<p>*It should be noted that DLA is already said to be a benefit which is based on a social model of understanding – that is, that disability is rooted in social and environmental factors which renders a person's condition or disability 'disabling'. From this perspective, DLA recognises that it is these factors which drive a person's disability costs – not just their impairment or condition. It will be a challenge to establish an assessment which looks at both the functional impact of a person's disability, as well as one that takes into account the social and environmental factors impacting on an individual's day-to-day costs.[13] *</p> <p>*We understand why the Government would want to take any relevant new legislation into account when considering someone's disability within the social model and welcome the implicit commitment to continue improving the lives of disabled people through legislation. However, we would urge caution when it comes to assessing to what extent such legislation has actually impacted on the individual concerned and would oppose any move to introduce standardised assumptions regarding the extent of beneficial outcomes.*</p> <p>*Taking more aids and adaptations into account</p> <p>*We are concerned by the proposal that the PIP assessment will take into account more aids and adaptations. For example under PIP, the individual's ability to get about in a wheelchair will be considered, rather than ignoring it as under the current DLA process. This could then affect their eligibility for PIP, yet it is based on the incorrect assumption that using a wheelchair will mean all physical barriers and resultant additional expenses are overcome. Another potential example could be aids for people with sensory impairments such as long canes and hearing aids. These are just one part of successful mobility and communication for people with single and dual sensory impairments; they work in conjunction, for example, with any human support or transport. Therefore these individuals have an ongoing additional cost related to disability, despite successfully using aids and adaptations. Additionally, taking more aids and adaptations into account must not create a perverse incentive whereby individuals do not take up aids and adaptations for fear this could jeopardise their entitlement to PIP.*</p> <p>*Eligibility, automatic entitlements and reviewing awards</p> <p>*Increase to qualifying period The consultation document states that "to ensure that support goes to those with the greatest need, Personal Independence Payment will only be available to those with a long-term health condition or impairment." We are concerned about the extension of the 'qualifying period' from 3 months to 6 months, alongside the continued expectation that an individual will be required to continue to satisfy the entitlement conditions for at least a further 6 months. For claimants who are not terminally ill, this effectively doubles the qualifying period before a claim can be made. We do not believe it is right to make people wait for 6 months before they can access the support they need. For people with sudden onset conditions, their needs and the debilitating effects of treatment are immediate, as are their additional costs. In addition, the 'prospective test' will continue to be particularly problematic for certain groups of claimants – e.g. people with cancer and people with fluctuating conditions where predicting future need can be very difficult.</p> <p>*Focus on those with greatest need As already noted above, we are concerned about the focus on those with the greatest level of need and what this will mean for people who currently receive lower rates of DLA. In addition, we are not convinced that there is necessarily always a direct correlation between those with the "greatest need" and those with a long-term health condition or impairment. Elsewhere in the consultation document those with the "greatest need" are described as those "who face the greatest challenges to remaining independent and leading full and active lives". The DBC seeks clarity about what exactly is meant by 'greatest need' and how this relates to additional disability related costs. As a recent Demos report [14] suggests, the additional costs of disability are hugely wide ranging and therefore difficult to quantify. As is noted in this report, there is a difference between those</p>

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		<p>identified as having the greatest health and care needs (in terms of the 'functional impact' of their disability on their life) and those with the most prohibitive disability costs.*</p> <p>*Automatic entitlements and periodic review The consultation document also outlines the Government's intention to move away from a system that awards automatic entitlement for certain conditions. It is important to highlight that all DLA awards since January 2000 have been subject to reviews after appropriate periods. Similarly, the Government intends to introduce a new periodic review of all Personal Independence Payment awards. These proposals are based on the understanding that the impact of an impairment or health condition may change over time. The DBC acknowledges that for many disabled people this may be the case. However, for many disabled people it will not be. Someone who has lifelong or long-term condition or disability – for example, someone with a learning disability or someone who is deafblind – may continue to have the same support needs throughout their life. The extra costs associated with their disability will not change. From this perspective, the existing automatic entitlements to higher rate DLA are an efficient and effective way to allocate resources. It will not be cost effective for the Government to make people go through an assessment process (and potentially repeated assessments / reviews) where there is clear entitlement to the benefit. This will not only incur significant costs to the state but will be highly stressful and potentially counterproductive for the individual, potentially worsening their condition where it is exacerbated by stress and exertion. *</p> <p>*Reporting changes in circumstance For people with fluctuating conditions, there are real challenges for the review process and, in particular, the increased obligations on the individual to report changes in circumstance. We are very concerned about the proposal to introduce penalties for those who fail to report changes in circumstance. For those people with unpredictable and fluctuating conditions such as MS and HIV, asking them to report every change in their condition would be extremely onerous and stressful. Rather than introducing penalties, the Government should issue clear guidance about what represents changes in circumstance that claimants would be required to report and make it as easy as possible for them to do so. There should also be clear information about what reporting a change in circumstance could mean for the claimant. *</p> <p>*Linking to support The consultation paper states that the Government wants the new PIP to be a "more active and enabling benefit" by using the administration of the benefit to enable people to access advice and support that could help them improve their situation. While we welcome a more joined-up approach that provides disabled people with greater access to appropriate support, we are very concerned by the indication that accessing services and support could become a condition of receiving the benefit. Non-compliance with such a requirement is likely to be very subjective and highly dependent on the availability and quality of local services. Situations could arise where disabled people are forced to accept support that might not be appropriate for their needs out of fear of losing their benefits.*</p> <p>*DLA mobility for people in residential care</p> <p>*We welcome the Government's commitment to promoting social justice for disabled people and the focus that has been given to increasing independence, participation and opportunities for employment. However, we are gravely concerned that the removal of the mobility component of DLA for those living in residential care will undermine the realisation of these ambitions and will greatly reduce the independence and autonomy of this group of individuals. *</p> <p>*The mobility component of DLA helps people to pay for things like accessible transport, or mobility aids such as an electric wheelchair. It makes a vital difference in ensuring that people can leave their home independently and participate in everyday activities that non-disabled people take for granted, such as meeting friends, attending a leisure centre or getting to college. In some care homes there are schemes where people's DLA mobility allowance is pooled and used to buy or lease a car which care staff can then use to take</p>

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		<p>them out into the community.*</p> <p>*The assumption behind the proposal to remove the mobility component of DLA from those living in residential care is wrong. It is based on the misunderstanding that people living in residential care situations have all of their needs provided for by the package of support purchased by the Local Authority (in a similar way to hospital patients) and is therefore a case of “double funding”. This assumption is incorrect. The reality is that an individual’s package of support does not provide for ALL aspects of an individual’s life – it only funds basic care. As a result, removing the mobility component of DLA will significantly impede the ability of those in residential care to play an active role in their local community, be independent and maintain relationships with family and friends. *</p> <p>*The DBC urges Government to better analyse the impact of this proposal, to understand the potential harmful outcome and to focus cuts elsewhere.*</p> <p>*Passport to other support *The consultation document acknowledges that entitlement to DLA also ‘passports’ the recipients to additional help and support. DLA can link to qualification for other means-tested benefits, as well as services and concessions. We believe it is essential that these links are protected. As noted above, uncertainty about who will be found eligible for PIP under the new assessment highlight the potential knock on effects of the proposed changes, which are a serious concern and could potentially exacerbate the effect of the loss of benefit.*</p> <p>██████</p>
EM153	08-Jan-11	<p>I am writing to urge you to recall the Public Consultation on 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. In this letter I will begin by discussing the problem with your case for reform, and then address the consequences of reform.*</p> <p>*First, the case for reform. The reasons given for DLA reform are not robust, with little evidence to support the case for reform and, importantly, no independent academic research. My use of the word ‘little’ in this context refers to the two pieces of internal DWP papers used as evidence to build the entire case for reform – a footnote for one reference appears twice on consecutive pages. Thus the case for reform falls apart upon even cursory examination.*</p> <p>*The wildest claim to support reform is that ‘evidence suggests that DLA can also act as a barrier to work’. This passage is footnoted, referring to “DLA and work: Exploratory research and evidence review, 2010, DWP Research Report No. 648” (RR No.648). This report also finds that “the main factor affecting the employment rates of disabled people is their disability or health condition” and that “a larger than average proportion of DLA recipients also appears to be affected by the specific types of impairment that carry the greatest employment disadvantage for disabled people” – yet these findings are not reported in the consultation paper, thus skewing discussion.*</p> <p>*In fact, though the report claims that there exists a “perception of disability permanently precluding work is prevalent among individuals with disabilities not already in employment”, there is no evidence cited in the report that suggests DLA could be a barrier to work. The section and all references to it in the consultation paper could be interpreted as an attempt to misdirect, and should be removed forthwith. Further, it should be noted that the consultation commits the statistical crime of confusing correlation with causation. Whilst RR No. 648 does provide evidence that low employment is correlated with claiming of DLA, this in no way implies that one causes the other.*</p> <p>*It could be suggested that the lack of evidence pointing to a need for reform has meant that misdirection was used in an attempt to convince the public that DLA reform is necessary. In particular, the graphs presented as Figure 1 and 2, on page 8 of the consultation paper, used to show the DLA caseload increasing at an alarming rate, are flawed in many ways, not least in the fact that no baseline is established for when take-up of DLA by people with</p>

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		<p>disabilities plateaued after its introduction in 1992/93. There are further issues regarding the number of Pensioners as the report ignores demographic trends to show that there is a dramatic increase in claims by people over State Pension age. This is particularly questionable since a Pensioners' eligibility for DLA would usually depend on their receipt of DLA prior to this – otherwise, they would be eligible for Attendance Allowance, as I am certain you are aware.*</p> <p>*Figure 2 is also misleading as it could be read carelessly as showing that 8% of the population claim DLA. I am loath to interpret this as intentional misdirection but it is, at the very least, a sloppy drawing of graphs. Another example of sloppiness is the first sentence of paragraph 15 of the first chapter, on page 7 of the consultation paper, reading "In just eight years, the numbers receiving DLA has increased by 30 per cent." This sentence is utterly meaningless and a misuse of statistics although, once again, I do not wish to interpret this negatively. Yet another example of the spurious use of statistics is Table 1 on Page 9 which presents the "Distribution of current caseload by rate combination". This table appears between two paragraphs – 16 and 17 – arguing that the current system is too complex and the benefit is not understood. This is an odd, and potentially misleading, place for this data to be displayed.*</p> <p>*Beyond misuse of statistics, sloppy presentation of data and lack of evidence, there are further points to be queried. Whilst RR No. 648 does give evidence that DLA is complex and not understood by all claimants, as suggested in paragraph 19 on page 10, this is surely grounds for improving the current system rather than expensively replacing it with an entirely new one. Likewise the assertion, in paragraph 18 of page 9, that there is no system to check that rewards remain correct. The statement that "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" is a rhetorical tautology. Indefinite awards are given to claimants with conditions that will not improve. Whilst it is not unreasonable that medical advances in the treatment of a certain condition should prompt re-evaluation of those cases, this could be achieved by augmenting DLA rather than replacing it.*</p> <p>*The core argument of the consultation paper is that DLA is a benefit not fit for purpose. Paragraph 9 on page 6 of the consultation paper states that: "DLA is a benefit that provides a cash contribution towards the extra costs of needs arising from an impairment or health condition." The arguments presented in paragraphs 14 and 15 of page 8, claiming that the benefit is not fit for purpose, do not touch upon the original purpose of DLA or offer any argument as to why it is failing to meet its original purpose. The information presented is that the DLA caseload and expenditure is a "lot more than was originally expected" and the aforementioned misuse of statistics on the increase in DLA claims. No arguments are presented as to why this means that DLA is not fit for purpose. The only way an argument can be construed is to look at the issue with a preconceived idea that there is an acceptable level of DLA claims prior to evaluating the health and impairment of claimants.*</p> <p>*Finally, paragraph 2 betrays this preconception by stating: "We believe that now is the right time to reform DLA", yet offers no qualification or reasoning for this belief. Paragraph 3 continues by saying that: "We must ensure that our resources are focused on those with the greatest need", with no qualification or definition of the term "greatest need". This could be pointed to as a suggestion that those with "lesser needs" will have to struggle unsupported with their impairment, and that the definition of needs is at the whim of the Secretary of State for Work and Pensions.*</p> <p>*The arguments above demolish the case for reform presented in the consultation paper, dealing with each point made in the consultation paper. I will now address the second part of the consultation paper, explaining why the reforms intended by the DWP will be harmful to disabled people.*</p> <p>*Para 4 of Page 11 begins by stating that: "Central to PIP will be a new, fairer, objective assessment, which will allow us to identify those who face the</p>

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		<p>greatest need, in a more consistent and transparent manner.” The previous section of the paper does not suggest that the current DLA assessment is unfair or that it is not objective, and neither is there evidence that it is inconsistent or lacking in transparency. The current system is assessment by a variety of resources; information from a carer or support worker, the person’s GP, specialist consultant or physiotherapist. Trying to slim down this evidence base to on homogeneous assessment will mean that the impact of disability on the individual is ignored. This is definitely not objective. Para 4 also states that: “We are developing the new assessment in collaboration with a group of independent specialists in health, social care and disability, including disabled people.” What ‘independent’ means is that a private company such as Atos will be contracted to run assessments. This will include meeting with an ‘independent’ healthcare professional – not necessarily qualified as doctors - working for the assessors. The objections to a private company using unqualified staff who know their jobs depend on keeping to strict targets aimed to reduce numbers qualifying for a particular benefit are too many to list.*</p> <p>*Para 12 on page 13 of the consultation paper suggests that: “The criteria on which DLA is currently based, on care and mobility needs, are subjective and unclear.” It could be argued that this statement is subjective and unclear as there is no qualification of the statement, and no evidence is offered in support. As suggested in the previous paragraph, the lack of a formalized set of criteria for DLA awards is due to the varying impact of disability, meaning that such a ‘tick-box’ test would not be objective either. The following paragraph in the paper suggests that ‘care’ and ‘mobility’ may not be the best proxies for the additional costs faced by disabled people. The paragraphs also state that “there is currently conflicting evidence on the factors that affect the extra costs that disabled people face in the 21st Century”. The very fact that the only two DWP research reports cited to support offer conflicting evidence raises questions about the DWP’s choice to accept one piece of evidence above the other.*</p> <p>*Para 14 of page 13 offers the example: “‘mobility’ as currently defined concentrates on an individual’s ability to walk, not their ability to get around more generally.” It is true, generally, that people with disabilities are more mobile as aids and access have improved. However, this additional mobility has come with extra financial costs, such as new mobility aids, adapted vehicles, taxis. Moreover, it is crucial to remember that additional mobility does not mean universal mobility. Paragraph 15 of page 13 suggests an intention to refocus the Personal Independence Payment (PIP) at those most impaired in their ability to carry out a range of activities, because: “There is some evidence to suggest that individuals whose impairments have the greatest impact are likely to experience higher costs.” This statement is bizarre, as this is exactly what DLA does. Paragraph 16 on page 14 discusses splitting PIP into a ‘mobility’ component and a ‘daily living’ component, with two rates for each component. This suggests that the change from DLA will be a vastly expensive rebranding exercise, as modifying DLA could achieve this.*</p> <p>*Para 17 and 18 on page 14 argue that “The individual must have a long-term disability” in order to claim PIP, so that “an individual’s health condition or impairment must be expected to last a minimum of 12 months”. This will punish those who suffer debilitating short- and medium-term illnesses, but eventually recover their mobility and ability to care for themselves. Whilst people are ill over the short- or medium-term, they will have mobility and/or care needs and face the same extra costs as those with long-term conditions. They may even have to purchase mobility or care aids for their temporary conditions. Yet this consultation paper seems to ignore their needs. Long-term conditions are also targeted as paragraph 19 on page 15 suggests the end of automatic entitlement for certain conditions. The example of renal dialysis automatically entitling on to the medium-rate care component of DLA is given, and it is argued that: “As a result, eligibility for DLA is sometimes based on medical condition rather than the impact of that condition, meaning</p>

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		<p>that support is not always appropriately targeted.” The meaning of this sentence and argument is completely opaque, unless it is to suggest that one should be denied support because they are too ill to use it; a thoroughly distasteful argument which I refuse to believe that the DWP countenanced.*</p> <p>*Para 20 on page 15 of the paper confirms that PIP will continue to apply the same presence and residence criteria as DLA, but may consider a habitual residence test. This will impact on workers not born in this country who develop a disability. This seems extremely harsh as, although it will make PIP consistent with other benefits, whatever one’s attitude to immigration, I cannot believe that anyone would argue that a foreign-born individual living in this country should be denied support if unfortunate enough to become disabled.*</p> <p>*Para 21 of page 15 argues for the full removal of PIP from individuals in “hospitals or similar institutions or care homes”. As care homes take income and savings into account, this will mean that care home residents no longer have any independent income to pay for short journeys or other ways of retaining independence, and become entirely institutionalized.*</p> <p>*Para 24 on page 16 states that: “We remain committed to the social model of disability. The new assessment will not be based solely on the medical model of disability and focused entirely on an individual’s impairment, but will instead focus on the ability of an individual to carry out a range of key activities necessary for everyday life. “ The meaning of this statement is unclear. Para 26 adds little clarification, stating: “Activities we assess could include, for example, planning and making a journey, and understanding and communicating with others. The extent to which an individual could carry out these activities would determine their eligibility for Personal Independence Payment and the level of their award.” As I have argued above, such a tick-box approach to the impact of disability is counter-productive and not objective. A person able to complete the activities in your example may still need the same type of support as another who cannot.*</p> <p>*Paras 27 and 28 state that PIP will “take greater account of the successful use of aids and adaptations as part of the Personal Independence Payment assessment”. This means that successful use of aids – including wheelchairs – could mean that claimants are not eligible or eligible for a lower rate of PIP. This is a ridiculous suggestion. For example Tanni Grey-Thompson – one of the most successful athletes of all time – is a 6 times winner of the London marathon. She is obviously ‘successful’ in her navigation of London streets. Yet she will face the additional costs of her mobility needs just like any other person with a disability. The general truth is that successful use of an aid does not negate additional mobility costs.*</p> <p>*There are other minor points that I could raise, and will do so if you proceed with the Public Consultation. For now I will turn to my conclusions.*</p> <p>*The point that most angers me is the focus on DLA as a disincentive to work, which is both false and disingenuous. People who receive DLA do often have lower work expectations as the reform consultation paper suggests, and rightly so as many conditions and impairments make work impossible. Disabled people are often unable to compete equally in the labour market, because of ignorance and fear amongst employers and a lack of willingness to consider making adjustments that may well be relatively cheap and straightforward but are perceived as too onerous. People with high rate awards have the highest levels of impairment and are most likely to be unable to work, regardless of benefits. Those who do work are often only able to do so because of the aids, support or adaptations that DLA or Access to Work allows them to purchase. The focus on moving to work has no place in discussion about DLA other than to make the important clarification that DLA is not work related, and exists to assist with the additional cost incurred when living with an impairment or long-term health condition.*</p> <p>*Other problems include the fact that the PIP proposals will see some current recipients of social care losing financial benefits now paid at least in part to the local authorities for receipt of that care. This will force the LAs to make up the shortfall in funding or, more likely, cut care packages. Another aberration in the recommendations made is the impact of these plans on independent</p>

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		<p>living, making that harder to deliver. Removing DLA from those who receive care packages, and especially those in residential care, will not promote independence. Lastly, some people may lose money as the aids and adaptations they use to enable them to live with their impairment or long term health condition will be seen as negating the need for that financial support, ignoring the fact that the DLA Mobility Component may be the only way of paying for adaptations such as wheelchairs or taxis.*</p> <p>*Although the caseload may be cut, PIP will still look very much like DLA. The current system allows for automatic entitlement to DLA for certain conditions. The new system will not allow for this, and will re-asses all claimants every few years. This is not only foolish but also costly as automatically entitled conditions are by nature the most severe and incurable. The only things achieved are the extra cost of unnecessary assessment, and hardship for severely ill people. Further waste comes from ignoring the fact that, unfortunately, people will remain disabled and have impairment-related support needs even if they no longer meet the new thresholds under PIP. They will be ignored up to the point they become seriously ill and end up costing the NHS and local authorities more in terms of hospitals and residential care. Further, the proposed reforms don't take into account the reality that some conditions are severe but acute. Not supporting people with acute illness and disability makes it more likely that this will become a costly long-term problem therefore increasing dependency.*</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 ESA, IB, and DLA 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 IB 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>
EM154	08-Jan-11	<p>I would like to give my comments on the DLA proposed changes. The changes seem very harsh to those who need them most. The mobility allowance is an essential part of the system and simply allows the needy to get around. I strongly oppose all the changes and disagree with the suggestions. the system seems to work well. This seems like a cost cutting exercise hitting people who need the money most. I would like to register very strong objection.*</p>
EM155	08-Jan-11	<p>I have carefully read your document no where does it state about those in work claiming full dla for care and mobility which I do with the help of dla I do work but only because I can pay for a car and adaptions to get me to and from work and pay someone to do all my household and care which I cannot do. I have found a job which suits my needs only part time but I agree that to work benifits anyone with a disability because you feel you are making a contribution instead of living of other people.*</p> <p>*What I am concerned about is that if people who work and use adaptions to be able to do so are penalised for this in not being given awards they would not be able to afford to work and would then become a drain on the state.*</p> <p>*At present because of DLA and my wages I do not claim anything else but if I was not in receipt of it I could not afford to get to work or pay for the care which enables me to have the energy to work and pay for the equipment which I need and would therefore not be in a position to work. I am really concerned about this as is a number of people I work with because where I work in a police control room employs quite a number of disabled persons of varying needs but all of them could not work with out some form of dla *</p>
EM156	08-Jan-11	<p>I believe the current disability living allowance works very well for the vast majority of those people who receive it and gives the authorities every chance</p>

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		<p>to weed out abusers. In other words there is NO NEED FOR CHANGE. The biggest problem with the proposed change is that it puts thousands of disabled people under massive stress while they wait to see if their much needed allowance is withdrawn. You may say that all those who need it will still get it under the new rules, but that does not take away the worry for thousands of disabled people sitting at home waiting for that dreadful review. There are already significant rumours that the government are to use private consultants, who are not doctors, who are paid to fail people; i.e. the more they fail the more the consultant gets paid. This only adds to the worry even of the most disabled and the government has said nothing to alleviate this fear.</p> <p>*We hear today that the proposed legislation is illegal, though we doubt that will make any difference. The government just wants to be seen to be doing something, even if it is wrong. Governments do many unlawful things so why should this one stop them distressing thousands of disabled people?</p> <p>*It would be better to continue the current system and chase down those cheats, NOT to label every disabled person as wrong doers. As you well know almost all DLA claimants are upstanding and honest people who would no more cheat from the country than for their own family. No doubt a few cheats have crept in but the authorities are adept at sorting those out and prosecuting them. There is no need for change.</p> <p>*The change costs will be enormous, when we can least afford them. better to crack down on cheat but alleviate the distress to good honest people. Don't waste out money fixing something that is not broken. Please cancel this review now and get on with saving the country*</p>
EM157	08-Jan-11	<p>we are worried sick about the proposed changes. After working two or three jobs all my life and paying my ni and tax since the age of 15 I became ill and permanently disabled. means testing is an evil thing to those of us who have tried to pay our way and contribute to society. what little we have will now be counted against us.*have ministers any idea what the additional costs are of having to pay others to do when you become unable to carry out these for yourself? no means test for the old and disabled! The conservatives are supposed to look after the likes of us not penalize us. What sort of society is it that comes down on the old and sick! I ask you? RM*</p>
EM158	08-Jan-11	<p>There are much needed reforms that are needed that could be beneficial to both the claimant and the government department that would save tax payers money in the longer term. After I lost my health in 2000, I endured 2 years of trying get the assistance that was needed and spending excessive money to visit the GP to obtain a medical certificate.*</p> <p>*As such, the whole process needs to be reassessed based on the following issues;</p> <ul style="list-style-type: none"> *medical condition, *medication being used, *side effects, *if side effects impacts using vehicles, *locality of where the person resides *access to public transport if driving is banned due to medication <p>*All these factors restrict people in obtaining employment if they are unable to drive and live in rural areas.*</p> <p>*DLA allows access to using taxi services to the nearest town to attend the GP, obtain prescriptions, affordable shopping and local council offices and social interaction.*</p> <p>*Taking away DLA would place people in rural areas at risk from independent living as they would then be unable to get to the local town or shops to survive and would be financially a burden on attending medical appointments etc.*</p> <p>*Therefore, assessment has to be based on what medication is being consumed and side effects so that people are not penalised and placed further in poverty because they are unable to cover the daily needs of personal care and help that DLA helps people with.*</p> <p>*I would also simplify the claiming process, as having a department for DLA,</p>

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		<p>department of Incapacity and a department for Income Support means 3 departments that in reality could be processed within a single department.*</p> <p>*The computer systems are all the same and having worked for the Ministry of Defence know that a computer program can be designed to identify ailments, rural location, medication and level of disability that impacts peoples daily living standards.*</p> <p>*Welfare Reform is essential as I see too many people when I visit the GP that manage to live in the Pubs, betting offices, draw substantial sums of money from the cash point machines and then spend on a weeks supply of cigarettes, alcohol and lottery tickets and then treat 4-6 people in the cafe to a full english breakfast.*</p> <p>*I would welcome reform to include food vouchers and utility bill credits where the company that provides utilities is paid directly by the DWP to ensure all those on benefits have utility bills paid.*</p> <p>*Food vouchers would ensure the 5 - a - day rule would encourage healthy eating, but also would include dairy, meat and fish products so that a balanced diet is made available and people take account for their own health by removing the cash element to providing the food products to enhance peoples eating standards.*</p> <p>*The biggest issue with ill health is attending appointments in London, Cambridge and my GP each month as they take a financial burden on my income support and my DLA which is used to cover my transport ticket plus that of someone else to come with me to help me from taking away being around unfamiliar areas and strange situations.*</p> <p>*This burden restricts long term issues as in the winter months I have to choose between heating or attending medical appointments. Which usually means I cancel my hospital appointments as I need to have my heating on.*</p> <p>*I am not against the reform principle, just a simple claim process based on condition, medicine being taken, and side effects that restrict daily routines or holding down a job due to side effects.*</p> <p>*Many thanks for your time* *</p>
EM159	08-Jan-11	<p>Please don't mess with DLA. You seem to be spending a lot of time and energy reforming a benefit but only partially and I can't really say an advantages for people. What you don't seem to realise is that the very act of reform puts a lot of stress and anxiety on people as they wait to see if they are affected. Furthermore, a new system will need a new assessment, new forms, and staff to do the work. This will both be costly and time consuming. And worse still, it will put pressure on the very people it is meant to support. Finally, taking away the mobility component for people living in residential care, who have a measly Residential Care Allowance and whose support funding will be squeezed elsewhere by local government cuts, is just vindictive. Please leave it all as it is. The system works and is fair.*</p>
EM160	08-Jan-11	<p>The proposed reform of the Disability Living Allowance has me greatly concerned. I am 38 years old and have been disabled since birth. I am registered disabled with the government and currently claim DLA. So I am very worried that I have to be reassessed when all the information has already been gathered and is in the benefit system.*</p> <p>*I use my care component to pay for my 24 hour live in care and the mobility component for my Motability vehicle. I am extremely concerned that these payments will stop during the reassessment period. If this happens, how will I pay for my care? What will the Government do to assist. I have already raised these concerns with my Social Services team and due to cutbacks in Social Service bufget due to the Government, there is no more money to meet changing needs.*</p> <p>*I have read the DLA Reform Document and the below question is interesting:*</p> <p>*16. How do disabled people currently fund their aids and adaptations? Should there be an option to use Personal Independence Payment to meet a one-off cost?*</p> <p>*I currently work in full time employment and my disability is deteriorating. As</p>

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		<p>a result my social care team have deemed that my bathroom no longer meets my care requirements and is dangerous to me and my carers to use the shower. I need to have a wetroom installed. However, I have been assessed by the Care and Repair team as not qualifying for a grant because I work. How I pay for the adaptations is yet to be seen as I am now applying through Social Services. However, I do not have £6,000 for the adaptations and as I work I am being penalised. *</p> <p>*My reason for stating this is because, even if the new allowance could be used for adaptations:*</p> <p>*Would I qualify because I work?</p> <p>*Would the new allowance cover my care costs that I use the DLA for and the adaption costs?</p> <p>*I hope that my views are helpful in the consultaion. *</p>
EM161	08-Jan-11	<p>Firstly i am an individual not an organisation, and i am severally disabled. *I have never felt the need to respond to what Government intend to do before now, but i feel so outraged that you intend to subject such vulnerable people like myself to yet more re-assessments that i feel i must respond.</p> <p>*I have no left leg, my right leg is held together by internal rods and has degenerative blood-flow problems, my right arm's circulation has been permanently damaged by strong drugs to keep me alive, i take daily medication to ward off infection, and following thorough and in depth assessments was awarded DLA indefinitely. My condition has not changed and will never change i only face getting worse over time - it is a medical certainty that permanently disabled people like myself will not improve, and it is outrageous to suggest that we must be subject to yet more assessments.</p> <p>*DLA financial support for me, and many people like me, is the difference between choosing and being able to live or choosing to die - it is that important.</p> <p>*Those who are severally disabled and whose condition will never change continually need this support and should not be made subject to re-assessments - this is just plain wrong.</p> <p>*A society will always be measured by how it looks after its vulnerable members, and shame on those who are contemplating such measures. *</p>
EM162	08-Jan-11	<p>i receive the allownce becouse i am a genuin person i also have a car as well what im saying it is what cameron is doing is discusting disability is not an out of work benefit so why target the disability what they should be doing is targeting the benefit cheats not genuin people im disabled if you change that benefit what hapens to my car that is on disability i cant walk very far and wish i could go to work i have unexpected falls i cant count the amount of times ive banged my head through falling over i would give anything to be a normal person ive got arthritis in my back and it is creeping up my back spine my wife cares for me she 24 7 she never get any rest becouse she is always tired and why phase out care allownce that is going a bit to far he dosent no when to stop but one thing is for sure i will make sure he dosent get in in the next election you should try living my day to day life its not very nice i cant get about i am under the mental helth act when im depressed i do things to my self and cameron is making me depressed i cry averyday becouse of my disability i wish i wasent like it but thats how it is</p> <p>*anyway thats all best regards from [REDACTED] *</p>
EM163	08-Jan-11	<p>I am writing in connection with your plans to change DLA and replace it with the Personal Independence Payment. I am writing as a parent of a child with autism who is in receipt of DLA. The amount of money we receive helps enormously to support our son and offer opportunities that may otherwise be denied him. The money we receive on his behalf provides him with services that improve the quality of his life and his participation in our lives as a family. I would therefore strongly urge you to consider not replacing child DLA, and potentially removing the support disabled children need to help and encourage them to become self sufficient adults.*</p> <p>*I am pleased that that PIP will continue to be payable to people whether they</p>

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		<p>are employed or not, and the fact that it remains non-means tested. However, I would urge you to consider the anxiety and stress that autistic people often face on a daily basis when you make your proposals for application and re-assessment of the PIP, and be aware that the frequency or intensity of this will add extra burdens on these people. When examining the mobility component of the PIP, please be aware of factors such as being physically able to get on a bus does not mean an autistic person is actually capable of carrying out such a journey alone. There are many examples such as this that I am sure you are aware are causing concern to disabled people, and parents of disabled children, in this country. I am sure you have planned your consultation process in such a way that takes into account the views of people actually experienced and involved in the lives of disabled people, and I thank you for listening to us all.*</p>
EM164	08-Jan-11	<p>I am writing as a disabled individual concerning the latest reform document, there are some things I feel you may need to consider.</p> <p>*My wife and I have a range of disabilities and are in receipt of DLA, we try, and have to work as a couple to over come our difficulties.</p> <p>*We are both on full mobility, my wife is on middle care and I am on lower care. We rely on family for a lot of help.</p> <p>*I am in principle my wife's carer but not entitled to the payment because our income is above the required level.</p> <p>*We both use walking sticks to aid balance also I try help to support my wife when walking which is acutely painful for us both and limiting, my wife can't go out unaccompanied, I rarely leave her alone.</p> <p>*You could say, well use wheel chairs. We have steps to our property so how would we lift a wheel chair up and down?, will this be taken into account for those with the same problem?. There is nowhere to securely leave a powered chair.</p> <p>*My wife has little grip in either hand, I have little grip in one hand, how could we push a wheel chair. I have a serious heart condition amongst other things so lifting is not possible.</p> <p>*My house has main drainage pipes running across so the building of a power lift is not possible, we have looked into the matter by the way.</p> <p>*The point I am trying to make is that a lot of in depth thought is needed before reform goes ahead, things are not as simple as is first believed.</p> <p>*In order that you may understand just what level of disability we both have to cope with I have made a list below.*</p> <p>*Myself *</p> <p>*AGE [REDACTED]</p> <p>*ISCHEMIC HEART DISEASE*UNSTABLE ANGINA</p> <p>*HYPERTENSION*DEGENERATIVE DISC DISEASE, ORIGINATING FROM AN INDUSTRIAL INJURY1971</p> <p>*PALSY TO LEFT HAND FROM DAMAGED ULNAR NERVE*BIPOLAR DISORDER*</p> <p>*Wife*</p> <p>*AGE [REDACTED]</p> <p>*TYPE 2 DIABETES</p> <p>*NEUROPATHY TO HANDS, FEET, BLADDER*BODY TREMOR</p> <p>*COLOMBO BOTH EYES,(DEFORMED PUPILS CAUSING POOR VISION)*UNMANAGEABLE LABRYINTHITIS</p> <p>*HYPERTENSION</p> <p>*UNDERACTIVE THYROID*DUPUYTRENS CONTRACTURE (BOTH HANDS)</p> <p>*CARPAL TUNNEL BOTH HANDS</p> <p>*URGE INCONTINENCE*</p> <p>*The combination of these conditions cause a whole range of problems for both of us and other people in similar situations, when dealing with cases as ours I hope that thorough consideration is put into any changes introduced by the reforms, it is fine to just look at one issue but as you must see there are a multitude of issues that can arise.</p> <p>*I can fully appreciate the need for reform but it should not be based purely on</p>

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		<p>financial savings, and rushed through just for political gain.</p> <p>*We both worked full time before being disabled and feel that we are entitled to DLA, I can't imagine anyone wishing to be in our situation or that of any genuinely disabled person.</p> <p>*We are both very worried as to the outcome of the reforms, all too often you read about rules being incorrectly applied by overzealous persons trying to save money in order to get a bonus.*</p>
EM165	08-Jan-11	<p>Firstly the email address where to respond to the consultation does not work, it takes you to an error page!*</p> <p>*I am a [REDACTED] female with MS and am disappointed that DLA is being considered for reform. People do not want to be ill and need the money from DLA to live a life. I have car through the mobility component to get me to work. When I first fell ill and could not drive my own car I was told by access to work that it was better for the country to get me back to work.*</p> <p>*I feel disabled people are being unfairly treated and there must be other ways cuts can be made without ruining what life disabled people have. How about stopping giving nicotine patches to smokers? They started the habit and should pay to get off the drug. I did nothing to get MS yet have to pay for my prescriptions to manage the problem it causes!*</p>
EM166	09-Jan-11	<p>I am responding to this consultation on behalf of my daughter who has a multitude of disabilities. I am attempting to help give an individual and informed picture of how any changes to DLA will directly impact on my daughter.*</p> <p>*My daughter (20 years old) has had many disabilities since birth including learning difficulties, significant memory difficulties, social difficulties, tonic clonic epilepsy (taking full blown seizures during which she stops breathing) and gross motor skills difficulties including those of spatial awareness. Her Dad and I have worked hard all of our lives (contributing significantly to taxes) and in addition have been our daughter's carers, 24/7. We have never applied for any benefits as carers nor for our daughter as she grew up. As an adult, Stacey can not get any job at all, due to her wide ranging difficulties in a very competitive employment market at a time of the credit crunch. The only work she could get was on a voluntary basis, one day a week in a Cancer Research shop. She has been sorting clothes for them for 4 years now.*</p> <p>*The DLA allowance is vital for our daughter to feel at least a little bit independent and be able to go to areas (e.g. the Town Centre) that we have taught her over and over how to navigate. The DLA is vital for her to enable her to feel, in a very small and limited way, part of society - a society where she has no friends except her close family and no chance of being included by others in the working world.*</p> <p>*Sadly, our daughter's condition is never going to be any better medically and in fact every time she has a seizure her memory and capabilities are both going to get worse. We are resigned to having to care for her for the rest of our lives and would request that the DLA continues to be allocated automatically in cases such as our daughters as she does not understand all of the form filling and checks so it is always an extra burden on both ourselves and her if this had to be repeated every year. We would like benefit to be allocated to her with the minimum of formalities and to keep pace with inflation. It is all she has.*</p> <p>*I would like to see the allowance also including a working world mentor entitlement who would have the power and resources to secure practical work experience opportunities matched closely to the needs of my daughter or other disabled individuals, helping to give her a little self esteem. Despite all of the legislation in place to supposedly 'include' people with disabilities, our daughter is far from included in society and in fact because her disabilities are not physically obvious appearance wise, she regularly suffers from discrimination from others. The cost saving exercise to restrict and remove DLA is just another example.*</p> <p>*I would suggest talking to samples of individuals with disabilities to find out</p>

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		<p>what effect the removal, restriction and repeated application plans for DLA will have on their already limited lives, whilst at the same time weeding out people, for example, who receive disability payments to keep their car up to date whilst at the same time parking the car in a lock up and walking to and forth in addition to going on luxury holidays including the Caribbean this year. Please confirm that you have received my consultation.*</p> <p>*Footnote This consultation is not well publicised nor easy to find at all. The link to this email address does not work. Does the Government really want any responses? There should be an online questionnaire to help people respond. I suggest that the consultation period is extended and processes improved.</p>
EM167	09-Jan-11	<p>Dear Maria Miller, DLA exists specifically to help with the many hidden, extra costs of being disabled in our society. To replace it with PIP - reverting to an almost Victorian medical model of disability - is callous and unworkable. Meanwhile, genuine disabled people will lose out and their quality of life drastically reduced as they will be less supported in real terms than ever before. The fury, stress and anxiety amongst disabled people is palpable. The threats to our financial (and DLA is not generous anyway) and emotional well-being is extreme. From where I sit this feels like a eugenics-style hate campaign, not a way of supporting people as you suggest. All we keep hearing about are new ways to attack us even when such tactics may be in breach of human rights legislation, yet still you persist. *</p>
EM168	09-Jan-11	<p>I, along with other disabled people alike are very anxious re the forth coming cuts to DLA. I was knocked down in 1977 which has left me with head and brain injury resulting in hand tremors, serious vertigo / dizziness, palsy down left side of face, dramatic weight problems, maculopathy in the eyes and diabetes along with depression and anxiety attacks. I walk with great difficulty aided with crutches or quadraped stick. Making meals from scratch is impossible, if it wasn't for a George Foreman Grill & microwave I would not be able to eat a meal. I have worked in the local Jobcentre since 1987 after 3 jobs where employers would not retain me after the probationary period as I could not cope due to my disability. I did not give up and eventually gained employment via Sheltered Placement Scheme (as it was called then), then on to Workstep. After 13 years on the disability scheme Jobcentre managers had faith in me and I am now a fully employed member of dwp staff. Unfortunately, due to the deterioration in my mobility I now take taxis everywhere I go, even to and from work where I get help via Access to Work. DLA costs help towards my travel costs and meals which are more expensive as I am unable to cook for myself. I live in local council housing where they have adapted my ground floor flat to suit my needs. I am so worried regarding these cuts I am now on medication for depression and getting counselling.*</p> <p>*As far as the questions in the consultation paper is concerned here are my views:</p> <p>*I am in favour of getting disabled people out working either in employment or in a voluntary role. Getting into a routine and meeting people helps people like myself feel as though we're not worthless and lets us interact with people. Making friends isn't easy when you are disabled, meeting people through work has given me more confidence.</p> <p>*PIP should still be called an allowance as DLA is presently, not a benefit. For those people who have a disability that will not get any better should still be awarded for life. This would save on administration costs.</p> <p>*As for myself I would not be able to work or get about without DLA for my taxi costs. DLA is also used for a home help on a weekly basis. Disability aids are costly too.</p> <p>*Personally I think there should be a low and high rate for both components. Disabled who have a disability that will not improve, ie those for life should be given the higher rate and those with a time limit should be given the lower rate.</p> <p>*This is a hard question. I would suggest as above, those people with a disability that will not improve and life threatening illnesses like cancer should</p>

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		<p>be awarded immediately. These people have gone through enough medicals etc on numerous occasions and what they don't need now is another medical to add to their stress.</p> <p>*Medical staff, ie GPs / clinic doctors etc and Jobcentre Plus staff should be encouraging those people to apply.</p> <p>*DEAs & IB staff in the local Jobcentre Plus office should have a 2 - 5 year visit from people getting this allowance producing a form stamped and signed from their GP stating whether everything is the same or there is a change in health.</p> <p>*Any one who uses disability aids should be taken into account, especially if it's used for mobility or for living an independent life. *Applications could be made electronically or over the phone just like making a claim to JSA. The form will then be posted to the claimant to browse through and sign with a signature and stamp from their GP or medical adviser. As above, Jobcentre Plus, medical/NHS staff and even local council staff should encourage eligible disabled people to apply.</p> <p>*I propose Medical & NHS staff are the best people to advise on the needs for the disabled person.</p> <p>*I think having the option of being met in an office or at home is a good thing. The visiting officer to the home would actually be able to see what the disabled persons living arrangements are like ie. adaptations etc. Depending on the disability / illness should this meeting face to face occur. For instance those people who have life threatening illnesses may need to have this meeting waived. A GPs decision may be needed.</p> <p>*As stated above claimants for PIP who have a disability that will not improve should be given for life. Jobcentre Plus staff should meet others on a 1 - 5 year basis where they produce a form signed by them and also for their GP to sign and stamp explaining the improvement of the persons disability. Jobcentre Plus staff will then input the evidence for the PIP staff to decide on whether any deduction should be made.</p> <p>*As above, forms should be made readily available whether electronically or at GPs surgeries reminding PIP recipients if they have a change to their disability to complete and return. Again GPs are the best to advise recipients whether to complete a form.</p> <p>*Advice is always beneficial whether it's from Jobcentre Plus staff, GPs or any medical/NHS staff. Post offices, libraries and schools should also have advice leaflets.</p> <p>*A one off cost may be all that's needed for someone with an award to PIP on a limited period. Disabled people with a permanent disability need aids / adaptations on a regular basis. The PIP allowance should be taken into consideration towards the costs and for the time adapting to the new adaptations.</p> <p>*Children should have yearly checks, especially if they are below 10 years of age as children change as they grow older. Schools should play a vital role with disabled children and advise parents with disabled children on what to expect with this new allowance.</p> <p>*Thank you for taking the time to read my opinion.*</p>
EM169	10-Jan-11	<p>We are writing to respond to the consultation on Disability Living Allowance reform. Our son is 19 and attends University. He has Duchenne Muscular Dystrophy and is an electric wheelchair user. This is our joint response to questions 7 and 8 in particular.*</p> <p>*Response to Question 7 - As noted in the consultation paper, society's attitudes have improved greatly over recent years. However, it is very naïve to state "It is now universally accepted that disabled people should have the same choices and opportunities as non-disabled people." If this were the case then wheelchair access would be universal but this is far from the case.*</p> <p>*The duty to make reasonable adjustments is far from understood or accepted by many, many service providers. It is a positive duty, requiring service providers to do things differently and sometimes to do things for disabled people that they would not do for other members of the public. Many companies still do not understand that a failure to comply with this duty</p>

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		<p>amounts to unlawful discrimination just as much as deliberately treating a disabled person worse because of a disability. When challenged their attitudes are dismissive.*</p> <p>*The lack of effectiveness of the DDA and EA is not in the legislation but in the means of enforcement, which currently requires a disabled person to fight an individual claim in the civil courts. The courts are not yet familiar with disability discrimination claims, and nor are many legal advisers. This lack of familiarity meant that we were prevented from bringing a simple case (of a wheelchair user who could not get into his RBS Branch) to the Small Claims Court. Instead of agreeing to comply with the law by arranging access for wheelchair users, the bank decided to contest the necessary litigation and in fact fought the case through a 3-day trial in the county court, then the Court of Appeal and the Supreme Court. We succeeded with the help of Sheffield Law Centre but it took 4 years!*</p> <p>*The costs of civil litigation are prohibitive for many disabled individuals and the availability of legal aid for cases is the exception rather than the norm. Action has to be taken by the individual rather than by any organisation such as trading standards and the individual is often set against the resources of a large corporation. In consequence, very few cases have ever been taken through the courts and barriers to access to services largely go unchallenged.*</p> <p>*Please open your eyes we live in a society which is far from accessible despite what the law commands.*</p> <p>*Response to Question 8 - You single out wheelchair users yet wheelchair users face a huge number of obstacles, as noted above, in daily life and this inevitably has cost implications.*</p> <p>*In the case of Allen v RBS, [REDACTED] had to travel to the courts to enforce his right of access, he was only able to attend by virtue of his Motability vehicle, which is funded through his award of Disability Living Allowance. We find it appalling that in future he might not qualify for the mobility component of DLA (or PIP) because he has a wheelchair and because of an assumption that places are now accessible which astonishingly far from reality.*</p> <p>*You wrongly assume that any increasing wheelchair independence means an economic level playing field with ambulant people. This is absolutely not the case.*</p> <p>*Clothing needs to be professionally adapted to aid independence.*</p> <p>*Electric wheelchairs need to be insured against damage and personal injury claims costing hundreds of pounds annually.*</p> <p>*Taxis are rarely (if ever) adapted for the electric wheelchair users who need to remain in their chairs and therefore a Motability Adapted Vehicle is vital. This must be paid for by using the higher rate mobility component of DLA. Vehicles need to be much larger to accommodate electric wheelchairs but seat numbers are fewer. Car sharing is rarely an option for electric wheelchair users so petrol / diesel costs are higher.*</p> <p>*Motability required advance payments such as the £2000 we paid in 2010 because the assessment was based on total family income even though David was 19 years old.*</p> <p>*Family rooms in budget chain hotels do not accommodate wheelchair users as the bathroom doors are not wide enough to allow a wheelchair through. A disabled accessible room is for two people only. This doubles the accommodation cost as two rooms must be booked.*</p> <p>*Hairdressers / barbers are often not accessible so choice is limited to the more expensive salons.*</p> <p>*Internet booking discounts are often not available because wheelchair access and needs must be discussed with call centre staff.*</p> <p>*Pre-event visits must be carried out by carers to ascertain the true extent of wheelchair access. Disabled toilets piled high with stock or even up several steps are common as are huge plants and tables placed in front of platform hoists.*</p> <p>*Diets high in protein and low in fat and carbohydrates are incredibly expensive but necessary for wheelchair users to prevent excessive weight</p>

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		<p>gain as wheelchair users require fewer calories and easily put on weight exacerbating their medical conditions.*</p> <p>*Wheelchair users need to keep their homes much warmer than normal as they cannot move around to keep warm. Gas and electric bills are therefore considerably higher. And no cold weather payments because we both work.*</p> <p>*Carpets wear out much quicker because of the traction of the wheels and dirt / mud brought in by the wheels. *</p> <p>*Washing machines, tumblers etc are used more often, increasing water and electricity consumption, as well as needing to be replaced more often.*</p> <p>*Working families need to adapt their work patterns around the caring role. Unpaid leave is taken for numerous hospital appointments, social service appointments court cases etc. This also reduces hours that can be worked and impacts on opportunities for promotion. The whole family's income earning potential is therefore reduced.*</p> <p>*Hospital appointments may require travel to specialist centres in different cities. In our case we have travelled to Hammersmith Hospital in London, St James's in Leeds, Newcastle-upon-Tyne Hospital, James Cooke Hospital in Middlesbrough. This has all been in our Motability Adapted Vehicle with diesel and hotel bills paid for by ourselves.*</p> <p>*Vital disability aids need to be replaced instantly at personal expense as re-application and re-assessments mean replacements take too long to arrive. *</p> <p>*Many vital aids which enable independence are not funded by NHS or Social Services. Wheelchair covers (to keep the user dry) are not supplied by the NHS or Social Services and cost between £40 to £70. Many enabling products such as dressing aids must be bought privately.*</p> <p>*Building adaptations are only part funded via grants, the rest being funded via personal loans / increased mortgages which incur interest.*</p> <p>*Local shops are often not wheelchair accessible. Our greengrocer and local chemist are not accessible. Each individual service provider must be taken to court by the wheelchair user, we currently do not have the time or energy to take on any more legal battles at this point in time. Therefore if [REDACTED] wishes to choose his own food or have privacy for his medications, this necessitates a trip in his wheelchair adapted vehicle to a supermarket. He consequently needs his Motability vehicle which is funded by his DLA.*</p> <p>*So you can see that although DLA is a welcome benefit it does not nearly cover the extra expenses that normal hardworking families incur as a direct result of one family member who is an electric wheelchair user. *</p> <p>*Furthermore in point 27 you compare the increasing independence of a wheelchair user to that of a person with a prosthetic limb. DLA is not meant to somehow be a recompense for disability. It is designed to level the financial playing field between the disabled and non-disabled; the mobility component in particular between the ambulant and non-ambulant. Outlined above are one family's increased expenditure incurred as a direct result of having a son with Duchenne Muscular Dystrophy. We propose that none of the expenses outlined above would be incurred by a person with a prosthetic limb. However most of the above expenses would be incurred by most electric wheelchair users. *</p> <p>*We understand you feel the need to cut national expenditure, however your proposals seem to single out those wheelchair users who are valiantly attempting to lead an independent life and by seeking to remove their DLA or PIP undermine all their courageous efforts to participate as fully as possible in everyday society. How can the electric wheelchair user compete equally in the job market and travel to a far off place of work without a Motability Adapted Vehicle? (a requirement of which is the higher rate mobility component of DLA). We hope that once David leaves university he will find rewarding graduate employment. His DLA will only enhance this quest for independence, not hinder it. *</p> <p>*We have amply demonstrated the extra costs which non-ambulant wheelchair users incur with our genuine extra expenses and we look forward to your reply.*</p>

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EM170	10-Jan-11	<p>I am a recipient of DLA which does not strike me as particularly complex or confusing. One of the symptoms of my primary medical condition is acute fatigue so I shall not waste valuable energy in making a more detailed response especially as such "consultations" in my view are time and money-wasting activities when decisions have been made already. *</p> <p>*"The rising caseload and expenditure is unsustainable" makes it evident that this is a cost-cutting exercise against a soft target. People might have looked to saving money by tackling the obscene salaries, share options, "bonuses" of the bankers (and others); by addressing tax avoidance - [REDACTED] and Vodafone are far from atypical, I am led to understand - and tax evasion; or the continuing of conduct of wars of, at best, dubious legality.*</p> <p>*This financial year I spent well over my annual DLA in having alterations made to my home such as door-widening to enable easier wheelchair access to rooms. A few years ago I was obliged to have my adapted shower room significantly updated / improved which, from memory, would have equated to a good 2 years of DLA. Should I mention the maintenance cost of a stairlift and the likely need in the very near future for its replacement by a new model as it becomes increasingly obsolete with parts more difficult to source. I could go on but what is the point? And the tame gutter press will echo the politicians with denunciations of benefit "scroungers" and "cheats". I should like to know why I paid National Insurance contributions when I was able-bodied.*</p>
EM171	10-Jan-11	<p>1 - Why change the name - this will just confuse more disabled people.</p> <p>*2 - Am concerned that the 20% reduction in costs will effect those who are honest and unable to challenge rather than those who are able to lie and deceive at the drop of a hat.</p> <p>*3 - To remove the mobility component from those in care homes will only result in virtual prisoners and this would be unacceptable.</p> <p>*You state that "It will help disabled people remove the barriers they face to leading full and independent lives."</p> <p>*4 - Is the current criteria different to this?</p> <p>*I can walk 200m, on a good day only, in significant pain, and disorientated. I am therefore not entitled to mobility rate....I cannot walk any further and my GP Surgery, bus stop, dentist, shop, parents and friends are all well beyond this distance. I am a virtual prisoner in my home - how has this improved my quality of life? Will it be any better, or worse, in the new system.</p> <p>*5 - Would it not be significantly more cost effective to employ the currently unemployed to act as Benefit Cheat Police and root out those who are abusing the current system???</p> <p>*6 - Most of those who are disabled are poorer than the rest and therefore are less likely to have a PC. In addition, those with mental health disabilities will not have a PC, nor those with manual dexterity problems. This ensures that disabled people will have little access to the new system without the direct help of an able bodied person. This is not fair and discriminatory against disabled people - it restricts their privacy at the very least. I work with the mentally and physically disabled and they do not, in the main, have computers. Perhaps the "minority" of society have no access, but the "majority" of disabled people have no access as they are the "minority" you refer to.</p> <p>*6 - I am totally sick of electronic systems and the cold clinical way we are being pushed into this kind of communication. Disability is hard enough without forcing isolation further upon us. Why is it that we as a society are increasingly being forced to distance ourselves from those who provide our services. While the cabinet are spending 3 million on car hire, we have to make do with a phone call and a computer - have we lost our humanity? - is being human too expensive? - it is for the vulnerable it would seem.</p> <p>*7 - Is the Disability Discrimination Act and the Human Rights Act worth the paper it is written on - apparently not.*</p>
EM172	10-Jan-11	<p>I fail to see how the government can equate those people in hospital to those who live in residential homes for people with disabilities and therefore feel</p>

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		<p>justified in withdrawing the mobility component of the DLA.</p> <p>*It is important that the people involved in this cut should experience firsthand the reality of life with severe disability and living in a residential home. These people wish to lead active and meaningful lives participating in many of the activities experienced by their able-bodied peers.*</p> <p>*Below are the opinions of many residents of St Bridget's home</p> <p>*We are a group of people with various disabilities and we live in a Leonard Cheshire residential home in West Sussex. In our different ways we need the same access to the outside world as is enjoyed by able-bodied members of society and in our case this requires adapted transport. At present our needs are met by the mobility component of the Disability Living Allowance.</p> <p>*We understand that, at present, the coalition government intends to remove this benefit. We feel that the government doesn't really understand the implications of this action and therefore we would like to give an open invitation to Mr Cameron, Mr Clegg or any of their representatives to visit us. This would allow them to see the reality of our lifestyle and the opportunity to discuss the effect the proposed cuts will have.*</p> <p>*[REDACTED], [REDACTED], [REDACTED], [REDACTED], [REDACTED], [REDACTED], [REDACTED], [REDACTED], [REDACTED], [REDACTED].*</p> <p>*[REDACTED].*</p> <p>*Following a head injury in 1991, [REDACTED] has been unable to walk, read or write and has just a few words of speech. He lived at home with his wife until 2003 when he moved to live at [REDACTED] home in [REDACTED].*</p> <p>*[REDACTED] was only prepared to move into residential care on the condition that he would still get out and about which he does. This summer in particular has been very busy, with [REDACTED] and his wife out at least 4 days each week watching their grand children play cricket. His wife cannot imagine telling [REDACTED] that they will no longer be able to follow their progress, but without [REDACTED]'s DLA Mobility they will not have the means to keep an adapted vehicle on the road.*</p> <p>*[REDACTED] lives in a [REDACTED] Disability home in [REDACTED]. After [REDACTED]' care fees are paid, all he receives is his Mobility DLA and £22 a week Personal Expenses Allowance. [REDACTED] uses his Mobility DLA to pay for his car and it covers all his servicing, insurance, MOT and fuel costs. [REDACTED] spends most weekends at home with his family and relies on the car most days. They use it for trips to the theatre cinema, shopping, visiting the Wildlife Trust nearby and for visits to friends and relatives. Having the car also means [REDACTED] can pursue his hobby of carriage driving as well as enjoying more everyday activities, such as taking garden waste to the tip! Without his Mobility DLA [REDACTED] would have to give up most or all of these activities*</p> <p>*[REDACTED]: The Mobility Allowance enables me to go and see my sister and brother, my only remaining relatives, who live a considerable distance away from me. I have to use vehicles from the home where I live but I have to pay 63 pence per mile, book well in advance and they are subject to availability of the vans and drivers. Without the allowance I shall be unable to visit them. That's not fair.</p> <p>*My residential home is in a small village and I need transport to go to the nearest shopping centre, 8 miles away.*</p> <p>*[REDACTED]: I do not have an adapted vehicle any more. If I want to go out anywhere I have to use the vehicle from the home. If the vehicle is not available then I have to use a special taxi at great expense. These are not always available. I need my mobility allowance very much because without it I wouldn't be able to go anywhere. I would be trapped in my residential home.*</p> <p>*I have lived in a residential home for 15 years and I am very happy. My disability means that I need the availability of 24 hour care. I have an adapted car that allows me to go out as and when I want to as long as one of my family or friends can drive me. I use the car for all sorts of things. I love shopping, going out for meals, to the theatre, visiting my friends and family or just driving into the countryside to enjoy the fresh air.</p> <p>*I especially like going on holiday. I have to go to a special holiday centre because of my needs and I have to pay for my own transport. I cannot go by</p>

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		<p>public transport. This transport is extremely expensive and my family usually drive me. I am lucky to have family living close by to my home. Other people don't.</p> <p>*If the mobility allowance is cut then I will not be able to run my car. I will not have sufficient money to pay for transport to my holiday. I will be stuck. I will have no choices. I am unable to work but I would if I could. I can't help the fact that I am disabled - I didn't choose to be. [REDACTED]</p>
EM173	11-Jan-11	<p>After reading your document of proposed DLA changes, and would comment that, I feel physically sick. Yet again, you seek to change the goal posts and make our life's harder why go to all this bother. Why not just be truthful and say to us disabled we wish to euthanize the disabled population and send us a cheque to go to the Dignitas clinic instead of protracting our miserable existence of pain and suffering. We must now be subjected to extra financial hardship and bureaucracy not that it is easy now by any means at present. I hear these stories on the media of hundreds of thousands of pounds being fraudulently claimed by disabled people and I ask myself just how and where is these vast amounts when most of the people I know in my community struggle financially.</p> <p>*Our care packages are now being charged for by a further fifty percent extra in the last 12 months alone; we have also the fact that County Hall are now charging us to attend day care and some of us only get out once a week, in what they call a enablement payment reform. The cost of fuel has increased to such an extent so one must think before going out to shop or to visit family. Has the DLA increased no, yet you can expend thousands of pounds to ensure you can save a few quid but you will not as this will just bounce back unless of course you wish to euthanize which will save you no end of cash.</p>
EM174	11-Jan-11	<p>1. The barriers are the costs of disability and the attitudes of the general public and the government.</p> <p>*There are extra costs from needing extra heating, laundry, special diets, clothing, equipment, transport as well as needing to pay other people to do things that non disabled people can manage for themselves. There can be costs incurred in, for example, buying ready prepared foods to cook for yourself rather than starting from scratch. You may not be able to use an ordinary tin opener that costs about 50p and have to get one with larger, padded handles at £2.50. One often also has the problem that many disabilities are hidden - you cannot see deafness or arthritis for example. The use of the wheelchair as a symbol for disability gives a false impression that you need to be a wheelchair user to be disabled.</p> <p>*2. DLA should still be focussed on need, not reduced because you have worked out how to manage differently than others.</p> <p>*3. Heat, transport, equipment, cleaners, carers. Medical costs eg parking for hospital appointments, high prescription costs - even a prepayment certificate is expensive. Many costs are the same sort as normal people have but a disabled person may need to keep their home warmer, or use a car or taxi instead of a bus or bicycle.</p> <p>*4. • Will having two rates per component make the benefit easier to understand and administer, while ensuring appropriate levels of support?</p> <p>*No, I have found this consultation difficult to understand and I have years of experience helping friends, family and colleagues with DLA. I also wonder what effect it would have on people who are currently getting the lower rates of support - my son in law gets lower rate mobility to allow him to be accompanied when he is outside - without this he would be housebound.</p> <p>*• What, if any, disadvantages or problems could having two rates per component cause?</p> <p>*The people currently eligible for the lower rates could find themselves without necessary support. It also seems unfair that sight impaired people are ineligible for the mobility element of DLA, as they have much higher transport costs than the general public.</p> <p>*5. Individual needs should be considered, and the views of the claimant be believed over those of 'independent healthcare professionals' who may have</p>

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		<p>no knowledge or experience of particular disabilities or disabling condition. When you consider how wide the range of effects a single condition can have it makes a nonsense of having an automatic entitlement just because you have a certain condition.</p> <p>*6. What is more important - that I spend an hour putting on my own compression garments or that I get some help with that and spend the hour being economically or socially active? I believe that getting the help and spending the time enjoying quality of life is more important - many occupational therapists believe I should spend more of my energy on 'activities of daily living' than having quality of life. I fear that using health professionals as part of the assessment process will concentrate too much on the medical model. Using GP reports is also not accurate - generally a GP sees you walk from the door of the consulting room to the chair, and can make false assumptions about your ability to get to the surgery, to get out of bed or get dressed. I may be well presented when I see him but it took me and my carer an hour or so to get me that way. Also, I see my consultant once or twice a year for ten minutes or so. This is time to review my test results and medication but gives no indication of my day- to- day difficulties or how I overcome them.</p> <p>*7. I have had so many discussions where medical professional have said that it cannot hurt that much, or that such and such a condition is not a problem that I have got to the stage where I start a consultation by saying that you may be the doctor, but I am the expert in me. It is important that you ask the individual how his condition affects him over a period of time - not ask for the current 7 day snapshot, and also get someone who understands that condition to assess the form. Stop using lists of 'usually prescribed drugs and dosages'. Ask for an average pain score for a good day, a bad day and a normal day - and ask what proportion these days occur. Do the drugs make you confused or drowsy, is fatigue an issue, does it affect your sleep, cognitive function, memory, social or work life? Disabled people also have a sex life that can be adversely affected by their condition..</p> <p>*8. Not really, because the aids and adaptations used may change from day to day particularly if you have a fluctuating condition. After all, if you did not have the disability you would not use some aids but may use others, like a food mixer.</p> <p>*• What aids and adaptations should be included?</p> <p>*None because the benefit is supposed to help with the extra costs and that can be as simple as a special knife or as complex as a computer run house.</p> <p>*• Should the assessment only take into account aids and adaptations where the person already has them or should we consider those that the person might be eligible for and can easily obtain?</p> <p>*The need for aids and adaptations tends to vary over time, so should not be taken into account. The benefit is supposed to help with the costs, including buying some aids.</p> <p>*9. • How could we make the claim form easier to fill in?</p> <p>*Make it shorter and clearer. Provide larger further information boxes and encourage people to use them.</p> <p>*• How can we improve information....?</p> <p>*Use the media more to advertise what is available and less about the minority of benefit cheats.</p> <p>*10. The disabled person and their family are going to know the situation best. Ask the claimant to nominate someone if you need further evidence. A carer may be able to give information about the things they help with but not about the things a disabled person may ask other family members to help with. . A GP or consultant is likely to know the name of the condition and the medication used, but not the day to day effect on the claimant. One of my GP's did not realise for 4 years that I was housebound!!</p> <p>*11. • What benefits or difficulties might this bring?</p> <p>*Health care professionals know about some conditions they have studied medically but are not expert in being the claimant and living in his body. This is particularly true when one has multiple conditions, It is also very</p>

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		<p>emabarrasing, almost demeaning, to discuss bodily functions with a stranger. There are also difficulties communicating with people you do not know and who may have a different background .These difficulties can often occur when one has a mental health condition.</p> <p>*• Are there any circumstances in which?</p> <p>*Yes, if someone has problems relating to other people, or has other communication difficuties. It is also necessary to remove restrictions on claimants taping /videoing or otherwise recording visits. When you get to the end of a visit the assessor often reads out their notes and asks you to sign that they are true and accurate. If you are not given the chance to read them how can this be done? It is not unknown for a claimants notes to differ substantially from those submitted by the visitor.</p> <p>*12. • What evidence and/or criteria should be used to set the frequency of reviews?</p> <p>*Reviews should occur at least every 5 years as this gives enough time for changes to become apparent. There is also a problem when one's condition may worsen or one may acquire another condition but it does not mean that ones needs change to the next level of care - should one report that or not? How is one supposed to report a change in circumstances? I know that when I telephoned to report a change as above no one knew what to do with the information.*• Should there be different types...?</p> <p>*No - a review every 5 years should be sufficient in most cases. This is a long enough gap to make a difference to deteriorating conditions and not too soon for those cases where there will be no change.I am assuming that necessary communication aids will be provided, whether a BSL interpreter or another form of assistance.</p> <p>*13. Make it clear how you expect people to report changes. The current forms just say that you need to report them, not how or to whom. This is especially a problem now that the benefits are paid straight into the bank. With the old payment book you were at least able to see the requirement in the book and you signed that you were still eligible.</p> <p>*14. They need to know how long the clain will take to be assessed and how long it will take to make an appeal. It is also important to point out which other help may be available. I think you should also make the questions on the form less ambiguous. For example 'how far can you walk without severe discomfort' has two problems - what is severe discomfort and what if you are in pain before you even stand up, let alone take a step? A clearer definition of 'walk' is also available but not given on the form: but that qualifier as to manner, gait, distance and time is very important. Should you take into account the time it takes to walk from A to B including rest stops or without them? How come the requirement is walking outside on level ground but visiting officers ask you to walk indoors and up stairs? Shopping is not counted as an activity of daily living, and nor is doing housework or gardening, but they are necessary to live in a clean environment and to be nourished.</p> <p>*15. If they are not likely to claim in the first place how are you going to know who to offer the advice and support to?</p> <p>*16. Most aids are paid for out of income, including DLA. Larger adaptations are funded in many cases by a disabled facilities grant - but this is not available to social housing tenants who have to wait until the landlord has the money or paythemselves so it would help if you could get extra payments on a one-off basis for some adaptations. Most people look at their income as a whole - not breaking it down into different sources as they do with the way they spend it.</p> <p>*17. That children have different communication skills at different ages. Whilst a 5 year old cannot reasonably be expected to tell you what help they need a 15 year old can. It is also important to remember that older children need to have independence from their parents in some degree to allow them to live as far as possible as their peers do. Seeing a 19 year old man being given toileting care by his mother is demeaning to him and embarrassing to others. Could you use something like 'Gillick competence' to determine if a</p>

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		<p>young person is able to answer the questions for themselves?</p> <p>*18. Mostly DLA is only specifically useful in getting a blue badge. As long as the other benefits give information about what DLA helps with you do not need to worry. Against that a leaflet of useful non -benefit related things DLA passports you to - like the free cinema ticket for your companion- would be a great help.</p> <p>*19. Using DLA as a passport often disqualifies people who are not disabled enough to get DLA but need help prevent them getting that help.</p> <p>*20. I don't think any of these can really be combined. Passporting to other benefits only requires you to tick the box that says you are in receipt of DLA. For getting a direct payment for help with care needs requires different information. Getting a carer also requires a different set of information about your needs.</p> <p>*21. Consider the fact that whatever ones colour, ethnicity or sexuality all human beings ingest, digest and egest and basically have the same body.</p> <p>*22. Disability is a huge subject and cannot really be assessed by ticking boxes on a form. Too many people associate the elderly with disability. However, there is a problem in that there is no way to make a fresh claim for DLA after your pensionable birthday (currently 65 for men). This means that older disabled people cannot get help with mobility needs, and the need to get out and about does not cease when you get your pension. Perhaps what is needed is not to change DLA but to scrap AA and put everyone on to DLA - keeping the current lower rates to help those who have minor age related difficulties. For example minor arthritis can be very disabling but is not very easy to treat. This would allow a whole benefit and its related costs to disappear.</p>
EM175	11-Jan-11	<p>I would like to put forward my concerns. I am a service manager in a small residential home for people with severe learning and physical difficulties.*</p> <p>*Due to the nature of the disabilities of the people we support it would have a great impact on their independence and social inclusion if their DLA was to be stopped. They rely heavily on this allowance to access the community by disabled transport and special disabled taxis (who charge extra for the service, as I am sure you are aware) and require 1-1 support whilst outside the home. One lady has her own disabled vehicle through Mobility Care and this is her main pleasure in life as it allows her to get out and visit different environments*</p> <p>*I am worried that as they live in residential care this would stop and would just like you to consider this at consultation*</p>
EM176	11-Jan-11	<p>I write to you today to raise my issues with the removal of my daughters DLA as she is in residential school. Currently I send you details every 6 months telling you when she is at home in order to sort out her care component. *</p> <p>*Even though she is attending a residential school she is in an electric wheelchair which can only be conveyed in the minibus which we purchased and had converted just over 2 years ago. We had a lot of charitable help with the conversion side of things but the basic vehicle we pay for via dealership credit over 60 months. We would have not been able to purchase this vehicle without my daughters DLA mobility. I am very aware that if I default on these payments the credit company will reprocess the vehicle even though the credit amounts to about 30-40%*</p> <p>*To make matters more complicated I am currently out of work, surviving on my redundancy and in the middle of moving into rental housing. The loss of DLA is going to hit us very hard and I fear that I will lose my daughters minibus. *</p> <p>*I will be also participating on the govt consultation, If it was such that our payments just continued until the loan was completed it would take so much pressure off us. *</p> <p>*The vehicle is vital for my daughters transport. Without it we would effectively be trapped in the house. I don't think I'm alone, the school my daughter attends are also aware of this issue but I felt I ought to email and express how this move will affect us. I look forward to your reply With kind regards *</p>

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EM177	11-Jan-11	<p>My husband is on high-rate mobility and care component due to him being diagnosed with Parkinson's disease over 3 years ago. His condition had deteriorated badly over the last 8 months and he was forced to take early retirement on health grounds, due to his inability to sustain his job as his condition got worse. He is a 52 year old man, who was a staff nurse within the NHS, he worked in addictions with drug users whom are prescribed methadone. He had worked for 25 years within the NHS and contributed well to society, I am concerned that these proposed changes to DLA, will affect his already depleted quality of life, if his benefit is cut . *</p>
EM178	11-Jan-11	<p>I should like to express my serious concern about the proposal to remove mobility allowance from people living in residential care. My son has a severe learning disability and is a wheelchair user. He lives in a residential care home and the removal of this benefit from him would dramatically affect his quality of life. He relies on this to pay for transport for trips out from the home. These are often by taxi to places like doctors and dentists, as well as providing him with opportunities for social outlets like going to a local social club or going shopping. Transport is also needed to enable him to go on holiday and make a variety of day trips. He is not in a situation to be able to comment on this himself, so as his mother, I am doing this for him. *</p> <p>*There is no question that it would be extremely sad if he were denied all the opportunities that he currently has to enable him to participate in normal life in the outside world. Therefore I would urge the Government to think again about the proposal to remove this benefit from the most vulnerable of people, those who it is claimed they are trying to protect.*</p> <p>*I understand the rationale is that living in a residential home equates to being in hospital, but it is obvious that the two situations are very different. People are in hospital for a short period of time when they are ill. They live in a residential home because they need permanent support to enable them to cope with everyday life. These two things are very different.*</p> <p>*It has also been suggested that there is double payment because the local authority already funds transport costs. I can assure Ministers that this is definitely NOT the case. Nowhere in any care plan or assessment is there any mention of transport costs. Not surprisingly since clearly for some years now mobility allowance has been legitimately paid from central government and is NOT included in the amount paid by the local authority to provide care.*</p> <p>*Please reconsider this decision to remove the mobility allowance from those in residential care as the impact on someone's life could be very considerable, enforcing them to lead a segregated and limited life which was the case decades ago and from which we thought we had progressed. With many thanks.*</p>
EM179	11-Jan-11	<p>*Please find attached a reply to the proposed DLA reforms relating to people who live in care homes</p> <p>*A reply would be appreciated, I expect you will have access to the letter [REDACTED] received from Maria Miller MP. [REDACTED] *</p> <p>*I am responding to the DLA reform – Public Consultation Document. This is on behalf of six people with profound and multiple learning disabilities that live in a registered care home in [REDACTED] London. Each of the six people is in receipt of the high rate mobility component of the Disabled Living Allowance and have been awarded this indefinitely.*</p> <p>*These six people use part of their mobility allowance to fund a Motability car, accessible to those in a wheelchair and/or those who have challenging behaviour who to use public transport or taxi's proves very difficult and stressful for them.*</p> <p>*For example we have to travel from [REDACTED] to Guys Hospital to receive dental treatment in a specialist department that can meet their needs. *</p> <p>*One service user [REDACTED] is blind, is profoundly learning disabled with Downs syndrome, mental illness and is dementing also, he can only walk a few steps and uses a wheelchair; his mood can be unpredictable, meaning we will only go out on foot to very local venues using his wheelchair. We need to get home quickly when his mood changes, vocally he may become very loud</p>

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		<p>when distressed. So when using the dental service at Guys it is vital we have access to a car which can accommodate his wheelchair and be ready to depart immediately. This is not possible without the Motability car.*</p> <p>*Another service user [REDACTED] is very similar to [REDACTED] now he is aging, he is able to recognise the car and gesture that he wants to use it to go out, socially to parks like Richmond, as well as for medical appointments. Recently he was so distressed at the G.P surgery he would not even sit down in the waiting area, the doctors kindly took him into the first room he was happy to walk into. Due to having the car he was able to leave immediately, get home and be calm.*</p> <p>*An autistic gentlemen ND has great difficulty going into certain buildings and even the house but if driven to and from a destination his anxiety and self harm appears to decline. Indeed when his previous care home was closing down it took three months for him to get through the door to this care home and spend the night, with the aid of psychology, psychiatry, multi-media and the car we were able to provide a successful transition and he is very happy here but he depends on the car greatly. *</p> <p>*Because of the noises he and others make plus some antisocial type behaviours he and other service users can display some cab drivers do not like to take some of the service users who live here. There are many occasions where it is simply more dignified and less stressful to the service user to travel in their own vehicle.*</p> <p>*Another lady who lives here is wheelchair bound and suffers from severe epilepsy, she is reliant on the Motability vehicle also, she has many health appointments and requires hoisting to change her and provide personal care, if waiting around for a suitable cab which can be unreliable with the Taxicard scheme the local facilities are insufficient to provide adequate personal care.*</p> <p>*The mother of another service user, [REDACTED], bequeathed her car to the home when she died, which we sold and put towards the Motability vehicle we have now, as it required adaptation to accommodate the needs of all the service users who live in this care home and hence the additional cost.*</p> <p>*And finally [REDACTED] who is a wheelchair whose Mother founded this care home some 25 years ago, before we merged with [REDACTED] after her death. He relies heavily on the car for all his social activities and health care appointments. *</p> <p>*If the Mobility DLA is taken away how do they afford a taxi to go anywhere, to afford trips out where they will need one or more carers or a short break? For hospital appointments they simply would not cope having to wait for hospital transport.*</p> <p>*I have expressed my concerns via Mencap and their link to [REDACTED] MP on their website and received the standard reply from Maria Miller MP.**I feel it is somewhat discriminatory to target 'state funded residents in care homes' the state funds placements for people in supported living schemes, under Supporting People, people with Individual Budgets, Direct Payments and the state funds the care of people in their own homes or while living with relatives. Different packages of care but all maybe state funded with Care Homes not necessarily being the most expensive for the individual. Indeed the proposed changes fail to see the person as an individual at all.*</p> <p>*Maria Miller states in her letter that 'all Budget and Spending Review measures will be equality impact assessed' this does not appear to have happened.*</p> <p>*Care home fees have been frozen for three years and cuts expected from this borough. I cannot see the fees being increased to allow the purchase of a vehicle and all that it costs to run. *</p> <p>*The service users access to the Motability scheme while living in a care home is vital to the quality of their care and standard of living. None of the people living here have chosen to be as severely learning and physically disabled as they are, not able to work and contribute financially, but it is certainly not a lifestyle choice to be reliant on the benefits they do receive.*</p> <p>*The last sentence of Maria Miller's letter 'the Coalition Government is fully committed to enabling disabled people to have the same opportunities and</p>

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		<p>choices as non-disabled people' requires some explanation as the proposed DLA reforms will totally isolate and deprive profound and multiple learning disabled people who happen to live in a care home. This care home provides very cost efficient care when looking at the needs of the service users, it is their home and I believe they should maintain the right to have access to this non means tested benefit that enhances the quality of their lives so greatly.*</p> <p>*Indeed I would recommend reading the report 'Raising Our Sights: services for adults with profound and intellectual and multiple disabilities' by Professor Jim Mansell.*</p> <p>*I am more than happy to discuss these issues with the relevant people from the DLA Reform Team. Our own inspection report is available on the CQC website. Or to visit the home to meet the exceptional people who live here. I look forward to hearing from you*</p>
EM180	11-Jan-11	<p>I write in response to your consultation on reform of DLA. I think that it should remain in its present form for the following reason: DLA provides a regular allowance, which enables disabled people to budget for their individual disability related needs. It does not cover all costs of care and mobility by any means, for as I am sure you are told many times over, living with a disability is hugely more expensive than normal living; however at least DLA contributes on a regular basis.*</p> <p>*The Mobility component is essential as public transport despite what is advertised and has been attempted is in no way safe or possible for many disabled people, including myself, who therefore need to fund their own transport. Those in their own homes, those in Residential accommodation and those in Residential Homes all need to get out into the world and "to have a life", not to be confined to the the four walls, as would otherwise be the case. Children at Special schools need to be able to get about in the holidays and when parents visit so they are enabled to explore the outside world.*</p> <p>*People have differing needs and can't all be provided for in the same way, and having the DLA allowance gives them choice. Of course some peoples' needs are greater than others but the DLA gives a basic and regular income which helps cover some of the costs of disability. There is no point in re-inventing a scheme which is working quite well. *</p>
EM181	12-Jan-11	<p>The biggest barrier which Disabled People experience is that of an attitudinal nature. This can lead to prejudicial treatment and discrimination and is based upon myths, falsehoods and misconceptions. Although improving Disabled People are thought by many people to be abnormal, unable to enjoy mainstream services and are second class. The next barrier is that of an organisational nature – the operating systems or rules by which an organisation uses to operate. These can screen out or restrict Disabled People from using the organisation. Poorly written organisational systems which are inflexibly administered and used can and do lead to the organisation becoming 'disablist' – not having robust systems to ensure aids and equipment or satisfactory staff training exist to ensure Disabled People can use the organisation.*</p> <p>*The last barrier Disabled People experience is one of a physical nature which are either made or of a natural type. Many physical barriers with sufficient planning and a general will to improve a situation can be reduced or removed. An underlining duty of the DDA 1995 introduced in 2004 which many organisations still do not deliver on.</p> <p>*A 'passport' to motability scheme and reduced Council Tax *Equipment to aid daily living, taxi fares, special diet, chiropody and major adaptations if not covered by Direct Payment or Disabled Facilities Grant.</p> <p>*No, by having two components paid at two rates will still cause confusion and misunderstanding. The flexible nature of DLA is good and fits with the concepts of 'choice' and 'control' as a result Disabled People may chose to save some of their DLA to spend on big items to aid their independence and daily living. Why has the design of PIP continued with the current needlessly complicated framework? Any new benefit should not have two components just one and should be all encompassing reflecting the barriers which</p>

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		<p>Disabled People experience every day. Any test used to qualify should take a 'broad church', be clear, explicit and properly explained from the outset. By still proposing to have a possible myriad mix of payments will continue the confusion.</p> <p>*No automatic entitlement for medical conditions apart from terminal illnesses. Everyone is different and will be affected differently by any particular medical condition. The current impairment entitlements should be maintained.</p> <p>*The concept of 'full' and 'active' has different connotations. For many people it would mean a person having the full functional ability to perform a certain task whilst other people enjoy full and active lives pursuing other activity rather than physical tasks. Why not spend money saved by forcing shops, restaurants etc to deliver on their legal duties regarding access and reasonable adjustments. What about giving Trading Standards officers the authority and power to bring organisations to court or close them down for not complying. *Have properly trained assessors, thorough assessment interviews, including taking evidence from a range of people including Disabled People. Ensure clarity amongst every one of what PIP is and what is being assessed.</p> <p>*Yes, but there must be clear explanations e.g. what aids or types of equipment? In addition, the level of functional ability required to use a piece of equipment together with ease with which an item can be used must be considered carefully i.e. the need to appreciate deteriorating medical conditions.*</p> <p>*Any equipment or aid that is identified and helps the Disabled Person must be explained and demonstrated. A one off payment could be given for this BUT an ongoing amount will still be required to compensate the individual for inevitable deterioration of an impairment or medical condition. Centres for Independent Living (CIL) are ideal for this.</p> <p>*However one packages it the mere fact an individual is applying for PIP means they are experiencing an impairment or medical condition, in other words a loss of some degree. In no way then can the process be made 'pleasurable' or a positive experience. The whole raison d'être of the process is the requirement to undergo an examination and answer intrusive personal questions, however, a number of suggestions would make the process better.*</p> <p>*Greater clarity of what PIP is and the differences it has from DLA, why it is given with examples of situations when it may be paid.</p> <p>*All communications must be easily understood with the range of media used and meaningful messages given</p> <p>*Disabled People must not be portrayed in any advertising as pathetic, incapable and need of handouts but rather full, active people who may need support which PIP can provide*</p> <p>*The intended 'shape' of PIP is still too complicated and confusing. The opportunity for a route and branch reform has not taken place so that money available is directed to people who can demonstrate greatest need.</p> <p>*Any supporting evidence must be provided by a range of people – professionals, relations and, of course, the Disabled Individual themselves. Information must be of a consistent nature to aid decision making. It is important that Disabled People are not denied PIP because they are holding down jobs, playing an active part in their community or leading a full life as possible.</p> <p>*Benefits – less fraud, less inconsistency in decision making, greater clarity of real issues affecting the individual.*</p> <p>*Difficulties – 'medicalising' disability and impairment, will process take account of social barriers? I.e. a disability philosophy, will assessor be sufficiently trained and competent and fully appreciate the Disability Experience.*</p> <p>*Health professionals employed to undertake assessment must be trained by Disabled People and appreciate PIP is new and not DLA. The present proposals do not appear to contain a particularly different design of benefit. There needs to be an option for an advocate to be present in the assessment</p>

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		<p>interview.</p> <p>*Any evidence required in reviews must be clearly linked to what is being tested. Is it a functional test of physical movement and/or a cognitive or brain functioning test?*</p> <p>*There is a large body of evidence and knowledge of the probable prognosis of most medical conditions and this should be used in determining frequency of reviews.*</p> <p>*Yes definitely together with spot checks made. Any views should be graded in terms of length, detail and costs – financial as well as stress for the individual.</p> <p>*No matter what rhetoric is used the shape of PIP as outlined in the consultation document is NOT simpler or less confusing than DLA. How can it be? The same complexities of DLA – two components with different rates are being envisaged this is unwise.*</p> <p>*Although fraudulent claiming of DLA is amongst the lowest of State benefits it still happens. The application and awarding process needs tightening up with thorough and complete assessments made. Putting much weight on self diagnosis leads to little constituency and is not satisfactory. Encouraging people to report changes is difficult, a simple easy to understand questionnaire could be used send out every year to help elicit any changes experienced by the individual accompanied by a strong statement of its importance of the need for its completion.</p> <p>*Any information required by applicants for PIP will obviously be related to the questions that are being asked. Some people may find the process of applying daunting and difficult, therefore clear questions together with examples would be a useful way to go. Also suggestion to applicants to think about their impairments, and how it affects them on a day to day basis. Once again CILs could provide a valuable service here supporting people through the process of applying.</p> <p>*Any form of compulsion of forcing people to seek advice is very problematic. Any advice and support that is available will be variable in quality and usefulness. However, it should be available, if required, confidential and open to all. Each area of the country, as recommended by the Life Chances Report a few years back, should have a CIL adequately resourced and staffed by Disabled People which could offer this type of service.</p> <p>*From savings, borrowing the money - if finance can be secured. Yes, but not instead of a regular payment for a predetermined time.</p> <p>*No comment</p> <p>*Very useful and important because of the confusing nature of DLA this may not be used enough.</p> <p>*More hardship by Disabled People, needless bureaucracy, less take up of services leading to less money spent in economy and potentially less employment.</p> <p>*Obviously any service or facility has its own reasons aims and criteria but clearly in the context of Disabled People much information is similar. The learning gained from the Right to Control Trailblazer sites – with different agencies working together must be shared and used to streamline requirements. *</p>
EM182	12-Jan-11	<p>I have read the DLA reform Plan on the Internet and the only way I can respond is to tell you our story.</p> <p>*We are both in our early 70's. We have 3 children aged 45, 41, and 36. They have all been diagnosed with Fragile X Syndrome which is the most common inherited cause of learning disabilities. All three have mild autism, our middle son being most affected. They all have mobility problems, unsure of steps and slopes and afraid of falling. We live in a rural county and mobility is vital to employment opportunities.</p> <p>*Fragile X Syndrome affects numeracy and spacial awareness. They are unable to do simple arithmetic and are unable to manage finance without a lot of help.</p> <p>*They live in their own house with a part interest only mortgage and part rent. Our youngest son claims Income Support, mortgage interest relief, DLA care</p>

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		<p>and mobility, lower rate.</p> <p>*Our second son claims Income Support , mortgage interest relief, and middle rate DLA (the old Attendance Allowance) and SDA.</p> <p>*Our daughter worked 30 hours, minimum wage for 14 years until 2007 when she was made redundant when the store closed. She paid her own mortgage and rent. She was unable to cope with attending job interviews at the Job Centre and applied for numerous jobs with out success. She subsequently claimed Incapacity Benefit on recommendation from our GP and an assessment was carried out by an Independent Medical Officer. She also claims DLA Care and Mobility, low rate. She continues to pay her own mortgage by topping up her benefits with her small amount of savings.</p> <p>*If DLA was taken away they would not be able to maintain their own home and move to be more independent.</p> <p>*Our daughter and two sons want to work but they will need a lot of support.</p> <p>* Our middle son has recently joined Mienterprise, which is a co-operative helping people with disabilities to run their own micro business. It is a pilot scheme in Hereford . Our son is supported to do this with his Personal Budget instead of using it for leisure opportunities. He sells local produce and is operating in the local community, which we think is contributing to 'the Big Society'.</p> <p>*Our daughter will also be joining Mienterprise in the next 2 months setting up a similar business to our son and again giving up some of the leisure and confidence building in her Personal Budget. They are also being helped by 'Jobs First'</p> <p>*Person Centred planning and a flexible approach to employment has been crucial in creating the right employment opportunities knowing that DLA can be relied on.</p> <p>*DLA is very important as it is not affected by earnings for someone who wants to work.</p> <p>*We trust that you will consider our comments when finalising the reform of DLA*</p>
EM183	12-Jan-11	<p>I am responding as an individual. I do not believe in your change in policy. My 2 years old son was diagnosed with Duchenne Muscular Dystrophy at 5 months old. With the sadness of hearing that my life has changed. The government of UK seems to be going downhill with its policies. Children deserve the right to gain an education and with your proposals disabled children will suffer. This is unacceptable from DWP to consider a proposal of this nature that affects so many unfortunate individuals.*</p>
EM184	12-Jan-11	<p>I would just like to say how glad I am at the reform of the mobility component of DLA. I was a nurse for over twenty years in care homes for the elderly. I saw many relatives driving about in new cars funded by the mobility part of the resident in the care homes DLA. The resident themselves never got out of the care home in the so called "Mobility Cars". This was due to them being bed bound or a deterioration in thier conditions that werent recognised in the system. The scheme I believe also let the have free insurance,servicing and a free new car every three years. It has been costing this country an absolute fortune. I even brought it up with an MSP, with no real outcome. WELL DONE!</p>
EM185	12-Jan-11	<p>Executive Summary*</p> <p>*Point 6: Certain individuals are already in receipt of the DLA and hold a letter stating that they are granted the Benefit "for life". How does HMG intend to deal with these cases? This will cause undue distress to the individuals concerned.*</p> <p>*Point 8: HMG states that the new Benefit – the Personal Independence Payment – will take into account aids and adaptations the disabled person uses to improve their quality of life. To their detriment or benefit? The document does not say (see later).*</p> <p>*Chapter 1 - Introduction and Context:</p> <p>*The changing approach to disability</p> <p>*Point 12: HMG identifies the advance in aids and adaptations. It fails to recognise that such aids and adaptations still remain expensive and difficult to</p>

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		<p>obtain. Disabled people use their DLA funds to purchase and maintain such aids and adaptations.*</p> <p>*Chapter 2 – The new benefit: our proposals</p> <p>*Our approach to reform*</p> <p>*Point 5: HMG suggests it will signpost individuals to support Is this financial or physical? Unlikely to be financial with the effects imposed via local authority budget cuts. Local charities and voluntary organisations will be under severe pressure to pick up those abandoned by Government policy.*</p> <p>*What will stay the same?*</p> <p>*Point 9: Essential the PIP remains non-means tested and non-taxable.</p> <p>*Detailed proposals for a new benefit</p> <p>*A broader focus on disability*</p> <p>*Point 14: HMG states that it wishes to update definitions of disability. It is absolutely vital that disabled people who use their DLA (or PIP) funds to really make an impact on their quality of life are not penalised for their effort. This point fails to take into account the additional physical and financial effort required for a disabled person to, for example, travel from A to B as compared to a fit and healthy person.*</p>
EM186	12-Jan-11	<p>The application process</p> <p>*The activities that will be assessed*</p> <p>*Point 26: HMG suggests it might assess, for example, whether a disabled person could plan and make a journey, understand and communicate with others. This fails to take into account that a severe disability can strike a most intelligent person who may still remain perfectly capable of planning and undertaking a journey, understanding and communicating with others. It fails to understand the heroic efforts and huge amount of additional time required to plan such journeys, which are only achieved by the disabled person's determination. Once again, penalising effort. *</p> <p>*Taking into account aids and adaptations*</p> <p>*Point 27: For HMG to suggest that it can take into account aids and adaptations as part of their assessment and decide to limit funds to those who have benefited most from such equipment is short sighted in the extreme. Aids and adaptations are still expensive and difficult to obtain despite the advances in design. They require initial purchase and ongoing maintenance and eventual replacement. A disabled person uses their DLA to contribute towards the cost of such aids and adaptations, often needing to top up their DLA funds with personal money. Social Services would come under severe strain if disabled people were no longer able to fund their aids and adaptations and had to rely on Local Authority help. The disabled person who buys their own mobility scooter to enable them to do their own shopping rather than have a Social Services carer shop for them is happier, healthier and cheaper to both Government and Local Authority! Yet again, penalising effort.*</p> <p>*OVERALL</p> <p>*DLA as it currently stands is cumbersome and the forms are overly complex. The system does need reform. But disabled people are marginalized enough already in society. Society is still about "what you do" rather than "who you are" and everyone is entitled to be part of our society. Being part of society and making a contribution (paid or unpaid) is beneficial for people's physical and mental health. *</p> <p>*It is vital to seek out and remove from the list those individuals who should not be receiving DLA (PIP) but do NOT penalise the efforts of those disabled people who are doing their best to be part of today's society.*</p> <p>*About me: I am 50 years old. I have multiple sclerosis, diagnosed in 1981. I am Patron of the MS Trust, also Chairman of Trustees of Gardening for the Disabled. I have extensive experience of living with a long term neurological condition and have contributed to work on Vocational Rehabilitation, Allied Health Professionals and MS Specialist Nurses.*</p>
EM187	12-Jan-11	<p>If t here are no changes in our needs, can we simply sign to say this ?</p> <p>*And save us an awful lot of trouble filling in pages and pages of difficult</p>

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		forms, which only add to all the stresses and problems that we as a family with two disabled children have to go through day to day , (not to mention saving your department a whole load of money and hassle having to collate and read through all this information) *Sometimes it feels as if I spend half my life filling in one form or another , this time would be much better spent playing with and helping our children.
EM188	12-Jan-11	<p>As someone with a damaged central nervous system that will never improve (unless there is a breakthrough in spinal cord deformity in my lifetime) I feel compelled to let you know the dread your proposals engendered in me.*</p> <p>*I became disabled in 2009 when my condition deteriorated without warning. The adjustment from being an able bodied professional person, a busy wife, mother and grandmother, the 'rock' professionally for a service supporting 40+ service users with severe mental ill health, and a 'rock' for my family practically and financially, is still hugely difficult for me to put into words, so traumatic do I find it.*</p> <p>*With the wonderful help of physiotherapists and occupational therapists and my GP, I gained sufficient control of my symptoms in 7 months, and returned to work. However, I am now dependent on an electric wheelchair, an adapted car, voice activated computer software, electronic door openers, and my long suffering husband who helps me bathe, dress, cooks for me, and generally fetches and carries...all without which I could not function.*</p> <p>*I am in receipt of DLA, higher rate mobility and lower rate care. Getting this benefit was THE most stressful performance, taking months of assessment and appeal. It really reduced me to being so low, I wanted to turn my face to a wall and not move again. I had to communicate in writing and by telephone again and again. Every professional supporting me produced a report, and an independent GP came to my home to assess me. When finally I was awarded DLA indefinitely, I felt such relief. I felt I could finally have the financial security to plan and move my life on. I was able to take out a bank loan to get the adaptations to transport, mobility aids, and home adaptations I need. Without this I am sure I would cost the country so much more.*</p> <p>*For the record, although I returned to work at the earliest possible time, I had to take a serious demotion and reduced hours, with a considerable hit in pay. I have exhausted my savings, and without DLA would not be able to finance the car, hoist, mobility aids etc that enable me to function. If my husband was not looking after me, who would wash, shop, clean, cook and provide personal care for £18 per week? Yes, I have an electric wheelchair and am deeply thankful for it, but the saving on shoe leather does not cover the cost of purchasing, maintaining and replacing expensive aids that I need to manage daily living.*</p> <p>*I believe there is a lot of rhetoric in your proposals about supporting disabled people to be more independent, contribute to their own lives and society by working, and enjoying a quality of life. However, there is a woeful lack of understanding of the realities for disabled people. I did not get DLA benefit by having a 'qualifying medical condition'. I had to prove over and over, and fight to show how my disability impacts on me. I lost months of wages, had to return to work on much reduced pay and conditions.*</p> <p>*I am dependent on my loving husband to ensure I can manage my daily living. Cars, hoists, electric wheelchairs etc are not 'one off' purchases... they need maintenance and replacing, and when one link in the chain does not function, the whole chain breaks for the disabled person. It is a constant struggle to keep going. Try going out in an electric wheel chair in snow and ice to get your shopping! Wheelchairs are NOT legs, they are mobility AIDS, not mobility, and very fallible ones at that. My wheelchair is currently suffering from what the engineer calls 'lazy batteries' leaving me slowed to almost a halt in the middle of a busy road, meaning I have lost confidence in going out alone.*</p> <p>*Many of us, I am sure, that currently receive DLA depend on it as a source of financial stability that allows planning and investment to maintain as much independence as our disability allows. Having gone from being able bodied to disabled in my 50's, I can assure you that it is a poor second, and I can no</p>

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		<p>longer truly see myself as independent, as I will always be dependent on others for help and support.*</p> <p>*Please, please do NOT say a wheel chair equals mobility, and please do NOT put severely disabled people through the humiliation and anxiety of having to re-assessed for a necessary benefit over and over again. How can security be built and dignity be maintained by your current proposals? Some people will not recover or improve without significant medical breakthroughs, which would surely be all the evidence you need, if a 'cure' is found. I for one would be first in line, and give up DLA or PIP in an instant.*</p> <p>*Until then, please leave me my dignity and a modicum of financial security to retain what independence is left to me. It should be very easy to determine those people whose situation is unlikely to change, except for the worse. My own condition is a degenerative one, and I need most of all to feel secure and positive, not feel that my 'ability' (i.e. disability-why would you assess the able bodied?) is being constantly scrutinised with the aim of reducing my benefit payments?*</p> <p>*Being dependent on a wheelchair is not like putting on a pair of glasses, believe me I know, I use both. DLA and its replacement is no 'compensation' for disability, no benefit could possibly compensate for that, and David Cameron of all people should fully understand that.*</p>
EM189	13-Jan-11	<p>I would like my views included in the DLA consultation process.</p> <p>*I have Multiple Sclerosis and recently started to develop Osteoarthritis. I have had MS for 17 years and although I have had remissions, have been getting worse for the past 5 years. If I had been re-assessed during the last short remission I may have had my DLA reduced only to need it again after a very short time? It is only because of the benefit that my wife is able to stay home to care for me as carers allowance alone isn't enough to live on. The mobility component allows us to visit family and go shopping.</p> <p>*During a past remission I did volunteer work with the probation service in order to try and repay the debt i felt but had to stop when my condition worsened.</p> <p>*My great fear is that a complex condition like MS may be misunderstood? I sometimes walk with crutches for short distances but in pain! I watch television at home but I am constantly being moved (every 5 minutes or so) due to painful spasm and neuralgia! I even use my laptop for short periods until the pain in my hands stops me. All of these things would count against me if taken out of context of my complete condition. The worst part of my illness is that in recent times I have started having cognitive problems which leave me confused and feeling lost, I have even lost whole days of memory which is very scary! How can the affect of this on my life be assessed? I am now totally unable to go out alone unless it is to the top of my street with my dog while my wife stands at the door watching. What a life ai? Who would choose this for the sake of a few pounds a week?</p> <p>*I understand the need for reform, I know the country must save money and I realise that the benefit system is probably complicated and costly to run.</p> <p>*Remember that children, the elderly, the sick and disabled are the weakest and most vulnerable in our country and we should care for the vulnerable otherwise what is the point? Yours sincerely</p> <p>*Ps; this e-mail has taken 3 days to do so may be a bit disjointed? (sorry)*</p>
EM190	13-Jan-11	<p>I accept that DLA probably needs reforming, but I think you should consider automatic entitlements to other groups of people apart from the terminally ill, which would probably save you time and money as well. My daughter is on the</p> <p>*autistic spectrum and has a diagnosis of asperger's syndrome, information about which can be found on the internet. It is a complex syndrome and involves social impairment. At present she has a lifelong disability living allowance</p> <p>*award, because she has a lifelong disability. She and others on the autistic spectrum are not necessarily going to answer accurately questions put to them by an independent healthcare professional, because they frequently</p>

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		<p>misunderstand questions and cannot always express themselves in a manner that is understood by others. This would put autistic people at a severe disadvantage if their PIP payment was dependent on ticking the right boxes on the day of their assessment. My daughter has three A levels and a number of GCSEs, and does actually have a scale 1 job as the government wishes for disabled people, however this is at quite great cost to herself and us because we have to give her at least two hours counselling every night to calm her down about the stress she copes with in dealing with social situations at work, trying to understand people and communicate effectively with them. This is why such a small percentage of autistic people can find and keep work (according to the National Autistic Society it is about 16%). As regards travelling to work (mobility) she can only use public transport on a bus that she knows (she can't work out how to use other methods of getting home should she need to).*</p> <p>*Similarly, I take issue with your plan to periodically review all awards. Perhaps you can explain to me how you think that one day my daughter will wake up and find she doesn't have asperger's syndrome any more.*</p> <p>*I hope you will take seriously what I have said in this email and that it is not one of those situations where you are going through the motions of "consulting" but have already made your mind up about where all this is going to lead to. *</p>
EM191	13-Jan-11	<p>I am writing in reply to your booklet and questionnaire: Consultation about changing Disability Living Allowance to a new benefit *</p> <p>*My interest is in the special rules part of the current DLA. The only question in the survey which seems to obliquely refer to this is Q5.*</p> <p>*I think that certain conditions, such as having less than 6 months to live, should continue to have a "fast track" application system akin to the current special rules. *</p> <p>*However, under the current system, I also feel that many people are claiming under the special rules because they have secondary cancer yet patently are not expected to die within the next 6 months. I do not think that secondary cancer in and of itself should be a condition which automatically qualifies for DLA or the new benefit.*</p> <p>*I speak from experience here, as I have breast cancer with bone metastases. I am currently undergoing another course of chemotherapy, and although obviously not 100% fit, I would not yet classify myself as disabled and my oncologist certainly expects my life span to exceed 6 months. Writing recently on a cancer forum I was attacked and ridiculed for not claiming DLA, and for suggesting that it was not right to accept money in this way. Every other respondent was already claiming DLA or planning to do so, despite the fact that some have already been receiving it for several years, and others do not appear to fulfil either the 6 month or other criteria for eligibility to this money. There are obviously people with secondary cancer who are suffering greatly and who of course should be entitled to DLA, but my impression is that the benefit is being distributed well beyond this group.*</p> <p>*The limited resources available should be available to those in need, for whom I have full sympathy. I hope that the application system for the new benefit will ensure that this is the case by being very specific about who is entitled to claim, whether through a fast track or normal application route.*</p>
EM192	13-Jan-11	<p>Thankyou for bringing to our attention the above mentioned document. *</p> <p>*Clearly the majority of questions are best answered by disabled persons themselves, however as a local authority supplying Mobility Support Services (freedom passes, blue badges and taxicards) you have specifically asked for our response to questions 18 and 19. which are given below.*</p> <p>*18. How important or useful has DLA been at getting disabled people access to other services or entitlements? Are there things we can do to improve these passporting arrangements?*</p> <p>*Firstly I would say that we welcome the proposal to make periodic checks on continued eligibility for Disability Living Allowance or the Personal Independence Payment that will replace it. It is most frustrating to receive</p>

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		<p>reports from members of the public who see an able bodied person using a blue badge and not be able to act as the person is automatically entitled to that badge under current legislation which "passports" those in receipt of High Rate Disability Living Allowance Mobility Component to receive a Blue Badge, Freedom Pass and Taxicard as well. It is also more than a little worrying if, as you say in the document, two-thirds of people currently in receipt of Disability Living Allowance have an indefinite award, meaning their continuing eligibility to receive this benefit may never be checked. *</p> <p>*I would say therefore that periodic checks on eligibility are the key to successful "passporting" arrangements since at the moment they work almost too well, to the point of even encouraging fraud since the possession of a blue badge entitles the holder to such a wide range of other benefits. *</p> <p>* 19. What would be the implications for disabled people and service providers if it was not possible for Personal Independence Payment to be used as a passport to other benefits and services?*</p> <p>*As stated above, it is my belief that the "passporting" scheme is entirely appropriate, but the way it has been applied has led to a great deal of unfairness within the current system. The key to a successful scheme has to be ensuring that information about each individual is correct, comprehensive and up to date. It would be altogether unfeasible for separate assessments to be made for each service or benefit applied for, therefore the passporting system has to make sense. For severely disabled people, getting to a mobility assessment as well as actually going through the assessment process has to be extremely stressful and difficult. It is therefore sensible to accept that once the assessment process has demonstrated that the required level of disability exists, one assessment serves to prove eligibility to other services available to those with the most severe disabilities (current legislation states that the requirement for a blue badge is that the person must be virtually unable to walk). Similarly, the cost of separate assessments for each service applied for would be astronomical, especially since the DfT is currently recommending a shift away from GP's letters and other unreliable proofs towards independent assessments by OTs to demonstrate eligibility for blue badges.*</p>
EM193	13-Jan-11	<p>I comment on the DLA consultation as follows</p> <p>*What are the problems or barriers that prevent....? I note the following - "Many disabled people in Britain are living socially isolated, cash-strapped lives and struggling to participate in normal activities." Life Opportunities Survey, Office of National Statistics, December, 2010*There is not a level playing field for disabled people. Statistics show that disabled people and their families are poorer than their peers and have less access to education, training and jobs because of discrimination and barriers in society. Therefore they are more reliant on benefits and services than other sections of the population. This is a very wide ranging question – There is no standard answer as different people have different support needs. This is not exhaustive</p> <p>*However I suggest the following</p> <p>*Not having aids and adaptations meeting their requirements – Some of the equipment offered by the NHS and social services is not fit for that persons requirements, or not available free on loan from the organisations.</p> <p>* Not being able to get out of bed, get washed and dressed, feeding, preparing a meal, toileting, overnight support, gardening, Shopping, Cleaning the house, walking the dog, not able to take medication, unable to take phone calls.</p> <p>* Not being able to get around - environment is inaccessible. Having to use taxis instead of inaccessible busses to get around. No transport near at hand or outside their front door. Not enabling people to go to the doctors, college, visit friends family, shopping, going to the post office, pub, theatre</p> <p>*Is there anything else about DLA that should stay the same? DLA should be kept in its current form.</p> <p>*What are the main extra costs that disabled people face? - This is a very wide ranging question – There is no standard answer as different people</p>

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		<p>have different support needs. This is not exhaustive. *However I suggest the following</p> <p>*to buy aids and adaptations meeting their requirements – Often the equipment offered by the NHS and social services is not fit for that persons requirements, or not available free on loan from the organisations. Often those who do not qualify for help from social services have to buy them. Maintenance costs of the equipment have to be paid for. The electrical consumption of using and charging up the equipment costs money. Adapting their homes. Buying computers to ensure no isolation in communication for deaf people and those who have visual, speech and dexterity impairments. Dexterity issues of mobile phones.. These items require replacement after a while They cost money.</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. Heating the home in cold weather all day</p> <p>*For getting around, buying a car (Mobility), buying a wheelchair, paying for a taxi which costs more than the bus. someone else to support the person for getting around, enabling people to go to the doctors, college, shopping, visit friends family,, post office and nightclubs,pubs. Public transport (IE busses and trains) is not right outside ones home. Most manual wheelchair users are not strong enough to push themselves so rely on someone to push them or buy a scooter / car /electric wheelchair.</p> <p>*The new benefit will have two rates..... Will having two rates per component ...? The benefit should be no harder to obtain than it is at present.</p> <p>*What, if any, disadvantages or problems could having two rates per component cause? No one should lose out. Different people with different impairments need support in different ways.</p> <p>*Should some health conditions or impairments ...? With the exception of sudden terminal illness as already defined there should be no automatic entitlement to this benefit for NEW DLA/PIP applicants. In the current economic climate if and when the PIP is introduced assessments/reviews should not apply to those whose impairments have not changed or will not change. To send a healthcare professional to everyone's home to give the client the same award as previously is not cost effective. Administrative costs have to be included - Doctors charge in the region of £250-£500 per hour for doing the assessment. At £250/hr this would be better spent on 5 weeks support at £50/week enabling a disabled person to remain in their own homes.</p> <p>*How do we prioritise support ...? Support for getting up, get 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. Hiring a sign language interpreter, Communicating through email. For getting around, buying a car (Mobility), buying a wheelchair, paying for a taxi which costs more than the bus. Someone else to support the person for getting around. Going to the cinema, swimming, Disabled people are entitled to some fun</p> <p>*How can we best ensure that the new assessment ...? Proper recruitment and training of PIP staff and assessors needs to be undertaken. Face to face Training should be given by people with variable and fluctuating impairments and other disabled people. On-line training is not effective as there is no interaction and real understanding of disabled people themselves. No false assumptions made by staff. Assessments should not be rushed.</p> <p>*Should the assessment of a disabled person's condition take into account ...? No. Disabled people are the experts. Aside they may or not be suitable. Many people have been given aids and adaptations which were subsequently found to be totally unsuitable. In these economic times it is a waste of money.</p> <p>*What aids and adaptations should be included? None</p> <p>*Should the assessment only take into account aids and adaptations where the person already ...? No the equipment suggested on a one off appointment</p>

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		<p>may be unsuitable for the person using it. It may not be available in the area or there may be a long waiting list. These facts makes this question invalid and unsustainable in the first place. The assessment should not be centred around the adaptations. E.g. S/he's got a wheelchair therefore no PIP. The ability to push oneself etc has to be considered. The question needs to be asked who is paying for the adaptation/ aid and maintenance some of which is very specialised.</p> <p>*How could we improve the process ... • How could we make the claim form easier to fill in? Availability of on-line application – Computer generated applications and accessible for all as some disabled people are unable to write or see the form and have to ask family to complete it for them. Family members may not be able to help for weeks. Some applicants currently have to copy the questions on the computer and in reviews this form would be updated accordingly. It would save a lot of paper and environmental issues and above all money. No-one should be excluded – Paper, audio copies and whatever other means should also be available. This could be kept on line and then sent to the disabled person for review. *How can we improve information about the ...? By itemising the impairment related costs they may incur.</p> <p>*What supporting evidence will help provide...? The disabled person, Members of the family, support workers, care managers. Trust has to be respected. Previous application forms. Anecdotal evidence says there is far less fraud in DLA than in other benefits such as housing..</p> <p>* An important part of the new process... professional. • What benefits or difficulties might this bring? No-one likes being examined by a benefits officer. Many people have been through the process many times before and will question why they have to go through it again particularly if the impairment is permanent and the impairment is not changing. With the current economic climate saving money is also an objective surely the necessity for a review should be considered – It will cost more to assess everyone. Pressure on the applicant as in the ESA applications – Not thinking of everything, The professional sees only what you are like on that day – might be their best day. We may as well have the online 24 page application form to complete anyway. Only new and borderline review applicants may be visited.</p> <p>* Are there any circumstances in which it may be inappropriate to require a face-to-face...? When a review is considered a waste of time as the persons impairment has not changed and will not change except for the ageing process . In these economic times when cost is considered in some cases the cost of sending a doctor may not be value for money especially if the doctor assesses the client to be on the same benefit.</p> <p>* How should the reviews be carried out? Should there be different types...? The criteria should be set on whether or not the impairment will remain stable. For example some people's impairments will not change during their lifetime except for the ageing process. We do not understand why the current system of DLA reviews is not considered. The current system allows the individual and the DWP to initiate a review periodically.</p> <p>*The system for Personal Independence Payment will be easier...? A reminder in different typecast in the annual letter sent. A separate reminder n the annual letter sent. No threat of automatic removal of benefits as different professionals have different opinions. *What types of advice and information ...? What the health professional is likely to ask in relation to their impairment and other details which is why they are applying!! It would be a better idea to have the 24 page form to complete so that nothing is omitted.</p> <p>*Could some form of requirement to access advice and support...? *How do disabled people currently fund...? Aids and adaptations are sometimes funded by the local authority and NHS. However some people are not funded by the local authority and rely on DLA , Family and charitable trusts to get money for aids. Some most appropriate aids are not available from the state and so have to be bought by disabled people using DLA and other sources.</p> <p>*Should there be an option to use PIP to meet ..? Yes This should be the</p>

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		<p>choice of the Disabled person. The option is available on DLA. E.G. buying a stairlift has the additional annual maintenance costs of servicing and call outs to be paid for.</p> <p>*What are the key differences that we should take into account when assessing children? Listening to parents, Growing up , getting heavier to carry, needs change. Assessments carried out more frequently to take this into account. The prime minister should be able to advise.</p> <p>*How important or useful has DLA been at getting disabled people access to other services or entitlements? Are there things we can do to improve these passporting arrangements? The mobility part of DLA can be useful for getting a blue badge for car parking – This should be automatic. The warm front scheme is only useful if your heating has broken not if its not energy efficient e.g. if the existing system is 25- 30 years old. This policy could leave the person with no heating for several weeks in very cold weather.</p> <p>* What would be the implications for disabled people and service providers if it was not possible for Personal Independence Payment to be used as a passport to other benefits and services? More bureaucratic assessments</p> <p>*What different assessments for disability benefits....? Disabled people should be able to do and keep a 'CV' which can be updated as their impairment changes and this could be used to avoid duplication.</p> <p>*What impact could... considered in developing the policy?*Is there anything else you would like to tell us about the proposals in this public consultation?</p> <p>The winners of this new benefit will not be disabled people and their families receiving up to £96 per week but the healthcare professionals lining their pockets with billions from the assessments carried out at £250-£500 /per hour and/or residential care homes charging up to £2000 per week.</p> <p>*Disabled people are not fraudsters. They are amongst the poorest of the poor. It is non disabled people who are caught claiming benefits that give us a bad name. It should be noted that people unable to work have to pay for social care whereas those working do not pay for services. Getting disabled people into work is vital but at the same time those unable to work under the age of 65 for whatever reason should not be penalised.</p> <p>*Together with the other cuts in ESA, Housing benefit, ILF, Social services, Access to work disabled people are being disproportionately affected in relation to the remainder of the population.</p>
EM194	12-Jan-11	<p>Q 1 – Access; Social inclusion; Attitudes towards people with disabilities; Low self-esteem; Cognitive problems*</p> <p>*Q 2 -I think that the mobility part of DLA is still essential for those in hospital or residential care.*</p> <p>*Q 3 –Transport; Equipment to make life easier; University – students who need an extra room for an overnight carer are penalized by universities as they have to pay a lot extra for their accommodation.*</p> <p>*Q 4 -It could if some people who were entitled to middle rate care component of LDA will be moved into the lower rate and lose money and some people who were in the low category could miss out altogether. *</p> <p>*Q 5 -Needs led benefits are a good idea as there needs to be gate keeping in place, and just because someone has a bit of money, it doesn't mean they don't face the same disabling barriers as less well off disabled people.*</p> <p>*Q 6 -Social activities; Ability to enter into the workforce or make positive contributions in another way.; To live where they want to live.;To choose the sort of support they need.</p> <p>*To have money to engage in the activities they want to.*</p> <p>*Q 7 People should be able to request a review if they feel their needs have changed, particularly if they have a deteriorating condition.*</p> <p>*Q 8 Yes – if people need to use taxis as they cannot get on public transport they will need higher rates of support. If people cannot be placed in their local authority as there is nowhere there that can meet their needs, then the increased traveling costs to go and see family and friends should be taken into account.*</p> <p>*Q 9 Put the part with signatures together – some people get confused at the moment as they are on two different pages. Advertise on TV, internet, give</p>

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		<p>information – spoke and written – to service users and organizations that support service users. Time and motion questions are too difficult for people to answer. It's difficult to gauge how long it can take to do things and it can vary.*</p> <p>*Q 10 Usually the person asking for the benefit! Any professionals involved in supporting the person Any family members close to the person – only with the person's permission*</p> <p>*Q 11 The independent person may not be able to perceive a person's disabilities having only met them once and potentially not in their home environment. For example, if someone with a brain injury lacks insight into their needs, they may say they're fine and come across as fine but that may not be the reality. If a person has high levels of anxiety, behavioural problems or very limited cognition then it may not be in their best interests to meet with an independent person.*</p> <p>*Q 12 The person's condition and whether it fluctuates or is a deteriorating condition should direct how after a claim is looked at again and checked.*</p> <p>*Q 13 - If you implement things like penalties for those who do not report a change in circumstances, it could penalize those with cognitive problems who lack insight into whether their needs have changed. They could find themselves faced with a fine for something that was beyond their comprehension. It should be made an easier process to report changes to the DWP*</p> <p>*Q 14 If it will change their existing claim. They should be given information on how much they will get. Of course help and advice would benefit those in need!*</p> <p>*Q 15 - People sometimes receive their aids and adaptations direct from their OT and at other times they will be means tested to see if they are eligible to pay a contribution.</p> <p>*Yes people should be able to use the benefit flexibly and if it helps them to overcome a disabling issue.*</p> <p>*Q 16 - Children may change more rapidly than adults and could request a review more regularly?*</p> <p>*Q 17 - 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>*Its really important that people automatically get help from other benefits and services as they will have even more disabling factors to overcome. We know people with disabilities have access issues = blue badge, and some require the need to have a warmer home = warm front.*</p> <p>*Q 18 - Have a database where information is shared among people at the DWP. It is problematic having to call different phone lines for different things as people haven't got access to information on different benefits, only the one for the phone line you are calling on so you can't get a comprehensive view of people's benefits.*</p> <p>*Q 19 - If a person has limited English they may not understand letters and may not fill in forms correctly or attend medical appointments. If people have short term memory problems they can forget to attend appointments.*</p>
EM195	13-Jan-11	<p>I am currently getting dla, since a cannot write with a pen i applied online can you please make sure this continues otherwise i cannot apply it took 2 weeks to because i cannot sit for two long because of back pain because my mum pushes me around in wheelchair because i cannot walk very far at all and takes alot off time, i lie down at home and very reliant on mom, i have had to type this with left hand because right hand is disabled. frankly i feel killing myself over worryes over my benefit, this is a anti-disabled government, i am taking legal advice on this matter.I am a christian what do i say to God when i kill myself because i would rather die than work in the pain i did work made it worse simply as that</p>
EM196	13-Jan-11	<p>I am responding to the consultation reform of the DLA. I am particularly concerned about the article on page 15 and Question 5 number 21. 'Payment will stop if the individual is in hospital or a care home. *</p>

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		<p>* I am a parent of two daughters with a learning disability. My eldest daughter lives in a care home in [REDACTED]. She is 37 years old and has a very severe learning disability. She cannot walk and is confined to a wheelchair, she cannot speak and has profound difficulties. At present she receives the mobility component of the D.L.A. which she contributes to the running of the mini-bus which was purchased by all the residence at the Home. There are 8 residence living at the Home and they all have challenging and severe problems. They all contribute to the purchase and the running of the mini-bus which provides them with transport to different places, including shops and outings in the summer. This provides for them some pleasure in their lives, and it also gives them some degree of choice in their lives.*</p> <p>* I was horrified to read that the Government are proposing to cut this benefit for people in Care homes. This will be a retrograde step as it will be impossible for people in Care Homes to go out and about. It will in fact be returning to the dark ages when people with any form of Mental illness or disability were locked away in large institutions!! It will make the most vulnerable in society even more reliant on their Home to provide this activity. Unfortunately Homes are bearing the brunt of the spending cuts and will not be able to afford to use their money for this purpose as they are being hit more and more by these cuts. The Home where my daughter lives is a wonderful Home and the staff and people who run it, have a high standard of care! they are a model of excellence in Homes for the disabled, the Care and concern they have for the service users are second to none, and I wish that they would receive more support not less!! However they will not be able to continue to meet these needs for the service users, and it seems that people who are living in residential Homes are being punished because they are living in a Home and not in the so called 'community living'. As a matter of fact if my daughter was living in supported housing like my other daughter it would cost a great deal more. [REDACTED] my daughter living at the Home has very great needs and her package would be very expensive indeed if she had to leave and move into a place like are other daughter. She needs 24 hour care which would mean that someone would have to live on a one to one basis with her!. In the Home there are 8 residence and it is a lot cheaper to care for 8 than 1. Each person should be looked at individually and that I agree with your documents, but to penalize very severe disabled people in Care homes is callous and is very unfair.*</p> <p>* I agree that there are people who abuse the system, and I would be the first to clamp very heavily on those individuals. I agree that there must be a system where the most needy are helped the most. Also IF people can work and there is work for them to go into to, then of cause that should be encouraged. However as far as my daughters are concerned, certainly [REDACTED], sadly she will never be able to work or lead a 'normal' life, and now even the small pleasure she has is being taken away. I don't feel that there will be support from the public on this matter when it is realized who is going to take the brunt of the cuts. Disabled people have not got broad shoulders so WHY are they being targeted?. The very fact that a person is in a care home at all means that they have a severe disability. In fact it is very hard for people to qualify at all, but there has to be a reason. I have long term health problems myself including chronic back problems! and I also am in remission from breast cancer, so sadly I cannot care for my daughter. In any case she and others should have a right to lead an individual life in the best place possible to care for their needs. My other daughter lives in supported housing and with the extra support she receives at least at the moment she can live a reasonably independent life, but she hasn't got the problems that [REDACTED] has, and unfortunately [REDACTED]'s situation is different. I would urge members to reconsider this proposal, as it WILL have a dreadful consequence on disabled people living in Care Homes. *</p>
EM197	13-Jan-11	<p>I am responding to this consultation document as a carer to my adult son who suffers from a chronic psychotic mental illness, and who lives independently with assistance from myself and mental health professionals. I have not answered questions that relate solely to situations of purely physical disability</p>

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		<p>as I do not feel that I am sufficiently knowledgeable to do so. My answers relate to my experience with Mental Illness.</p> <p>*1 For mental health sufferers, the problems present differently for different conditions. However, in general the problems are:</p> <p>*Social – difficulty dealing with others</p> <p>*Practical – inability to deal with normal day-to-day activities like paperwork, planning activities, making appointments, organising themselves</p> <p>*Personal health and welfare – looking after themselves</p> <p>*Getting around where fear, distrust and paranoia are involved</p> <p>*General perceptions of the general public – there is still a considerable stigma attached to mental illness and many misconceptions about the nature of various illnesses creating fear and distrust towards mental health sufferers</p> <p>*2 No comment.</p> <p>*3 Mental health sufferers can incur extra costs for getting around if their condition makes it difficult for them to manage public situations such as taking public transport, or they may need someone to accompany them in order to feel 'safe' taking part in activities. They may have to 'buy in' services to help with personal care, cleaning, shopping, admin support etc.</p> <p>*4 Having two rates per component may make life simpler for those who administer the system, however it may make it more difficult to obtain consistency of approach when people are being assessed, as the difference between the two levels will be greater.</p> <p>*At the moment, being on middle or high rate care component DLA has an impact on the rules being introduced to Housing Benefit in relation to single people aged between 25 and 35, in qualifying for a one-bedroom flat instead of just the shared room rate. Presumably of those currently falling in the middle rate, some will transfer to the new lower rate and some to the new higher rate. For anyone who currently meets the above requirement in relation to HB, if they were to be moved to the lower rate care component it could cause substantial difficulties if they were aged between 25 and 35 and found they were no longer exempt from the shared room rate.</p> <p>*Young people with mental health issues (and indeed other disabilities) would find the restriction to a shared room rate almost impossible. Shared accommodation would be totally unsuitable for many disabled people, particularly those with mental health problems, and could easily result in homelessness with the associated repercussions.</p> <p>*5 Having looked at the short list of those getting an automatic award which was included in Annex 1, I can see no benefit in changing this. It's hard to imagine that, if assessed, their assessment would come out any different, and going through the process would just add to the workload (and costs) of administering the system.</p> <p>*6 In developing the detail of the assessment, I hope you are consulting with Mental Health specialists as the needs of people with mental health problems are often quite different from those of people with physical disabilities, and less easy to see and define, and can vary significantly from day to day.</p> <p>*Ability to get around – not just being physically able to walk, but being mentally able to go out and mix with people in order to go from 'A' to 'B'</p> <p>*Interacting with others – fear and distrust can make interaction with others very difficult for mental health sufferers</p> <p>*Managing personal care – mental health sufferers may be physically able to wash, dress, etc., however they may also need to be told and encouraged to do these things on a regular basis.</p> <p>*Managing treatment – mental health sufferers may need someone else to look after their medication, making sure that prescriptions are obtained at the right times and making sure that the person actually takes their medication on a regular basis. The consequences of this not happening can be catastrophic. They also often need to be reminded, or indeed taken, to appointments. This can involve making sure the person is awake, dressed, and actually arrives at their appointment on time.</p> <p>*Access to Food and Drink – mental health sufferers often don't look after their diet any better than their personal hygiene, and often need to be</p>

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		<p>checked up on to ensure that they are eating properly and that their fridge isn't full of out-of-date food.</p> <p>*Maintaining Environment – left to their own devices they may never put any rubbish out, wash sheets, wash dirty clothes, do any cleaning, washing or washing up, creating over time, an extremely unhealthy environment. They may need to be told and encouraged to do these things, or they may need someone to do these things for them.</p> <p>*Organising their Life – Some people with mental health problems find it really difficult to motivate themselves to organise anything for themselves without substantial coaxing from someone else</p> <p>*Dealing with Admin – Some mental health sufferers will not even feel comfortable opening their mail, let alone dealing with the contents of letters. Clearly, bills need to be paid and forms need to be completed (particularly in relation to benefits) and often this will not happen without the intervention of someone making sure that it is done.</p> <p>*Impaired Financial Acumen – Many mental health sufferers have great difficulty dealing with financial matters, and need help in budgeting and making sure that bills are paid.</p> <p>*Admittedly, these factors are relevant to a different degree for different mental health conditions. However, for most of the activities listed above, there is no visual indication that mental health sufferers are unable to do these things, and in fact, if asked, they may say that they can do them. Whereas, in reality they think they can do them but in fact it doesn't happen. There is often a large element of denial about ability to cope. Do not mistake unable for unwilling. Mental health conditions often mean that people are not able to do things that they appear to be capable of doing and would like to do.</p> <p>*7 For mental health sufferers, because of fluctuating conditions and the nature of these kind of illnesses, a face-to-face assessment of half an hour or so is unlikely to give the assessor a realistic impression of their needs. It can take GPs and mental health professionals many appointments and hours to get to know their patient well enough to sensibly make assumptions about their condition and ability to manage it. They have a variety of 'good' and 'bad' days, and only after observation over a period of time are you able to make judgements about the impact of the condition on their life.</p> <p>*Because of this, I feel that face-to-face assessments for mental health sufferers are of little use, and they should be assessed using information provided by the people who have observed their condition and are best able to define the impact on their life: Their carer(s), Their GP, Their Psychiatrist, Community Psychiatric Nurse, or other psychiatric key worker</p> <p>*8 No comment</p> <p>*9 In the consultation document you say 'disabled people are experts in their own lives'. This is often not the case with people with mental health conditions. They are often in denial about all or some of their condition, and their responses to forms should be assessed in conjunction with responses from their healthcare providers.</p> <p>*Claim forms can always be made easier to complete. Often questions are straight-forward to answer if you're commenting on a physical disability, because they are written with that in mind. It would be useful to have two separate sections – one for physical disability and one for mental disability with the questions phrased accordingly as the assessment is likely to need different information.</p> <p>*It is useful to refer to any new benefit by adding the words 'replacement for DLA' for example so that people have some understanding immediately as to what the benefit is for. The 'old' name includes the word 'Disability' which gives a clue straight away. The 'new' name does not and therefore one would not necessarily know what it was for.</p> <p>*It's important that all JobcentrePlus staff are fully aware of the new (replaced) benefit and how it works. In the past I have made phone calls to JobcentrePlus asking about a certain benefit and been given totally the wrong information which meant that my son did not receive all of the benefits he was entitled to for a significant period of time. *Staff should be trained to point out</p>

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		<p>that the PIP benefit is non-taxable, not related to being in or out of employment, not means tested, not dependent on having paid NI contributions, not deducted from any award for Universal Credit (or ESA, IB, or IS), not just for people who are 'registered disabled'</p> <p>*There should be sufficient stocks of leaflets available explaining the benefit so that anyone asking for information about it can be given or sent a leaflet, and the leaflet should point to other sources of more detailed information about the benefit. People should never be told that they wouldn't qualify on the basis of a short conversation. They should be given all the relevant information and be allowed to decide if they want to apply for the benefit.</p> <p>*10 As already said, for mental health sufferers the appropriate people to comment are: Their carer(s) ,Their GP, Their Psychiatrist, Community Psychiatric Nurse, or other psychiatric/social key worker</p> <p>*11 Again, as already stated:</p> <p>*For mental health sufferers, because of fluctuating conditions and the nature of these kind of illnesses, a face-to-face assessment of half an hour or so is unlikely to give the assessor a realistic impression of their needs. It can take GPs and mental health professionals many appointments and hours to get to know their patient well enough to sensibly make assumptions about their condition and ability to manage it. They have a variety of 'good' and 'bad' days, and only after observation over a period of time are you able to make judgements about the impact of the condition on their life.</p> <p>*Because of this, I feel that face-to-face assessments for mental health sufferers are of little use and have the potential of causing undue stress to people who are already dealing with difficult conditions.</p> <p>*12 If you implement a system of say, bi-annual reviews for all PIP recipients, any money saved by the newly structured benefit will be swallowed up in administrative costs of implementing reviews in a rigid way.</p> <p>*Conditions can be categorised by medical and mental health professionals which could mean that different categories had different intervals for review.</p> <p>*In terms of mental health for example, someone suffering from acute depression has a good chance of their condition substantially improving in time. It may recur, but they have a chance of having good periods of good mental health. However, someone suffering from schizophrenia has a chronic psychotic condition which will require careful management throughout their life. I would suggest that this difference be reflected in the review periods.</p> <p>*Previously the few conditions which currently are awarded automatic DLA were commented on, and for example if someone is blind, or deaf/blind, their condition is unlikely to improve and they will always need extra help.</p> <p>*13 I don't completely agree with your statement that 'PIP will be easier for individuals to understand'. Certainly the name is less quickly understood as it does not contain the term 'disability' as does the current benefit. It will depend on how it is presented to the general public and that remains to be seen.</p> <p>*One of the problems I have encountered with the issue of reporting changes of circumstances, is that often benefit claimants are receiving a variety of benefits from different sources. I understand that grouping together Incapacity Benefit, Jobseekers Allowance, and Income Support under the umbrella of Employment & Support Allowance, and then moving to Universal Credit, should simplify the reporting of changes of circumstances.</p> <p>*It has, however, been my experience that for each benefit, there is a slightly different list of changes which you are meant to report.</p> <p>*So if you are receiving money from, HB, IB, IS, DLA</p> <p>*There will be 4 separate lists of items which you are meant to report and this makes it very difficult for the applicant to make sure that they are reporting the right things to the right people.</p> <p>*Also, the leaflets always say that you should report any change in income, but it does not say 'unless that change is to a revised amount of benefit which we will already know about'.</p> <p>*If there are changes to Incapacity Benefit because the applicant moves to a different band rate based on the length of the claim, or the award changes</p>

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		<p>due to increased amounts because of budget changes, there really is no need for the applicant to advise all the other benefits of this change in income.</p> <p>*Just unnecessary admin, taking up the time of benefits staff who are already struggling to keep up with their workload.</p> <p>*14 It would be beneficial if anyone applying for any benefit was also given leaflets explaining other benefits with guidance about how to apply if they think they might be entitled.</p> <p>*All applicants for any benefit should be made aware of all of the main benefits (PIP, UC, HB) in this way.</p> <p>*Some benefits ask for information about other benefits you are receiving, and if people are applying for more than one benefit at the same time, it can be difficult to sensibly complete the forms, and therefore they wait until the first benefit is assessed and granted before applying for the next one. This process can take some considerable time, and in the meantime applicants are losing out on benefits they are entitled to.</p> <p>*People should be advised to apply before the first benefit is granted, and benefits processing should allow for the fact that there may be a time-lapse outside the control of the applicant, before certain questions can be answered. The forms should allow for this, and benefits staff should liaise (say DLA and IB or PIP and UC) and take a more co-ordinated approach.</p> <p>*15 I don't think this is appropriate. People who find it difficult to face up to asking for more help shouldn't be punished by having their benefit withdrawn.</p> <p>* 16 No comment</p> <p>*17 No comment</p> <p>*18 DLA is useful as a passporting tool. As already mentioned, middle or high rate care component is already planned to impact on the new HB rule relating to single people between 25 and 35 and the size of accommodation they are deemed to need. This link needs to be safeguarded.</p> <p>*It would be useful if information on 'passporting' was provided to DLA (PIP) recipients to give them an idea of some of the other resources which may be available to them in the way of leisure facilities, blue badge etc. Generally one just stumbles across these things over a period of time.</p> <p>*19 The implications would be that the PIP money awarded to applicants would not stretch as far. For example, a discounted membership at a leisure centre for DLA (PIP) recipients means that less of their PIP money needs to be used to pay for what is a very beneficial resource for disabled people.</p> <p>* 20 I see no reason why information from PIP assessments and Work Capability Assessment used for IB (ESA or UC), could not be shared. They each might need slightly different information which presumably could be asked for specifically from the GP.</p> <p>* 21 No comment</p> <p>*22 I trust that your consultation process has included specialists in Mental Health, as this is a unique area of disability where there is a general lack of understanding within the population at large.</p> <p>*It is crucial that any healthcare professionals taking part in face-to-face meetings/assessments with people with mental health problems, be specifically trained in mental health.</p> <p>*We have experienced difficulties communicating with benefits offices, where, when you phone, you are only able to speak to a call centre person who is only trained to deal with a script. You are not allowed to speak to assessment personnel, and if you ask for them to contact you, they do not ring back.</p> <p>*Letters have sat in in-trays of staff on long-term sick leave not being actioned, and letters have been received sometimes up to 2 weeks after the date on the letter. Some letters have never arrived at all. When these letters include threats to stop benefits if they're not replied to, the timing become crucial.</p> <p>*In view of these matters and the lack of reliability of the Post Office and other contracted mail carriers, I am concerned that requests for reviews may be missed and benefits stopped for people who badly need them.</p> <p>*Perhaps, before stopping payment if a claimant has not replied, it would be wise to try to contact the claimant by telephone or contact the claimant's GP</p>

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		to see when they last saw the patient and make some effort to ascertain the current circumstances.
EM198	13-Jan-11	<p>*I feel that overall that the theme of the document is correct and that the most vulnerable must be protected. The benefit should reflect the needs of people with a disability today. and that the payment should reflect the impact on an individual's impairment or health condition has on their daily living. That it is not judged alone on their medical condition. It should be a payment to enable an individual to play a full part in society.*</p> <p>*1. The lack of clarity of payments and their purpose; Accessibility; Ability to use appropriate transport.*</p> <p>*2, The fast tracking of cancer patients.*</p> <p>*3. Specialised transport; Specialised clothing; Need for an individual Carer; Daily living equipment*</p> <p>*4. Why should there be two levels of mobility, when the person also has to apply for a blue badge when on the lower level. The criteria for a blue badge either at the lower level or with the local authority should be consistent and sourced at the same agency for all needs for mobility and disability. At present the criteria for a Blue badge is a post code lottery .Why not incorporate the attendance allowance into the system and which will eliminate age discrimination.*</p> <p>*5. The benefit should be on need not the medical condition as this varies between individuals*</p> <p>*6. Need to feed ones self ; Ability to dress and use bodily facilities e.g. toilet bathing</p> <p>*To be able to be mobile and able to access bed, toilet, living facilities, company *</p> <p>*7. The initial and two subsequent assessments must be face to face by an individual professional with clinical knowledge and access to the individual's medical and social information (there are individuals who regularly complete the form on behalf of others).*</p> <p>*8, (People a have a disability not disabled)Yes this may enable individuals to have the mobility component but not the PIP. to enable them to work. Wheelchairs, guide dogs, special seating etc should be considered when assessing an individual*</p> <p>*9, The form should be shorter and only available via a health professional or social worker. It should give permission for the independent assessor to have access to their social and health records and have a short assessment from that individual professional who gave them the form. Explanation on the purpose of the benefit should be explained by the assessor and in writing which the person signs as understanding.*</p> <p>*10 The most appropriate health professional is an Occupational Therapist The Clinical Professional must have an understanding of conditions and there effect. and have access to social and clinical information*</p> <p>*11. The initial problem will be the numbers of individuals but within three years this will resolve it's self. The benefits will be the elimination of subjectivity. It will bring credibility to the allowance and prevent fraud i.e. The completion of forms by others rather than the individual.</p> <p>*I can not think of any circumstances except in advanced cancer where it would be inappropriate*</p> <p>*12, The evidence and/or criteria on reviews should be decided by the face to face assessor to assess the condition and needs of the individual.*</p> <p>*13 By regular reviews*</p> <p>*14 Clear information what the PIP is for and what the process will be.*</p> <p>*15 Clear simple language, help line, easily readable instructions and examples*.</p> <p>*16 Some of these presently are provided from public services, where not the individual should have the option of paying for them or where assessed as essential and expensive a grant/loan should be available *</p> <p>*17. The needs of a child can change during their development as can the equipment/aids they need. Therefore regular re-assessments are needed .A</p>

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		<p>lot of the aids/equipment /support can /is provided by the number of agencies children are involved with.</p> <p>*Careful consideration to be given to the needs of the child and not the wants expressed by the parents.*</p> <p>*18 The ability to access other services should be clearly stated on the information with the application form also at the assessment.*</p> <p>*19 The quality of life and independence of the individual would be impaired.*</p> <p>*20 The information held by social services and health should be available to the assessor.</p> <p>*There should only be one entry/application form to obtain PIP, mobility, Attendance Allowance or Blue Badge this would prevent duplication, age discrimination, particularly as the age for retirement has changed. Postcode lottery and the ability for fraud where individuals claim for more than one of the same/similar allowance/benefit*</p> <p>*21 I do not think there is any impact*</p> <p>*22 I believe that there should only be one system for people with a disability to access resources/benefits regardless of age or degree of disability.*</p> <p>*At present an individual has to complete a number of applications with very similar questions to a number of agencies to obtain a variety of benefits. With the staff in these agencies requesting similar information from each other. One Agency could assess all the needs and the level of benefit i.e. financial, blue badge etc without the constant duplication there is at present of forms information or personnel and agencies.</p> <p>*Making a more cost effective transparent, fair equable system less open to fraud*</p>
EM199	14-Jan-11	<p>We were shocked to hear through the news media that there are plans to abolish the Mobility Allowance for all disabled people in care, with no explanation of why or whether it would be paid within another new benefit. We heard before and after the election, notably David Cameron, re-assuring us that people with the most severe disabilities will not suffer from Government reduction in spending plans. *</p> <p>*We cannot imagine a more cruel economic measure, as this will severely reduce our disabled daughter's ability to enjoy trips and outings and will almost certainly prevent her from having a one-week holiday each year away (in appropriate facilities). This is on top of the closing down of her residential home's transport department which had previously provided low cost specialised transport and is now to be provided at commercial cost.*</p> <p>*We are answering your questions attached to this letter having personal experience as parents of two daughters. One is severely epileptic (i.e. cannot be fully controlled by medication) adult with severe learning difficulties with an academic age estimated by professional test of 5-6 years. She is now in a residential home for adults specialising in epilepsy, The National Society for Epilepsy. Our other daughter had a stroke at age 22 following an operation for a brain aneurysm. There is no family history of either condition. We have also been involved in parent representative groups and some special school governance, transport support for disabled people, financial advice for some disabled people or their parents, plus the design of some equipment for the disabled. We believe we have some unique experience of disability care.*</p> <p>*We hope our answers will be useful in your decisions to re-design disability benefits and that they explain why the mobility components for severely disabled people in residential care must be retained. We understand these must be submitted before 14th February 2011.*</p> <p>*Ignorance, lack of confidence, historical attitudes, prejudice, poverty, access to facilities, political correctness influence or current policy, lack of special facilities and equipment, lack of funding, fashion, news media pressure or commercial interests, limited job scope description and training, Health training specialisation and restriction of professional attitudes, Fear of the law, fear of change, lack of publicity and acceptance of their condition, myths, professional obstruction or omissions of communication due to fear of prosecution for negligence, poorly worded laws, commercial interests of insurance companies not properly directed by equality laws to protect them,</p>

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		<p>no full Human Rights equality for the disabled in residential care (ref. EU directive), embarrassment due to their own condition, low self-esteem, society indoctrination of children by adults with some of the above, poor television research and script writing, unable to compete on a level basis, lack of encouragement to participate or compete, their comprehension of their condition (e.g. special needs).</p> <p>*Wrong priorities or poorly targeted policies set by governments, constant pressures of change of legislation and re-tests, pressure to save money.*</p> <p>*DLA or its replacement must meet the full needs of the individual and be fair in assessment of that need. This must include mobility and parking requirements in a care home and while at home temporarily or permanently based on the individual's detailed care needs document.</p> <p>*Specially adapted Transport may be required.</p> <p>*Transport with more privacy than public transport may be required (e.g. severe epilepsy may result in incontinence with faeces or liquids and application of necessary seizure control medication while out).</p> <p>*One or more people may be required to help them to wash, dress, makeup, and participate in activities such as swimming/paddling/floating or going to the toilet when out or at home.</p> <p>*Special equipment such as helmets to protect against a seizure fall (i.e. tonic clonic) or special wheelchairs due to their physical non-standard body shape (e.g. thalidomide). Even an electric toothbrush to help people with special learning difficulties or muscle disfunction to help to clean their teeth properly.</p> <p>*Special clothes and shoes sometimes outsized or special design, easy to put on design or unusual shape such as to allow for ankle splints (lateral support for a previously broken ankle that prevents further anklebone breakages)</p> <p>*Higher car park charges in some car parks due to shopping taking much longer due to reduced mobility or all the disabled parking places being used. This makes it more difficult to get into/out of the vehicle because the parking space is not wide enough.</p> <p>*Special, more expensive holiday accommodation needed with specially trained staff on site to help participate in activities and more staff ratio needed for dressing, drivers, 24/7 care, and pushing wheelchairs up hills!</p> <p>*Travel costs to/from parent visits, hospital appointments (non-emergency hospital ambulance service not always appropriate or timely)</p> <p>*Parents face extra costs too: for severe disability residents more travel to the few appropriate residential homes, research to find placements, costs of travel to care home meetings, costs of travel to/from London and specialist hospitals, trips to visit their resident, legal costs for trusts, travel for fund raising, replacement of clothes ruined by poor washing procedures training, thefts or loss due to the resident and staff forgetting a coat, extra cost if they arrange a holiday with the resident. Also more washing of bedclothes when at home tumble drier facilities, machine replacement, etc.*</p> <p>*4. It may make it easier to understand, but may also reduce the flexibility needed to meet the resident needs efficiently unless they are upgraded to the higher level, where a lesser payment might have been appropriate to meet that need.*</p> <p>*Ideally all claims should be based on their needs and circumstance but to do this efficiently has extra costs. There should be some discretion or automatic entitlement to reduce this cost and speed the benefits process. The worst case is for somebody who is permanently injured such as a soldier with 2 legs blown off waiting months for the assessment and administration process. It also implies that the needs have already and instantly been assessed correctly and are available, which is almost never the case we would imagine.</p> <p>*The answer will not be the same for all. A person with behaviour difficulties may need a wrecked car to play in more than a holiday away from the care home. One person may get in an agitated state and have an epileptic seizure because they do not want to return to the care home after a visit to see their parents, yet a home visit is essential to their feeling of belonging and self-esteem.</p> <p>*These priorities have to be left to the parents and Care staff to decide from</p>

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		<p>the unique experience they have of the resident.</p> <p>*Of course washing, dressing, bathing/showering, clothing, trips out, an option of at least one holiday for one week a year, exercise, a cuddle, encouragement to do something to help such as preparing food, cooking, and something creative such as painting, and for those with special learning needs (lower than normal academic level) continual education courses and sensory rooms. Why for special needs? Because they forget what they learn, may not be able to regularly practice them due to their disablement, and their brain needs exercise too. These are all essential activities. For those who are independent, they need to be able to work, regardless of the need to earn money or not. All need a feeling of achievement and someone who loves them – just like us, because they are all people!*</p> <p>*This is extremely difficult and it may be necessary to provide a special case for those with serious epilepsy, for example. If the medication is right they may not have a status epilepticus for some months or years. Get the dose wrong or do not ensure that the correct pills and dosage is given, or the wrong emergency “top-up” medication and they may be in hospital or critically ill, dead, or injured too within hours.</p> <p>*This requires specialists in epilepsy for their actual condition combined with parental input of history and experience to assess accurately. Parental input is essential in the case of special learning difficulty cases and complex, variable and progressive conditions such as serious epilepsy.</p> <p>*History of at least 5 years as well could be necessary. Because they failed a physical or mental test today does not mean they may not be able to do that activity next week or next month, and then again 3 months later be totally unable to do any test that day.</p> <p>*Regular testing or getting it wrong also has a cost for care homes, governments, local authorities and parents– appeals, re-testing appointments, training, recruitment, and production of reports. There may be a case for testing intervals to be varied to help assess some conditions, but in more serious cases their specialist consultants, care staff and parents input should carry the most weight. *</p> <p>*8. Again case by case. If an aid will help them achieve independence then it would be sensible to fund and provide it. If full independence can therefore be achieved then they may be able to work and therefore also perhaps pay taxes, providing a greater feeling of achievement. However support must then kick in quickly if the work is not there, and perhaps be at a different level where is work is part-time. Above all they must have the money to live.</p> <p>**• Should the assessment only take into account aids...? If the assessment is to take into account aids that may be available then a re- assessment should be made when they have received and been trained on the aids. After all, you would not expect a paramedic to treat a patient with equipment that they had not been trained to use would you?</p> <p>*9. Use colours or clear markings to highlight the relevant sections of the form. Ask only the questions you really need not too many “double check” questions. Make the questions larger type than the notes of explanation. Make the notes a large enough text for most elderly people to read easily. Keep the language simple for those who are less educated. Consult multi-linguists to try to use words that are similar meaning internationally to reduce cost of mediators and miss-understandings, provide a digital version that can be downloaded with Internet links to dictionary meanings for some technical terms, further explanation and examples to explain the question. Keep away from changing terms to present a political change of diction rather than a commonly used term that everybody would understand. Development testing survey before introduction is essential.*</p> <p>*• How can we improve information... Use all media approaches not just one. Memorable Animation, pictures or line drawings can speak louder than words. A teenager probably does not watch the news but follows “twitter”, older people appreciate TV ads/detailed programs and webpages. Such TV programs are educational for all – sooner or later they may be caring for someone else. Most of our knowledge of care and benefits has come from</p>

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		<p>word of mouth and experience as social services are not active enough in this area, although have been getting better. Perhaps the benefit forms should come with a software program that assesses what benefit you may be eligible for by live question and answer. This would save time in some cases for social workers that are very heavily loaded already.</p> <p>*10. Statement of care needs produced by people who know the resident is crucial and must be accurate. Past ones for comparison would help too. Any evidence on video (e.g. parent's home video), evidence from carers, parents, relations, relevant health professionals, academic tests, maybe even views of friends could be relevant in some cases.</p> <p>*11. With the greatest respect, there are health professionals and health professionals. If they are not relevant health professionals to the condition or conditions being considered it can be a waste of time and taxpayers' money. Some may have very limited knowledge of say epilepsy, as do many GP's. Examples – Zoë in geriatric ward given child dose to prevent seizures without consulting specialist neurologist. Parents asked normal doses for control of status epilepticus (sequential seizures) by A&E staff because they had never been trained or seen seizures. GP demanding parent stops child asking questions and being talkative when he was speaking – Did not understand her condition or special needs requirements.</p> <p>*Severe epilepsy is a very variable condition that is difficult to assess and treat for a neurological consultant, let alone a recent graduate who has never even seen a video of at least 10 different seizures that can occur with little, and sometimes no, warning.</p> <p>*Some professionals may try to use a defined test that is irrelevant or one that the individual cannot understand. E.g. somebody with special learning difficulties may say "yes" to "do you understand?" when in fact they do not understand at all what is required or what implications there may be if they do not perform it "correctly". Their care staff or parents would be a valuable source of assistance to the professional, saving re-assessment time and money. For example, they may have had a recent seizure and may look OK, but not be able to concentrate as well as they could on other occasions. However all tests/changes reviews put stress on parents and carers and this should also be considered, particularly where the disability is severe. Parents in particular endure a great deal of worry and man-hours doing paperwork and attending reviews, tests and hospital/medical appointments, ringing professionals, and extra travel costs over and also visiting their disabled sons and daughters.*It may even be necessary to visit two locations to achieve a relevant assessment result – e.g. home and work for someone more independent but unable to carry out some tasks they could do with an aid because of prejudice at work.*</p> <p>*12. For epilepsy this would be seizure charts, parent's reports/feedback, care reviews, hospital admissions, neurological reports, over several years. Bear in mind the condition in most cases is also regressive in nature, variable, unpredictable, and in many cases gets better from teenager to adult then worse again in middle to old age.*</p> <p>*• Should there be different types...Yes, and this would be more cost effective.</p> <p>*13. What changes should be reported should be carefully considered and explained. Reminders attached to claim forms to report changes are also useful but keep it simple. Also changes can be so variable with say severe epilepsy that some people could be in and out of a care home like a yo-yo up and down a string if applied very strictly! The effect on an adult with a severe learning difficulty as well could be catastrophic to their outward behaviour and seizure activity could increase with very significant extra A&E and intensive care costs to the NHS. The care reviews will give some indication of a change but do not tell the whole story, so history is important and so are views of neurological specialists, epilepsy trained care staff and Parents.*</p> <p>*14.For people with severe epilepsy and severe learning difficulties they would not understand the advice in most cases. The advice could be directed at parents and care staff – if it was relevant, so that they can apply on behalf</p>

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		<p>of the resident / applicant. Please bear in mind parents have a lot of form filing and worry over changes as well as residents, most of, which should be unfounded where the condition is severe. Therefore good communication is essential, true with any business or organisation.</p> <p>*15. From our experience, yes. Many parents or claimants do not claim what they are entitled to. Often they do not know what is available or cannot be bothered with the complex paperwork and meetings. Some are fearful of the process or speaking to professionals or afraid of Government departments.</p> <p>*Ways to reduce this are: - Simple rules, flexible system with some discretion and understanding in application, being pro-active in advertising, good communication between Government Departments to assure applicants are treated fairly but give confidence to them that fraudulent applicants are quickly rejected so public time and money is not wasted. Avoid involving more than one Social Services contact, clear forms, consistency including through changes or Governments. *</p> <p>*16. Funds come from parent's income, one-off payments from charities sometimes, NHS sometimes, and legal settlements, even the Mobility Allowance on occasions if there is anything left over from holidays and transport for the resident. Insurance claims for those who had a chance to earn money before becoming disabled. I believe there are no "one off" costs as everything wears out! However, we can see a need for a "capital advance" when a particularly expensive item needs to be purchased such as a protective helmet, special wheelchair for a paraplegic or a number of prosthetic limbs. As an amputated limb settles down and the patient's body adapts to a new way of moving. However, a separate fund for capital expenditure in some cases may be appropriate where it would be mean the disabled person could get back to an arranged and immediately available employment would be cost effective for the Government to provide.</p> <p>*Special equipment aids such as helmets and ankle splints should be stated in care needs and a budget allocated as these items wear out or get damaged on a regular basis. There is currently no separate individually assessed budget in DLA or Mobility Allowance for this.*</p> <p>*17. Parents should always be fully involved and present wherever possible. The term "children" should include adults with special learning difficulties that have an academic age below that of a "normal??" adult. They may be scared by the assessments and not understand instructions.</p> <p>*Police may need to be involved where there are cases of suspected abuse at home or in care.</p> <p>*18. Other than in item 22 below, the current system has served our daughter well. The Mobility Allowance has been the only way to ensure our daughter has a 1-week holiday away for the residential home and some money left towards some transport costs/trips out. However it has not covered all costs and some expenditure has been needed from our income.</p> <p>*The Mobility Badge has enabled us to park any car we transport our daughter in a suitably wide space in most trips out when she is at home. It is essential when shopping with her, as she cannot walk very far without a rest. We never abuse it, but we often see people parked in bays for the disabled that do not display a badge. The only answer is to keep reporting them to security at the car park or supermarket. We only use it when our Disabled daughter is with us and do not understand why people should disobey this simple rule. It would help to send a different colour badge each year (but review frequency as now) and make it a criminal offence to park without an authorised badge in the special bays, and all car parks must have a percentage of the park with free disabled bays.</p> <p>*DLA as a "passport" to other benefits reduces stress and costs to claimants, but their will inevitably be some overlap, unused benefit, or delay in renewals and this should be treated sympathetically where the original claim has been genuine. No system, and nobody is perfect and time everything exactly e.g. with self-employed earnings it should be made clear if the benefit assessment relates to their previous years accounts only.</p> <p>*19. For genuine claimants and their parents it would cause more stress, take</p>

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		<p>up more time (which has a cost to them too e.g. visits, transport, etc.), and would also cost more tax-payer's money, some of which would be in an excessive number of trained personnel.</p> <p>*20. What a good question, but we may not be qualified enough in current Government Department arrangements to answer it. Communication is everything. If the Communication is not understood due to lack of training or experience of the recipient it is the sender who is at fault. No genuine claimant worries about other departments knowing of their details surely, all they want to know is that the information is kept confidential to those who need to know. Data loss on CD's and poor IT security should be prevented and hated by everyone with very severe penalties. Costs can be greatly reduced by sensible information access authority at appropriate levels in each department. Costs can also be reduced by good training in communication and listening. Costs can also be reduced significantly by frequency of reviews tailored to the condition and individual. Why not ask the claimant/parents/care staff the most appropriate period before the next review at each scheduled review? The right for the parent/claimant to ask for another review at any time should also be retained (e.g. following a complaint this may be urgent).</p> <p>*21. Limitation by age is discrimination. It should be applicable from cradle to grave, as some disabilities need this. E.g. an 80-year-old may now need a wheelchair or they may need a wide parking space because they are fit enough o drive a car. Both of these could maintain their independence from care.</p> <p>*There needs to be individual consideration for some severe disabilities, in particular severe epilepsy and special learning difficulties for example.</p> <p>*Example1: epilepsy is very variable both by age, gender, general health, and sometimes temperature, environment, and medication. Some people's seizures are completely controlled with one regular dose of medication while other require several different seizure control drugs and just slight variation in the manufacture of one drug can cause toxicity or a seizures. It is so variable that categorising abilities into boxes for those most affected just will not work. Those that are controlled easily can lead very useful lives but those severely affected require 24/7 care.</p> <p>*Example2: Special Learning difficulties have special problems. There must be a parent /relative or experienced independent representative that can represent the interest of the claimant and help to communicate with them. *</p> <p>*22. There is no specific budget in DLA or residential fees specifically defined and ring-fenced as Clothes, or transport, or holidays, but a higher rate for increased personal care. There should be a minimum definition of need of these items in addition to the cost of care staff and replacement or rent of appropriate buildings. Each resident is different and therefore these needs should be defined in the statement of care needs and reviewed regularly. The Mobility Allowance provided part of this and some comes from parent's income, some of whom are already retired and on a restricted budget.</p> <p>*If the Mobility Allowance is scrapped for people in residential care the new benefit must include ring-fenced budgets to cover what the need is in relation to getting around. From what we understand from the Disability Act then and only then will each resident will have the same or better quality of life, satisfying the legal requirement. If the budgets are not ring-fenced the Residential Care Home or Local Authority will try to spend it on other care costs or other services that are only partly for disabled people.</p> <p>*Clothes may need to be a special shape or a style easy to put on to encourage them put it on themselves. They might need 3 sets minimum to wear in the home, nightwear, and at least 2 outfits for trips out including a change of footwear, and at least 1 warm coat for winter. Those with regular incontinence may require more. Washing and tumble-drying damage should be considered in the budget too, because the clothes may have to be washed more often.*</p> <p>*Transport budget should include:-</p> <p>*a) to / from education or experience courses needs</p> <p>*b) to/from social and recreational needs, including home trips</p>

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		<p>*c) to / from medical appointments needs</p> <p>*d) to/from and during the annual holiday *</p> <p>*Disabled people in care homes should expect an option of at least one week's holiday away per year if appropriate to their case. The care transport and accommodation budget for this will depend on their disabilities, age and financial situation of parents, availability of suitable accommodation and environment.</p> <p>*The statement of care should include essential personal toiletries and hygiene requirements, the cost of meals off site where appropriate, and personal dietary requirements. The actual discretionary expenditure budget per week for residents in care is £22.30 per week (financial year 2009/2010) should not be used for essential care items.*</p>
EM200	14-Jan-11	<p>I am a volunteer CAB advisor and helped a client yesterday and was flabbergasted to find out the following:*</p> <p>*They were a couple 53 and 65, both claimed DLA care and mobility and both claimed carers allowance for each other.</p> <p>*The 65 yr old had £4.64 a week occ pension this was then made up to £380 a week with state retirement pension and Guaranteed pension credit - both claimed the disability premium on the pension credit.</p> <p>*Overall they received £675 a week in benefits plus full council tax benefit and help towards their mortgage. This totals over £37,000 a year tax free. In order to earn this you would have to earn in excess of £50,000.*</p> <p>*Morally this is wrong and the new system should have an overall cap on what benefits can be claimed plus everything should be taxable. If you are receiving over the tax limit then it's only fair that you are taxed.*</p> <p>*I believe that the Employment Support Allowance should be easier to claim, however DLA should be the reserve of those really disabled, whereas at the moment it is fairly easy to get DLA and virtually impossible to get ESA.</p>