

## Disability Living Allowance reform consultation – email responses 1 to 100

Respondent Number	Date Received	Response
EM1	06-Dec-10	<p>i am registered blind myself and have been since the age of 16. I am disgusted to hear of the governments attempts to reform the disability living allowance. I feel again it is another attack on the less well off and people who cant defend themselves. I feel there is no need for a huge over haul of this benifit what so ever. So i do hope these plans are scrapped. Maybe a little tweaking herea nd there and a bit more encouragement to work possibly but no mass over haul is needed at all.</p> <p>I am angered by these plans to take people off of DLA and take away their chances in life. People struggle with teh little money they do get on DLA at the moment i feel there is room to improve this amount not decrease this amount.</p> <p>I am horrified to learn of these proposed changes and the language used for the proposals.</p> <p>Hope that helps i will be protesting against these changes if they go through i swear</p>
EM2	06-Dec-10	<p>After reading the glib tongued view on reform of DLA on the DWP Website, I have come to the conclusion that the reform proposals must have thought up by some sick minded *****.</p>
EM3	06-Dec-10	<p>Isn't it bad enough that you have taken my Incapacity Benefit and left myself to live on the £247 per month (Mid Rate DLA ) now your going to take that away. Why don't you just give us a lethal injection and be done with it. I for one will NOT attend any of those assessments. You take the income away i simple die. I don't think I will see this year out as I've no food left. I have had enough of the stomach cramps I've been getting since April when you took my main income away. Yes! I'm one of the 37% that never reclaimed because of being to ill. Already survived one overdose during that time. How can you justify asking someone to live in their pasts consistently due to those assessments I can't do it any more. Please give us the lethal injection there's nothing left.</p>
EM4	06-Dec-10	<p>have been trying to get the moblity as I got wear and tear in knees carnt bearly walk and in neck and know my back also got unler neve troble in hands carnt grip and a conition called degerogebut at 45 they sayl am two young a should have carer 24 7carnt get housebound most of the tme I mam having consent opertions but not working told I be in a wheel chair within two how bad my codition is</p> <p>[Second email received immediately afterwards] also put people in charge at blackpool who know what meical promblems are some don't even know what degeogre is also diebetes</p>
EM5	06-Dec-10	<p>I am responding to these questions as an individual. I am registered blind and currently receive the lower rates of both components of Disability living Allowance. My responses are personal and all opinions my own. I fully understand the information set forth in chapter 6 of the consultation as regards the Freedom of Information Act and hereby consent to my responses being shared in whole or in part, under the proviso that any part copies made include this paragraph in full and unaltered from its original form and with my E-mail address, seanr@randylaptop.com, included, should any reader have questions or comments they wish to address to me. This response will also be stored online in the blog section of my personal website at www.randylaptop.com where commenting and discussion of the points I raise is encouraged.</p> <p>1. Having no vision means I have to approach daily tasks very differently to many of my sighted peers. my preferred approach is always to do whatever I can for myself where practical: this includes things such as using computers and scanners to read my own post, relying on satellite navigation systems to</p>

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		<p>aid me in mobility, using online shopping and banking, and generally relying on modern technology to enable me to live as actively as I possibly can. To do this naturally requires money. Scanners and computers are not inexpensive, and the initial payment and continual maintenance of access equipment is a constant financial burden.</p> <p>the most complex (and indeed needless) barriers I face in an attempt to lead a full and active life are most readily summed up by the social model of disability. In particular people's attitudes and organisational barriers draw the lion's share of my attention. This is most keenly felt when organisations fail to accommodate my disability (by not providing or accepting documents in alternate formats, refusing to recognise that transport is very difficult and working from guidelines that attempt to tar all disabled people with the same brush, just to name a few instances). I see no reason why with financial support and drives to change these attitudes and remove barriers that I could not have a healthy, fulfilling lifestyle akin to that of any able-bodied citizen.</p> <p>2.As you have rightly pointed out, maintaining the key principles of DLA (and in particular the cash nature) is vital. I know scores of disabled students who have been provided with thousands of pounds of unnecessary technology by well-meaning assessors who feel free to spend money because it isn't their own. Should PIPs take the approach of forcing recipients to be assessed into receiving aids of the government's choosing then the entire concept of saving money may as well be abandoned here and now.</p> <p>3. costs for transport and technology are the main extra costs I face. Free bus travel is an excellent starting point, but only a third off rising rail fares and absolutely no assistance with taxi costs where necessary makes independent travel very difficult, for work or leisure. Only frugal saving and the help of family has allowed me to attend job interviews and partake in social events in the last few years and the lower rate of mobility which goes towards these costs provides very little security.</p> <p>the care component would not meet my technology needs plus those of paying a carer or assistant where I were to need one. many aids and accessibility tools are very expensive to purchase outright and also cost a great deal to maintain.</p> <p>4. Clearly having a single rate is impractical. mobility payments for a person with vision enough to read a bus timetable should not be as high as for someone like myself who cannot, for instance. Whether it's best to have a two-tier system, or scaled payments for premiums is beyond my expertise to advise.</p> <p>the issue that needs to come forward here is that of consistency. I know people receiving middle care or mobility or both, with no other disabilities than a visual impairment which in many cases is less severe than my own. this is patently unfair and ridiculous and harms not only the dignity and independence of the disabled but the taxpayer as well. A tiered approach is undeniably needed (you can't put all disabilities in one basket) but those levels need to be set in stone and applied across the board.</p> <p>5. This question seems to imply that an automatic entitlement glosses over any "needs and circumstances" of an application. Surely this is far from the case - an automatic entitlement should simply mean that an individual has an overwhelming need for the benefit. you already recognise that claims made by the terminally ill will be fast tracked, "to provide financial support as quickly as possible". an automatic entitlement should do the same for those who may need the money to go on living.</p> <p>The example cited in the consultation is that of renal dialysis (chapter 2, section</p>

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		<p>19), a topic on which I am not qualified to comment. Severe visual impairment comes under the same heading (as described in Annex 1). Were I to suddenly lose my eyesight I would expect the government to recognise the severity of the issue and fast track my application. This also applies to your plans for the "qualifying period", where a layman's reading of the current proposals seems to imply that I would need to be totally blind for six months with no financial aid before I could even consider getting any fiscal assistance, and then only if someone could guarantee the blindness remaining for a further six months. Clearly this is unacceptable and cruel and I trust that this point will be modified accordingly.</p> <p>To sum, I believe that abolishing automatic entitlements ipso facto would cause more problems than it solved. the definition of automatic entitlement may need changing and the rules on how and for how long automatic payments are provided may need changing, but a disabled person should not be told that they aren't entitled to anything for half a year unless they're dying.</p> <p>6. For me personally, being able to live independently, to manage my own affairs as much as possible and to be able to get out and about are my essentials. With these things in place I should be able to maintain my household, with the privacy and dignity due any citizen, and be able to leave my house and socialise with friends or participate in any activities of my choosing. This means that I need computers and various technologies around the home where others may choose a full or part-time carer. I want to be able to use buses, trains and taxis without worrying about filling the fridge because I spent the money on a short trip to meet friends, and not be forced into attending only those events put on for the benefit of the disabled because of prohibitive transport costs. In an embarrassing state of affairs, I am currently able to do more over the phone and internet with my bank than I am with my government, who's bureaucratic heights seem purpose-built to disempower me simply because I have a disability. These are just a few of the things that need to happen for my full and active life to be equal to that of the person reading this.</p> <p>7. My particular situation doesn't change from day to day or even year to year. I may need additional support at certain times, such as if I move home and need to learn routes with a mobility officer. For me, the best thing that could be done regarding changing conditions is for the government to remember that for many people the circumstances do not change and that harassing those people only wastes time, effort, and of course money.</p> <p>8. By "take into account", I hope the assessment doesn't mean "cut the payments by an appropriate amount". Walking to work may be slightly quicker for someone using a guide dog than for someone using a white cane, but that does not change the person's circumstances and should not effect their entitlements. As well as money the government should almost certainly empower people with resources and aids they may find useful, but it is the place of that individual to decide what they want to use or not, with help provided if they ask for it.</p> <p>information should be provided on all practical aids, irrespective of how easily they can be obtained. perhaps the government could even secure employment for some disabled people by creating some posts where individuals can phone or e-mail with questions on what aids are available for their particular disability. it may seem a novel concept, the disabled helping the disabled, but it may go a long way to showing the public that a PIP is much more than a handout to those who seem less able.</p> <p>9. The government could start by examining the current information available on DLA from people like the RNIB. Then maybe the government could ensure that the staff dealing with the information understand it themselves. I have</p>

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		<p>been at too many jobcentre interviews where the advisor had been advised, and not the other way around. The points about the form are also well-taken. An online application would be a good start, along with clearer instructions and a much more objective and fair assessment process.</p> <p>10. Individuals need to be able to make their case and state their circumstances without being told what's wrong with them by well-meaning professional bodies or organisations. Similarly, the assessors need to have clear, defined standards to apply where people with the same issues receive the same amount of money. Anyone with input on an individual's case should be allowed to submit evidence for the claim.</p> <p>11. a healthcare professional would need to fully understand the individuals case before their evidence was valid. I have no social worker or therapist and have never needed one, but my GP, though he may understand the technicalities of my disability, mightn't be the best person to fully explain the daily consequences of that disability on paper. those disabled but attempting to live their lives normally should not be penalized just because someone has written something out of their control.</p> <p>As stated, the only professional I have to hand is my GP, who even with the best of intentions may not be fully aware of my difficulties. For the majority of cases there's no reason a professional could not be involved, but care needs to be taken so that an individuals testimony is not overshadowed by those supposedly expert.</p> <p>12.I cannot answer this question in depth until criteria for what types of disability engender what payments. Someone totally blind with no other disabilities may be entitled to a specific amount, which no professional can alter. In that situation, an interview would be pro forma and simply serve to prove the individual was disabled. Without further insights into the proposals I cannot comment further.</p> <p>13. The onus needs to shift to the DWP, not the individual. it is true that people should report a change. more examples of what constitutes a change should be provided and someone specifically assigned to determine whether a change is significant when it is reported.</p> <p>14. An adviser with a complete understanding of the benefits system could be provided to help fill out an application and answer any questions. If the government are truly serious about changing DLA, a pool of resources and information needs to be maintained so that an applicant can be told about particulars applying to their specific situation.</p> <p>15. the government should not force people into situations where they aren't necessary. for example nothing will change the fact that I cannot see. Whilst buying expensive GPS systems or living in a house in a big city may increase my independence, this should always be my choice. temporary conditions are different and, should the government continue to provide PIPs for conditions such as depression treatment should be encouraged.</p> <p>16. Certain equipment is very expensive and an option to allow PIPs to be provided for a purchase would be useful to many. This would need to be implemented in such a way as to minimise overheads. With advances in online banking and such, this is hardly something that would need to take up a great deal of extra money.</p> <p>17. I was under the impression that DLA only started at sixteen years of age. There's no reason why children should be treated differently to adults, other than to monitor changes more closely. during my claim as a teenager the flawed system allowed a parent to receive my payments by declaring me</p>

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		<p>mentally incapable of managing my finances. naturally, if there is a mental impairment, provision needs to be provided - but this holds to anyone regardless of age.</p> <p>18. Simply receiving DLA entitles people to other things (a good example being help with the digital switchover). This needs to continue and increase where possible. a simple "are you receiving PIPs" from an organisation that participates in a passporting scheme could clear the way for much entangling complexity.</p> <p>19. The paperwork and overheads would increase needlessly. many cases take receipt of DLA as proof that individuals are entitled to whatever services they are offering and this should in know way be stopped.</p> <p>20. With the individuals consent, of course, anything that can be shared should be. if by looking at my PIPs claim my local authority can see that I am blind and therefore cannot read print, all the more paper and time would be saved by them not sending me letters I have to make special efforts to read.</p> <p>21. The payments you are providing are for disability and have little impact on equality groups, as your own initial assessment indicates. The former government was very intent on asking questions about age, race, ethnic group and so forth in a supposed attempt to improve diversity. This seems utterly inapplicable here.</p> <p>22. I can see the need for changes in a system which has grown needlessly complex and which clings to outmoded times and definitions. Far too much reliance is made on single reports from health care professionals, and it is a good fact that this government recognises that disabled people are expert in their own lives and should be able to express their needs, without being confined to ticking a box to define all their problems. care is needed so that payments are not stopped to those who need them (see my response to question five). With this consultation I am hopeful that the government will listen to such responses and make wise, balanced, and appropriate decisions.</p>
EM6	06-Dec-10	<p>1. The problems range dramatically dependent upon disability. For myself, transport is a major issue/barrier. Other problems can include, dressing appropriately /choosing suitable atire, managing health/hygene. Attitudes play a significant role- for instance I know a lot of visually impaired people who won't use their local gyms due to discrimination. Its a very difficult question to answer, as each disability is very different, which is a key point. Being visually impaired myself that's the easiest thing to focus on- however all VI people also differ in their needs.</p> <p>2. I don't feel that those who are severely disabled should be reassessed frequently, unless it will not cause them any stress whatsoever. For example; my uncle is severely epileptic and has learning difficulties - he's now 51, this is never ever going to change. If he can't make himself a sandwich now, he never will. Checking up on people like him just causes unnecessary worry for the carers and claimants. I do appreciate though, that people's circumstances do change - for instance someone with a fear of travel can overcome this, or learn to cook. Only the very severely disabled need be left alone- as long as a definition of severely disabled can be reached!</p> <p>3. Travel - for instance being blind and not particularly confident with public transport (+living very rural) I often have to take taxis. Help - i.e someone to garden, decorate, clean. Filling out forms and reading post can be a cost if done through an assistant. Again it varies by disability.</p> <p>Equipment- using myself as an example I have to have screen reading software to access my beloved computer. This set me back around £800- painstakingly saved for! Not all equipment and enabling technology is free, or</p>

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		<p>otherwise provided. Even something as simple as a weighing scales for the kitchen (talking one) can be easily double the price of its mainstream counterpart.</p> <p>4. If the lines between them are clear, i.e higher and lower rate - clearly defined.</p> <p>Making the lines unclear - for example currently some people who have more sight than myself are on higher components, something which is very unfair. Maybe only those with no chance of improvement or recovery should get permanent higher rates.</p> <p>5. Obviously the terminally ill should be fully entitled straightaway. For the majority it should be based on the needs of the applicant. Maybe there should be a shorter process for those with no chance of improvement with a severe disability - i.e epileptic, learning difficulties - needing 24/7 care. At the moment a lot of blind people are automatically entitled to many things - something I strongly disagree with, even though i'm blind myself. I don't feel its right to "lump" my disability in with those who are obviously much worse off than myself.</p> <p>6. Impossible to answer without discussing every disability. A quick process will help most severely disabled. Not having to travel for assessment etc. For myself travel costs feature high on my list- but this probably isn't the same for a deaf person, or someone with a wheelchair. Generally speaking, being able to get out, eat properly, dress and be clean are what I'd class as top priorities for every day life.</p> <p>7. By respecting what won't change, and what will. By listening to the claimant. i.e my uncle (mentioned above) won't change. My partner, also blind but with very limited skills, may (hopefully!) improve - in the sense of cooking, choosing own clothes.</p> <p>Fluctuating conditions are more difficult, maybe the PIP payment should simply be averaged out - for instance if someone is immobile for a month, then fine for a month, instead of start-stopping, payments can be averaged.</p> <p>8. Personally I'd say know. Each person is very different, some of us use very few aids- others rely heavily on them. To take into consideration could lead to assuming that those of us who don't use many are more capable - this often isn't the case we've just adapted differently, been taught differently, or are more comfortable/confident without them.</p> <p>Considering eligibility is fine, as long as the claimant isn't "forced" into getting these aids. I don't feel the entitlement should be based on this- otherwise you risk removing personal choice. i.e screen readers are fairly plentiful these days, ranging from around £1000 to free. I use an expensive one because it was my choice, my DLA and I researched what suited me best.</p> <p>9. An online version is essential - otherwise anyone with sight difficulties are excluded. Filling out over the phone, also. Simple "tick boxes" work great, but often the choices don't reflect what you truly want to answer: for instance: Can you travel independently? yes/no. For me, I'm in the middle -i can walk and have great mobility but cannot catch a train alone. So boxes for extra info will not only help the claimant feel they aren't being grouped into boxes, but provide more detailed info for the assessor.</p> <p>Nice simple English!</p> <p>10. Any medical certificates, i.e blind registration.</p>

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		<p>In most cases the disabled person themselves, or those who live with them can give the best answers. Doctors are often biased - or will write a letter to keep the patient happy which isn't really right, or fair. If medical assessments should be done they should be done by an external person - but with an open mind. Disabled people cannot be grouped, i.e not all deaf people are the same, etc.</p> <p>11. If the professional is open-minded and not ticking boxes it will enable an honest and true discussion of the disabled persons life/difficulties. Some conditions vary dramatically and are difficult to assess- many mental ones for instance. Travel could be a problem, a willingness to do these interviews in someones home will alleviate a lot of worry for many disabled folk.</p> <ul style="list-style-type: none"> <li>• Are there any circumstances in which it may be inappropriate to require a face-to-face meeting with a healthcare professional – either in an individual's own home or another location?</li> </ul> <p>Where the claimant is terminally ill or severely disabled.</p> <p>12. Maybe. Its difficult to answer - i.e if someone can't cook and therefore needs more help but is trying to learn, how can you assess this? i'm a good cook, but would struggle to produce a decent meal whilst being watched/assessed, so maybe a report from a teacher would be appropriate in that situation?</p> <p>13. Strict fines for those who are caught out. Random checks.</p> <p>14. Where they can gain further assistance, useful contacts, websites, organisations. It would be useful but only if provided as an extra- not something more forceful.</p> <p>15. It could. i.e claiming to have back issues but refusing to get treatment should be punished. But, using a guide dog and happily travelling on public transport should not be compared to using a cane and failing to travel independently.</p> <p>I think all options should be explained - i.e you can get treatment from here, but only enforced if appropriate to the person.</p> <p>16. I currently save my benefit to get what I require. For much more expensive items I'll occasionally apply to a fund. Many people I unfortunately know, use their DLA as beer money and for pizza delivery - so giving them payments to buy equipment would infuriate many! But it could just solve the problem! I think it should be optional though.</p> <p>17. Children cannot express as clearly what they can and cannot do. They develop at different rates and parents unfortunately will not often give honest answers - some will want their child to seem better (thus meaning they won't get the help they need) others will make there's out to be worse.</p> <p>18. Not terribly great! Maybe a PIP entitlement card (complete with photo) or something similar would be useful, to avoid filling out so many forms - which often cause difficulty and distress.</p> <p>19. Just more and more forms! relying on others, frantically searching for the right proof of entitlement, etc.</p> <p>20. Proof of disability, i.e blindness. Once you're eligible for PIP you shouldn't have to prove you're disabled time and time again, its degrading and stressful.</p> <p>21. All should be assessed fairly, regardless of age, gender, sexual orientation etc. I attended a college, for instance, where the girls proved cooking ability by</p>

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		<p>making a two-course meal from scratch. The boys simply had to make a toastie - really helpful!</p> <p>22. I fear I could rabbit on for pages, but probably shouldn't. I've tried my best to answer the questions above although some of them proved tricky!</p> <p>I agree DLA needs reforming, and I also agree it should only apply to the long-term disabled. My main concern is boxing, for instance suggesting all visually impaired people have the same needs and abilities. With research, and a willingness to listen to the people its aimed at I feel the PIP system could be much fairer and easier to comprehend.</p> <p>The views above are my own, as an individual disabled person.</p>
EM7	06-Dec-10	<p>I am very interested in how the changes will affect me, and people like me that have some need for support, but aren't very obviously (visibly) disabled, and have changed our lives to work within limitations.</p> <p>I currently work three days a week, and DLA enables me to work part-time. I can't work full time because my impairment leaves me fatigued, and I need the four days of not working to balance rest and housework. Were I to not be on DLA I wouldn't be able to afford to work part time.</p> <p>When I manage my energy levels, I need little support, but as soon as I use up my energy supply I cease to be able to care for myself, lose the capacity for speech, and struggle to leave my flat.</p> <p>The support I require (and get) is mostly informal, from friends. I also use my DLA to pay for things like proper food (so I stay healthy), and odd costs. For example, I am Dyspraxic, and seem to wear out clothes very quickly, possibly because I bash into thing / rub against surfaces / trip over more often than a non-disabled person might. Because of sensory sensitivity I am very particular about the textures of clothes I wear. This means it can be hard for me to find clothes that are sturdy and comfortable, and I have a more limited range to choose from meaning I often can't find clothes in places like Primark.</p> <p>I find point 19 on page 10 "DLA is widely perceived to be an out-of-work benefit and receiving it appears to reduce the likelihood of being in employment, even after allowing for the impact of health conditions or impairments." a ridiculous reason to be changing a benefit. If public perception of a benefit is wrong, you work to change the perception, not the benefit! The reason many people see it as an out of work benefit (which, disgustingly, seemed to include some politicians) is the media reports it as such, and no one seems to challenge that.</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.</p> <p>As for "There is evidence that people who receive DLA have lower work expectations." this isn't because of DLA, it's because of the challenges faced when seeking work as a disabled person! When I was looking for work it had to be local or involve a straight-forward journey of no more than an hour (ideally less), had to be part-time (three days a week maximum), not involve shift work, be in a small office with good acoustics, not involve a lot of "team work", and not require me to have a degree, as my impairment interfered with my ability to access a university education. I don't think these restrictions are atypical amongst disabled people, but work that meets our needs is hard to find.</p> <p>I need to read the document in small chunks, and will email further comments as I get through it.</p>
EM8	06-Dec-10	<p>It seems to me that one of the most abused parts of DLA is the Motorbility car scheme.</p>



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		<p>I know of two people who have been claiming a car fraudulently. I must admit that I did wonder how they managed to get a new car every couple of years but had no idea that they were claiming high level DLA. Surely Motorability cars should be easily identifiable as such to deter such fraud. I realise that some may see this as an infringement of their rights but then again it's not fair to the poor taxpayer not to do so. I would suggest that those who put their privacy before the provision of a free car may not need motorability.</p> <p>I hope that I do not waste my time in proposing such an easy measure to prevent what appears to be wide spread fraud.</p>
EM9	06-Dec-10	<p>I have read the Consultation Paper on the above subject and in general accept that reform is justified on the basis that the award of DLA may have been over generous in the past and to no small degree the subject of abuse.</p> <p>My interest is that of being the parent of an adult disabled son.</p> <p>I support the proposed assessment procedure re 'face to face' meetings and information gathering, <u>however</u>, I do consider that in some cases this face to face assessment is totally unnecessary and merely introduces a level of checking of an injury / condition the consequences of which would be only too obvious without assessment. This unnecessary assessment adds to the time that an individuals claim is processed, it increases the cost of same thus only serving to reduce any perceived savings.</p> <p>My son suffers from a spinal cord injury and the level of his injury is T12/L1 incomplete paraplegia. He has titanium rods / fixators and a synex cage implanted in his spine, his bowel and bladder functions are compromised, he walks only moderate distance with the aid of a walking stick, without which he would be unable to maintain balance. His walking gait is badly affected. He has a permanent urine drainage device fitted (suprapubic catheter). However, through sheer determination he works full time and relies on a car provided in exchange for his high rate DLA under the Motorability Scheme. Without a car his mobility would be badly affected to the extent that travelling to work and social outings would prove difficult if not impossible.</p> <p>Therefore with the type of Spinal Cord Injury (SCI) detailed above and others in a similar or more severe category, I fail to see and am totally unconvinced of the need for initial face to face 'independent' assessment and on-going periodic assessments – it being obvious to anyone with even the slightest understanding of an SCI that barring a miraculous cure (which sadly just don't seem to occur) that the outcome and effects of the SCI are not going to improve, though admittedly they may worsen, in which case an individual could themselves request an assessment.</p> <p>I would suggest that persons suffering from SCI's (quadriplegia / tetraplegia / paraplegia – complete or incomplete) should only be required to be assessed on the basis of medical evidence provided by those actually responsible for their on-going day to day care and treatment, they are far better placed to give a proper assessment than the 'independent' assessor, who will no doubt be working to a given criteria. Periodic assessments thereafter as stated in the preceding paragraph are both without need and involve unjustified expenditure. I trust the above responses will be taken into account.</p>
EM10	06-Dec-10	<p>Please find to follow my comments on the proposals. I am responding as parent of three disabled children all in receipt of DLA.</p> <p>Firstly I am somewhat confused by the need for 'periodic review'. Surely having to reapply three yearly is sufficient in this case? Any further increases in review would be expensive and increase beauracracy.</p>

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		<p>There is not sufficient information on statements made. Removal of premiums payable on other benefits such as income support, tax credits etc, what would replace this? It is very unclear at this point.</p> <p>Why should financial assistance be reduced based on assistance given in school? What effect does this help actually have on the additional costs of living with disability?</p> <p>You are not being specific as to rates of dla awarded. Are the disabled going to be significantly worse off on PIP? Or worse off at all? We have to use every penny of what we are currently awarded.</p> <p>Whilst aids and adaptations make life easier for the disabled they do not reduce the additional costs inherent in living with disability.</p> <p>To summarise - this is a very woolly document with not enough information. This is causing fear amongst the disabled and their carers. Please clarify the situation.</p> <p>I would also ask that you work closely with groups connected with the disabled when working on these proposals.</p> <p>I am really not confident that these proposals will protect the vulnerable.</p>
EM11	07-Dec-10	<p>This is in response to the DLA reform - public consultation.</p> <p>1. This question is far too generalist for the scope of a public consultation. Each individual disability provides it's own set of problems and barriers, and not even those with disabilities themselves understand all the problems all people with disabilities face. This is an unreasonable question to ask.</p> <p>DLA provides a direct cash benefit instead of tying payments to specific forms of practical assistance and aid, in order that those facing the problems and barriers could make their own choices in how to address them.</p> <p>2. Without more specifics of proposed changes to DLA, it is hard to address this question. It is easier to identify what proposed changes will result in, and this should be done in a second consultation on specific proposals.</p> <p>3. Again this question is far too generalist for the scope of a public consultation. Each individual disability has it's own associated needs and costs, and not even those with disabilities themselves understand all those needs and costs. This is an unreasonable question to ask.</p> <p>4a. While this seems logical, it may not since this will simply eliminate a category allocated into, not the system making that allocation.</p> <p>4b. The obvious implication would be that those currently on middle rate mobility allowance would either have their allowance cut beneath their currently assessed need or raised above their currently assessed need.</p> <p>5. The consultation document states the following.          "For example, someone undergoing renal dialysis in specified circumstances would automatically receive the middle-rate care component without an assessment of their needs. 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."</p> <p>It should be noted that this example is misleading. Renal dialysis is not a medical condition, it is a regular action required by those who perform it which would cause either extreme illness or death if removed. Requirement to perform Renal Dialysis is a complicated care need that these individuals face on a regular, sometimes daily basis. The recognition that those who require</p>

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		<p>Renal Dialysis have an obvious Care Need is simple recognition of evidenced fact, not "automatic entitlement based on condition".</p> <p>It then follows that this section of the consultation document has been based on confusion of "medical condition" and "medical needs". Identified existing medical needs should of course be taken as evidence of care needs.</p> <p>It is also concerning that the proposal to remove "automatic entitlement" would result in those with clinically recognised legal blindness, and other conditions with no current aids or mitigations such as upper vertebrae spinal nerve damage, would have to provide other evidence of what is clinically accepted as their medical needs.</p> <p>It is very important that DLA does not ignore clinically accepted medical needs as a basis for expedited recognition.</p> <p>8 &amp; 16. Aids and adaptations that have been personally funded should not be taken into account. The purchase, maintenance, repair and replacement of these aids constitute a significant cost to disabled people who use them. Their use actually demonstrates the existence of a care/mobility need, and the cost and difficulty the disabled individual faces.</p> <p>Payment of a one-off cost does not always mean a need has no been addressed. Wheelchairs break, bed lifts wear out and need regular maintenance, even a walking stick will need it's rubber end replaced regularly. Some aids and adaptations result in substantially higher electricity bills, or purchase of replacement batteries. The upkeep of these aids and adaptations should be considered.</p> <p>Aids and adaptations are mainly mitigations, they do not remove the problems disabled people face only help them to mange. Removal of entitlement because of existing aids and adaptations would be ignoring the real care/mobility needs they still face, as well as ignoring the cost of upkeep of those aids and adaptations.</p> <p>11. Many disabled people have associated depression and anxiety problems due to coping with their long term problems. It is hugely important that the process not be adversarial. Disabled people are not often in the best place to answer questions on their own condition, and can often diminish their own needs due to pride. It is important that the disabled individual be informed that they are to identify their worst case needs, how regularly that occurs, then move on to how they "can manage". Considering the stated intent to introduce punitive fines for providing incorrect information, it may also be that Article 6 of the ECHR may require access to funded representation to provide legal support to ensure that the individual understands their obligations and rights during the process.</p> <p>12.The regularity of the reviews should be timed with consideration that these reviews have a significant impact on the day to day life of the individual.</p> <p>For working disabled, the requirement to take time off from work is a significant hardship and a distinct disincentive for employers. For those with significant needs, it requires planning to attend to appointment, or it requires the individual to gather evidence to demonstrate the need for a home visit. It would be of great benefit to those who need home visits if they were not compelled to provide medical evidence of their need for a home visit multiple times.</p> <p>There has also been significant criticism of privatised operations of medical reviews by the firm ATOS-Origin, particularly with the application of ESA assessments. It would seem inappropriate to expand their role, and consideration should be given to avoiding privatising this role, or using an</p>

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		<p>different private firm in order to assess if the problems experienced are due to inherent difficulties, or specific to ATOS-Origin.</p> <p>14. Providing for public funded independent advice, advocacy and legal support towards claimants. While the new system may be easier to understand than the current, there is strong likelihood it will still be considered complex by many claimants, and may be misunderstood by those with disadvantages that complicated the process.</p> <p>As previously mentioned, introduction of punitive fines into the process would appear to require Article 6 of the ECHR provision of independent council.</p> <p>15. Requirement to receive this advice could have negative effects. It would alienate those who find the system confusing, by seeming to make it part of "the test" that they have to face. Again, this would also place a burden on the working disabled, and those requiring home visits, in order to attend 'mandatory' training or interviews about the benefit system.</p> <p>18. There is some problem with the assignment of the Higher Rate Care to identifying "the most disabled", as some very disadvantaged disabled individual have only Lower Rate Care needs but Higher Rate Mobility needs. It would be more suitable for this identification to be a threshold of the combination of Care and Mobility needs. For instance, someone with Lower Rate Care, and Higher Rate Mobility should be identified as similarly disadvantaged as someone with Higher Rate Care alone.</p> <p>19. DLA is the only assessment available for Working Disabled, and the only gateway for other aids they benefit from. It would be a significant burden if this was removed. It is also hard to identify where these "passports" would be transferred to in the current system for those incapable of work.</p> <p>20. As specified, assessments are a huge burden on working disabled, and those who require home visits. As such, it would be beneficial if there could be a reduction to no more than one assessment for all suitable benefits. However, considering the already identified need to exclude ATOS-Origin from any new assessment until it has been identified if they are providing a suitable service, this may not be practical.</p> <p>21. Any initial rollout of this new benefit should require independent auditing of the process and individual claimants. And that this audit should be kept sequestered until the end of the trial to identify the effectiveness of the benefit in meeting it's stated goals, unless the auditor identified an individual who was under immediate risk of harm for some issue.</p> <p>In previous cases of trial rollout of benefits, successes in meeting the goals has been ultimately judged by the Minister responsible. This obviously leads to risk of politicisation of the trial's results.</p> <p>Additional Response: Payment will stop if the individual is in hospital or a care home</p> <p>Needs relating to Mobility for access to services and independent community involvement are not nationally provisioned nor handled by hospital or care home provision, nor is there indication they ever will be. While some care homes and hospitals provide these services, they are usually charity funded, and are often provided inconsistently and are do not provide an 'independent' mobility. This contradicts the consultation statement that the benefit is being withdrawn as "an individual's needs are being met by public funds in a hospital or similar institution or care home".</p> <p>I hope that this information provided is useful to your consultation.</p>

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EM12	07-Dec-10	Given the present financial climate the sheer cost of the change in stationery alone will cost a small fortune. Also after twenty years of experimentation it would seem to me that we are returning the original model.
EM13	07-Dec-10	<p>Working for many years in External relations, Partnership and outreach work with the "harder to help" , prior to current job I don't think I can really add anything to the questions posed in the consultation as they don't ask a question that I feel needs answering, that of how DLA is used, or abused.</p> <p>I have come across many examples of what I believe is misuse of the benefit and causes extra cost to the government without tackling the needs of the individual, this is mainly where DLA is awarded to under 16s and parents are not using it for its intended recipient.</p> <p>The best (worst) example is someone known to me who used the DLA for her son on her Banatine Gym membership and was horrified when told she should use it for her son to give him extra tuition as his school work was suffering due to his condition.</p> <p>I feel the benefit would be better administered by central agency, council, school ad used to put in place those things required to support the individual – e.g. If they need a taxi to school or clubs, extra tuition, home help then the "fund holder" pays directly to the supplier. I know this creates an extra level of work but councils and schools already have some of these systems in place and I believe the savings for those that actually don't need/use the money now would create savings.</p> <p>The benefit needs to go to those that need it and should be monitored to ensure that it is used for what it is intended. This includes adults with disabilities, when managing an outreach team it was surprising at the number of people using the money for things (including alcohol/drugs) that the benefit wasn't designed for and not used to help the individual either progress back to work/improve their lives, overcome barriers as mentioned in the consultation document. I believe that sometimes increased spending on monitoring of benefit improves the application and "quality" of the spend and if in an area funding is required for a number of people, of all ages, e.g. Taxi service, bulk buying could save money.</p>
EM14	07-Dec-10	<p>Recently on the Broken of Britain, a link was posted with the DLA reform papers published in full. I have to say, I am not entirely surprised that such a life-changing plan for many people was released rather stealthily so that very few disabled people would see it, nor am I surprised at the incredibly short rebuttal time given for such feedback as mine to be sent to your offices. Even with pain and fatigue, I have constructed mine, and will be sending it to my MPs as well.</p> <p>I read through the paper with a rather sinking heart - as I am a disabled lone parent who is still struggling for DLA and housebound, tending a child also on DLA, I can see my future slipping through my fingers. The DLA forms seems to want to seal that future fate and cast me out into the street. I quote from the statement from The Broken of Britain as it is put succinctly:</p> <p>The focus on DLA as a disincentive to work is false and disingenuous. People who receive DLA do often have lower work expectations as the reform consultation paper suggests, and rightly so. Regardless of desire, many disabilities and conditions make work impossible. Disabled people are often unable to compete equally in the labour market, even if there is work for them, which too often there is not. People with high rate awards have highest level of disabilities and are least likely to be able to work regardless of benefits. Those who do work and with lower awards are often only able to work because of the aids, support and adaptations DLA allows them to purchase. The focus on move to work has no place in a discussion about DLA other than to make the important clarification that DLA is not work related and exists to assist life with a disability.</p>

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		<p>I admit I utterly appalled that work is considered a main focus for receiving DLA; whether I work or not will not remove my disability and I'm aghast that the push to work should be even considered a facet of reform. DLA has nothing to do with employability, but entirely to do with just living your life, which a disabled person is entitled to by law. Access to Work and IB are woefully underfunded and not fit for purpose, which is another discussion entirely - and should be treated as such.</p> <p>I am equally disturbed by several sentences in the report: 'focusing on those with greatest support needs for example. As a disabled person with a chronic condition which is not even remotely visible - just as my son is - I am often mistaken for being 'perfectly fine' but I am currently housebound and unable to travel, especially as my son is also disabled and caring for him becomes impossible without mobility aids - none of which I am currently eligible for without a battle. Yet time and again I keep getting told by both DLA now and by Adult Social Services that, due to the fact I appear to be physically able I am not a great need. I am completely excluded due to being without aids to help me get about (I am going to miss my son's school play this year because I am physically unable to walk around in the school to attend), or to tend my son whilst doing so, and this looks to be even more impeded by a panel of people who have no knowledge of my symptoms on a daily basis to make a final judgement on what I receive.</p> <p>This is of course exactly the problem with DLA now - and why I am already dreading regular panels to have to "prove" I am not a fraud, causing incredible stress and symptom flares and throwing my entire life in turmoil on a regular basis. I do not for a moment accept that this is to "monitor symptoms which are so gradual you don't realise you're having them". With the GP and specialists I work with now I have more than enough case history and, like most people with a disability no one can see, you get used to having to keep track of your own symptoms to present them to the GP for further treatment. I feel this is just a flimsy excuse to put us under even more stress and pressure in the rather barbaric hope that some of us just give up under the pressure and fade away, thereby saving a few pence for the budget.</p> <p>Nor do I believe this reform saves any money whatsoever. Again I quote: "Although the caseload will be reduced PIP will still look very much like DLA albeit with a 21<sup>st</sup> century name at a time when government spending, is supposedly, being squeezed. The current system also allows for automatic entitlement to DLA for certain conditions. The new system will not; all claimants will be required to be reassessed 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 thing that will be achieved is extra cost of unnecessary assessment, additional complication instead of simplification and inconvenience for severely ill people. Additional waste comes from ignoring the reality that people will remain disabled and have needs even if they are no longer able to qualify for benefits. 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. Furthermore, the proposed reforms ignore the fact that some conditions are severe but acute. Not supporting short-term illness and disability makes it more likely this will become a costly long-term problem therefore increasing dependency."</p> <p>There is a wildly optimistic belief that there is a load of funding in local councils to "pick up the slack" and that there is some form of "overlap." However I am on my second appeal for assistance through the council for a care plan, and I know of many people who have spent years petitioning and appealing for even the most basic care. My council has told me that they will not give care plans to anyone unless without it, they face being placed in a care home. Yet to believe that the only disabled or vulnerable are over the age of 65 is a</p>

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		<p>ludicrous view, and a shocking example of the complete lack of touch with the plan. The loss of DLA will put even more pressure on local councils and individuals to try and dig deep for money that isn't there to provide even the most basic needs such as commodes and wheelchairs. I would imagine in many cases, people will end up having to go without, and live in squalid conditions you would be more expecting in a third-world country than in the developed world. Right now, I am living in a barely-insulated home with no ability to shower or bathe as I can no longer get in and out of the bath - I wash in the sink, and I spend my days on the couch downstairs, only venturing up (often on hands and knees) to use the toilet. According to current strictures I am not in need, even though I haven't washed in weeks and eat food which friends put into the freezer for me. I dread to think how much more I stand to lose with these new reforms...not to mention my seven year old child.</p> <p>There is also a vast assumption at the moment that a diagnosis written upon a page is the only diagnosis worth taking into consideration. I am diagnosed with fibromyalgia officially, and yet I have been exhibiting symptoms for the past year which are not in keeping with fibromyalgia; they're infinitely worse and will require me to have a fair bit more testing and possibly even seeking other opinions as it is very difficult to diagnose. However, I am being led to believe that the ATOS panel, who has never met me, does not know my case, or been following my health on a regular basis can somehow determine whether or not my case is "serious" enough to give me a PIP package. I am led to believe that a group of people in an office whom I have never met will somehow be able to determine, just by looking at me, whether or not I am disabled and capable of doing a typical job. Without blood tests, or x-rays, or scans; without chasing up worrying symptoms or consulting with GPs to check for other possibilities.</p> <p>That isn't their function: the function is not to be doctors, but to be judges. To decide who will be assigned to the workhouse, and who will be cast to one side and forgotten for another year. It is not their function to do anything but make a judgement on what they can see with their own eyes, and yet even if our symptoms change we know just how long it can take before the Powers That Be acknowledge our changes; months, if not years. That is long enough for someone hanging in the balance to lose their home, their health, or their life. It's a "extensive process" for your paperwork and administration, but it's our lives which deteriorate with startling rapidity.</p> <p>In the end, I feel the function of Welfare and disability reform is not for compassion or to make us well - as we would expect from medicine - but to cater instead to a financial diagnosis written by people with only a rudimentary knowledge of our ailments and to perhaps cut out those who are not "fit enough to survive". It's shocking that disabled rights which were hundreds of years overdue and only recently established will be taken away just as quickly.</p> <p>I have forwarded this on to everyone I can think of, and have cc'ed my MPs as well. I will not allow this to be passed quietly without outcry.</p> <p>I am disabled, and I have had enough.</p>
EM15	07-Dec-10	<p>Your proposed reform/s is nothing more than a spiteful,vindictive assault by a bully on a vulnerable section of society.</p> <p>Where are the jobs? Who are the so called "independent" medical specialists? What right do they have to access personal medical information? Disabled people have enough worries without the extra stress caused by this cruel,vicious, unwarranted and expensive exercise. Perhaps you could hire unemployed concentration camp doctors.</p>
EM16	07-Dec-10	<p>I am a Welfare benefits adviser for the Peabody Trust, a large London Housing Association. I work with many disabled residents and am in a position to really see the advantages and disadvantages with the DLA and proposed PIP reforms. My views reflect the evidence I have seen on the front line but may or</p>

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		<p>may not reflect the views of my employer.</p> <ol style="list-style-type: none"> <li>1. The main barriers appear to be that employer perception still lags behind disability discrimination legislation. Fluctuating health problems are not sympathetically or even flexibly viewed. Especially in economically distressed times, disability is often viewed as a financial burden it would seem.</li> <li>2. The Lowest Rate of Care Component provides for a disabled person to realistically hold down work, whilst receiving targeted support through the tax credit and Housing and Council Tax Benefit regime. It would be counter productive to loose this element.</li> <li>3. Laundry costs, fuel costs, travel costs, and dietary regime all impact on the budgets of the disabled and affect choices they make.</li> <li>4. No, it is readily understood that low rate care reflects periodic help at key points of the day, middle care deals with all daytime needs and highest rate deals with a day and night care need. Mobility is based on walking, or walking unaided. It would be no easier to have an "all or nothing" based system – the gaps would be too large.</li> </ol> <p>4.(b) People on Middle and Highest Rate Care are the hardest to convince that employment is viable. They fear being reassessed and loosing everything. People on lower rate care have more confidence in the system and with the tie in with Working Tax Credit, they feel able to consider work. If you take Lowest Rate away, then claimants have incentive to make themselves vulnerable enough to need the support and then feel too afraid to risk employment. Lowest rate is a safeguard.</p> <ol style="list-style-type: none"> <li>5. Where a condition is terminal then automatic entitlement makes sense. In other cases it would have to depend on circumstances and needs.</li> <li>6. This would be difficult as differing conditions can create different support needs in the same person. Beyond personal care, cooking a main meal and social contact are essential living aspects.</li> <li>7. Guidance MUST stress that variable and fluctuating conditions can still create disablement. At present the evidence shows that this is dismissed when assessing Employment and Support Allowance and it is clogging up the appeals system needlessly.</li> <li>8. Examples should include wheelchairs and walking aids, as these are practical items.</li> </ol> <p>8.(b) Items that can be afforded, actually ROUTINELY being supplied by occupational therapists, or available by a grant should be taken into account. An item costing hundreds of pounds that someone simply cannot budget for should not be considered available to them.</p> <ol style="list-style-type: none"> <li>9. Removing the idea of how long it takes to be helped to perform a function. It is difficult to gauge and can vary wildly from good days to bad days. You could ask if a task can be repeated regularly through the day.</li> <li>9.(B) Include the main disability charities in the process as much as possible and don't overly rely on Occupational Therapists or healthcare specialists who simply look narrowly at the issues. Then those closest to the claimants will have an accurate understanding and can feed information across to other organisations and promote the take up through their work.</li> <li>10. The Carer, friend or neighbour can be an excellent source of information, as can welfare workers, sheltered housing managers, social workers and others who see the day to day realities of the claimant. All too often our opinions are not counted, or over ruled by a healthcare specialist spending 20 minutes with a claimant.</li> <li>11. ESA medical examinations are already showing flaws and problems. MS workers routinely don't record what is said, seem to have little understanding of the claimants health problems and make ridiculous judgements not based on fact. For example if a claimant can stand for one minute it is reported that they can stand for 30 minutes, which is ridiculous. It simply clogs up the appeals system needlessly and SSAC reports confirm this.</li> <li>11.(B) Where a claimant has mental health problems they will often underplay their symptoms, or be in denial that they have them. Therefore back up</li> </ol>



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		<p>evidence should be sought, especially in schizophrenics who often present as though there is nothing wrong with them.</p> <p>12. Like ESA, reviews made every 2 – 5 years would be reasonable in most cases.</p> <p>12.(B) In the case of the terminally ill, perhaps a GP report to confirm the situation would be less intrusive in the first instance before calling claimants for review after 1 – 2 years.</p> <p>13. You really must understand that reporting an improvement, however marginal could cause the claimant to go from High Rate DLA Care with ESA Support component worth £235.55 per week risking ending up with just £65.45. Imagine losing over half your income because you advised your employer your mortgage payments had gone down. Claimants are terrified of “rocking the boat”. Taking away the three components and making only two will do nothing to reverse that – in fact it would make it worse as there would be further to fall. You could encourage reporting a change of circumstances by offering a “wellness bonus” of say four weeks extended payment if they are reviewed and drop to a lower rate of DLA or come off altogether. This at least creates a “buffer zone”.</p> <p>14. The DWP consistently give inaccurate and misleading advice to people – the sixteen hour rule being a typical problem (people are told they can get benefit if they work less than sixteen hours – where as in fact that is only half the issue as income dictates whether benefit is payable) Therefore independent advice is seen as impartial and far more trustworthy, and in practice it usually is.</p> <p>15. This sounds ideal in theory, but is problematic in reality. Whilst making a requirement that someone attend an alcohol recovery service sounds positive, it can be difficult to measure compliance. A mental health group could have positive effects on well being, but only if such a service is available locally. I would consider more work needs to be done before this is put into practice.</p> <p>16. Most people buy items or amend what they already have, as aids and adaptation costs are too high to be met as a one off payment. A form of budgeting loan payable from PIP could assist larger payments for one off items.</p> <p>17. A child's needs will always be different in as much as there is an amount of care required anyway for a child. There will always need to be an assessment of what goes above and beyond basic childcare.</p> <p>18. Disabled people frequently need an escort to attend leisure pursuits and the concessions offered to carers make this affordable. Additionally reduced or free travel on public transport opens up the possibility of getting around, increasing the chances of employment. The exemption of Non Dependent Deductions where a disabled person receives Housing Benefit allows people to have a carer living with them. These are all very valid and important features of the scheme.</p> <p>19. To lose the passporting benefits would restrict the lives of disabled people greatly. Reduced access to travel, carer and leisure facilities would probably increase the costs to the NHS as people would suffer from mental health problems and without carers would likely have more physical health problems. It would need far greater research than there is scope for here.</p> <p>20. A combined Social Services assessment/OT assessment could be made with the PIP assessment so that one set of information could be used to consider eligibility. The disabled person could sign a consent to have the data sent to the Local Authority for consideration if they were deemed in need by the decision maker. This could speed up the assessment process.</p> <p>21. It would appear to be neutral in relation to different equality groups, and it would be difficult to foresee how this would change without seeing specific details.</p> <p>22. Whilst I broadly support the reviews for claimants of Disability Living Allowance, as it would more realistically assess actual care and mobility needs, attention must be given not to simply narrow the scope to save money.</p> <p>For example; if only left handed people could claim JSA then unemployment would more than halve at a stroke – that wouldn't mean there are less</p>

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		<p>unemployed people.</p> <p>We already know there are serious problems with the implementation of ESA, with costs to the Tribunal Service as a result. Care must be taken to avoid such mistakes and not take too narrow a view of disability.</p> <p>HIV/Aids, Cancer, and Heart Disease etc. that would have once killed people, are now chronically manageable illnesses. This and not fraud are the likely reason for higher expenditure on Disability related illness. This should be remembered instead of simply comparing one decade with another and implying that people must be fraudulently claiming benefit.</p>
EM17	07-Dec-10	<p>I suffer from Multiple Sclerosis and wholeheartedly rely on my DLA as small as it is, I do not live in a home, i have a mortgage and i have to eat and i drive a Motability car. David Cameron assured us in his camapigning that he would not attack the vulnerable - what a lie. HELP</p>
EM18	07-Dec-10	<p>I have received DLA since losing my leg to cancer in 1987, my leg was amputated above the knee to a very high level. I have since managed to maintain full employment. My health was also effected by regimes of chemotherapy and surgery to my lungs. I have also had to relay on crutches and walking aids since 1987.</p> <p>I have always had a mobility car and this has enabled me to get around and attend work , without this support I feel I would never have been able to get to work and lead such a full life.</p> <p>I have always seen DLA as an enabling benefit and never regarded it, or associated it with being out of work. In this way I would see myself as an ideal example of how the new benefit should work.</p> <p>I hope with these reforms people are not penalised for trying to make there life better. Without my car or the support I receive from DLA such as a blue badge my quality of life would be greatly reduced.</p> <p>Having worked for the DWP for 11 years I fully understand the need to control the payments of DLA and have myself seen many undeserving cases who are no doubt playing the system.</p> <p>When I first received DLA I was assessed by an independent doctor which is a lot better idea than the current form based system.</p> <p>I would be more than happy to be involved in the consultation work for the new benefit as having both worked as a Disability Employment Advisor and worked with disabled groups outside of work , I would consider myself ideally placed to support any reforms.</p>
EM19	07-Dec-10	<p>Rather than explain my concerns again, I am forwarding you the email I sent to my MP, David Mundell. The email has been acknowledged but I am still awaiting a response.</p> <p>My son is far from unique. Does the government really want to equate people in care homes to people in hospital? My son is not ill; he has been severely disabled by a brain haemorrhage.</p> <p>"Hi David!</p> <p>I think this has been the first time I have felt moved to write to you as my MP, although I have contacted local MSPs, including Derek Brownlie, about local public transport issues.</p> <p>I only just learned of the proposed cut of DLA to those in care homes and it fills me with dread. On 13 August 2007 (a date sketched on my memory forever),</p>

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		<p>one of my two sons, suffered a subarachnoid brain haemorrhage a month after his 30th birthday. Against all the odds, he has survived but his recovery has been far less than we had hoped. He is very paralysed and his wheelchair (tilt and space) is very large and cumbersome (comfortable for him!) His care needs are such that we had no option but to find him a care home and we have been so fortunate that he has settled well into [REDACTED] Care Home near [REDACTED]. We would have preferred him to be accommodated in [REDACTED] but there were no suitable facilities. Since this trauma happened at such an early age, we were delighted to find that he was eligible for the disability component of care because that enabled us to lease a WAV (wheelchair accessible vehicle) so that we can bring him home, take him out for lunch or afternoon tea, and even take him to a bar in [REDACTED] so that his friends can meet up with him. The home has a minibuss but [REDACTED] rarely gets out in it because his wheelchair means that very few others would be able to get on board. That said, they have taken him out on occasion to 10 pin bowling, for a pint, etc. We have never tried to get [REDACTED] on or off a bus but I guess it would not be easy to manoeuvre the chair on board, if we were brave enough to try. Anyway, there is a steep hill down to the bus stop and there is no way either my husband or myself would be able to wheel him back up the hill. Handicabs is a wonderful service and, although they are cheaper than a taxi (that could not accommodate [REDACTED] anyway), they are still relatively expensive and nothing beats the convenience of him having his own transport. If he is to lose that, you may as well lock him up and throw away the key.</p> <p>I just cannot believe the misery this particular cut is going to have on so many people. We arrange for our loved ones to go into care homes because their needs are more than we can cope with at home. How their enjoyment of life will be curtailed with this draconian measure."</p>
EM20	07-Dec-10	<p>I am appalled at the latest cuts you are proposing to cut allowances for the disabled. It is both callous and uncomfortable for a society which is rich in many ways, whilst leaving the bankers to continue to rake in millions in bonuses. My respect for IDS is diminishing. How low can he go in the name of ideology? His behaviour only depicts the right wing, Godless individual he is. I am very unhappy with the way this man is cutting the benefits of the poorest. May it haunt him in his old age. He is an unfeeling, arrogant, shadow of Thatcher and no better than the rest of the multimillionaire-ridden, cabinet.</p>
EM21	07-Dec-10	<p>Shortly after my son's 30th birthday, a vein in his head popped; he had an aneurysm. To cut a long story short, he ended up in a care home having to be hoisted from bed to wheelchair and everywhere.</p> <p>With the mobility component of his DLA he was able to get a WAV (wheelchair accessible vehicle) and I am able to drive him the 30 miles from the care home to the town he grew up in, in order to meet family and friends; he loves these trips. The van is also used for trips to the dentist, hospital appointments, family occasions such as his brother's wedding and even afternoon tea at the local garden centre. All in all this helps to make his life bearable. The care home does have a vehicle which is used to take residents on trips but not personal visits. The cutting of this allowance will basically mean that my son is confined to his care home with no personal choice of trips out.</p> <p>I cannot believe that a government in this day and age would even consider removing this allowance. To punish the most vulnerable in our society just because they live in a care home is an act of unspeakable callousness. If these cuts go ahead it would be the end to any independence he has. My wife and I are both pensioners and could not replace the WAV privately.</p> <p>So, finally I urge this Liberal Democrat/Conservative coalition government to rethink this mean-minded, penny pinching plan which would have a devastating effect on my son and thousands like him.</p>
EM22	07-Dec-10	<p>1. Stigma</p>

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		<p>Lack of understanding about what disabled people really need  The perceived expense  Ignorance about access and parking, and obstruction because of ignorance  Having to constantly prove you are sick, and being punished for trying to be well- the more you push to do for yourself, the more that is used as evidence that there is really nothing wrong with you</p> <p>2. YES! Save money by not paying an ATOS doctor to cheat people out of their help- exactly how many appeals result in restoration or provision of benefits?  It needs to be non-means tested to support disabled people who work  It needs to recognise that not every problem has a diagnosis, a name or support from the medical community, like chronic pain- some things are subjective. Variable illness and problems should be awarded based on the difficult end of the spectrum, not the easy one.</p> <p>3. I bought my own wheelchair- £6000- because I couldn't get the one I really needed. I can't get on the bus, so get taxis. I pay someone to iron, to do my housework, and I get more ready meals/ take-a-ways. I have to travel at a "higher class" to get the kind of seating I need. I have so many expenses, just due to disability....</p> <p>4. I don't know, I think it will be hard for those in the middle.  4.(b) That those who fall near the top of one and the bottom of the other are seen as the lesser of the two.</p> <p>5. I think there should be automatic entitlement, but also, some people should be awarded automatic entitlement based on their condition.</p> <p>6. People who work and who use the benefit to support being able to work should be given more help than those who don't work... if DLA is the only benefit someone gets, because they work, there should be more weight given to their DLA claim. If DLA keeps people off other benefits, then it pays to support them with DLA&gt;  Many people who get DLA use the mobility component for Motability- I have a motability car; not only is there an entire industry around motability adapted cars, many council sbase blue badge entitlement on DLA higher rate mobility approval. Being able to get around, work, get an education, shop... all these things are necessary.</p> <p>7. By not trying to trick nervous people, and listening as much if not more to GPs and specialist nurses as to the doctors you pay to prove people don't need help. Look at problems over time, and make the forms less an ordeal. A GP can give you good guidance- or allow specialist nurses to make assessments. Look at all the evidence about people being said to be "Able" because they made the doc a cuppa when he assessed them- take into account how hard disabled people try to keep up a good front, and don't punish them for coping.</p> <p>8. All, not just the prescribed ones  8.(b) Both- some people don't get things because they can't afford them, or because of the bureaucracy- for example, I have an electric wheelchair- wheelchair services wouldn't provide it, because I don't use it indoors, as my home is so small, but they wouldn't give me a self propelled chair because I am too unwell to use it: to you, it says "wheelchair services didn't provide a chair"... that doesn't mean I don't need it, just that their criteria works to save money!</p> <p>9. Have them all online! Have one for the initial assessment, and one for the review. Have review dates set further and further apart if the condition is static</p> <p>9.(b) Well, the way it looks, just list the name and address of the one person who will be covered, and the rest of us can rot.  You have to accept that thigns will sometimes be subjective... it's not important that we are all absolutely clear on what will entitle us- just to know that we will be fairly assessed- not judged- is enough.</p>

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		<p>10. Doctors don't know much about ability- many people don't tell their doctors what they need. Ask about specialist care and treatment. Ask the person themselves. Ask the GP about their condition, not about their ADL's as the GP doesn't operate in a social model of medicine, and all GPs will be too busy replacing the SHA's to care about patients anyway.</p> <p>11. People get white-coat syndrome- and professionals can be biased or ignorant about different conditions, for example, chronic pain, or about race. Take all the money you think you will spend on face to face assessment and devote it to benefits! If you work- having to take time out to be proven unwell in addition to all your other appointments might help you become unemployed... 11.(b) YES! When there is clear evidence of an ongoing health problem, and when there are cognitive issues. When the person has a fluctuating condition that means they may look completely well and this will bias their assessment.</p> <p>12. YES! Some people should be accepted as needing help and allowed to carry on. If a person has minimal help, perhaps only DLA&lt; and works, and is under review with their GP, just stop making their stress worse and let them carry on! Long term, chronic conditions need long term chronic support!</p> <p>13. Send out a 6 monthly questionnaire? Stop benefits unless they tell you everything you need to know in your attempt to not over regulate their lives?</p> <p>14. As I said, name the one person you plan on helping, give advice on how to get rich as one of your assessment professionals, and give a list of charities other people can beg to once you stop their benefits.</p> <p>Seriously, DLA is NOT broken. You want to save money. Admit it. Just be honest- we're crippled, not stupid. And now, we're all terrified too. Merry Christmas.</p> <p>15. So, here claimant- stop sponging off the system, work! But take off Monday to fill in this 75 page form, Tuesday for your review appointment, Wednesday for your GP, Thursday for your "encouragement to take action" and Friday you can go to JCP after you lose your job because you weren't there M-Thursday! You can't make it so difficult that people with chronic pain, depression, fatigue etc find it easier to withdraw from life than to comply with complex "encouragement". You say you don't want to interfere or over regulate- why don't you apply that to disability? Why are you so keen on punishing the 99.4 % of legitimate claimants to weed out the 0.6% of fraud? You just add to the stigma with things like this. Force me to attend "counselling" because I am disabled? Yeah. Then have all MP's have monthly visits from a realtor to assess which is their primary home: there is more proof MPs cheat the system than there is that DLA claimants do.</p> <p>16. I think consistent, durable, reliable funding is whats needed. There are the BIG SOCIETY things for one off items. I work, my husband works, and I pay for things I need with household money and DLA. When you take my DLA away, I'll have nothing- no job, nothing.</p> <p>17. That ALL kids rely on parents for support and disabled kids need the same things all kids need? Why pay child support AND DLA when it's a child's right to be cared for by their parent?</p> <p>18. I don't need other benefits because DLA bridges enough of my needs so I can remain in work. Without DLA, I would not be in work- I don't have enough</p>

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		<p>to care for me, my home and still work- DLA pays for the things I need someone else to do so I can work. It's the only thing I get- and somehow, I will be punished for that. Thanks.</p> <p>19. Maybe, if all you need is abridge, you don't NEED a passport. Some people, despite being crippled, can still access and signpost to their own treatment and services. You NEED a non-means-tested benefit for people who are disabled.</p> <p>20. Well, GP assessment is a place to start. That's right- you need them to run the health service, so we can't rely on them. If you simply shared information- like Access to Work records- then you would see who needs/ gets help and who doesn't. You have to accept that some people won't be as objectively disabled as others, because science isn't perfect- and you need to accept that some people will not look on assessment the way they are in real life and are known to be by those who see them regularly.</p> <p>21. White working people are in big trouble. People who can go to charities for BME will be better off. You need to make it fair for everyone, not just those who don't work or who get other benefits. Just because people work, or don't access all the services they are entitled to, doesn't mean they aren't disabled- it means they are trying to cope, to mainstream, and they shouldn't be overregulated. You don't want communities to have to prove they provide services for disabled people, but you want me to prove I access them? How is that fair?</p> <p>22. I think its terrible. DLA is proven to work. I am terrified. I work full time, even when it hurts so bad I cant sit up, and now I find I am a year or two away from disaster. I will lose my car, lose my job- all because some doctor who never met me will have to see what it has taken my GP 4 years to really understand. Why punish those who use the benefits to work and give back? My wheelchair costs more than I get in a year on DLA- why not see how things like that are proof of disability? That people will cope, and that doesn't mean they aren't disabled, or don't need help, but that they push themselves even though there is a cost? Why not involve disabled people like you involve people from BME about that aspect of diversity? You seem to think we are all such scammers that every one of us needs a face to face assessment- think – all the money you will spend on that, wouldn't it be more cost effective to catch the less than 1 % who scam? Or is it worth it to torture the 99% who just want to get on with life, but through no fault of their own have health problems that make it difficult? You talk about medical assessments, and about the social model of disability- but doctors operate on the medical model, not the social model... I think people who work but are disabled should be rewarded- or at least recognised- for the effort that takes, either through longer benefits, or through less assessment, I don't know- but make it possible for people to both have help and be employed.</p> <p>You have no idea how hard it is to get and keep a job when you are a cripple- now you want to make it even harder, and take away my help too. I wish you could see what it feels like to be me. You don't understand, you won't understand, and you can't understand, because you aren't disabled. I am sending this from work, but it wasn't done on work time, and is not the opinion of my employer.</p> <p>PS_ call me and I'll explain, in person, to anyone who wants to understand the real value of DLA.</p>
EM23	07-Dec-10	<p>Q. 1. Many of the barriers are well documented but one that has gone unnoticed is the problems caused for disabled people when those on Incapacity Benefit are being targeted for reform by the Government. Much of the propaganda that is issued to the press labels the majority of sick or disabled as</p>

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		<p>benefit cheats which has a negative impact on the way they are treated or tolerated in wider society.</p> <p>Q2. Assessments for those whose medical condition will not change or can only get worse over a period of time is both costly to the Government and causes stress and worry for those being assessed. Added to this, it should be noted that those least able are also those least able to access Advice Series such as CAB in order to appeal. It should also be noted somewhere that many disabilities are in fact illnesses which cant be cured, for example arthritis, MS, chronic lung disorders just to name a few.</p> <p>Q3. Everything. Put a label of Disabled Adapted onto any item and it will cost more. A careful diet is needed for those with mobility or care needs because of the inability to exercise for example. Continence can be an issue with the most effective products costing more. TV licenses and extra heating costs for those with severe mobility problems, particularly in the winter can be very difficult and under the current rules, although those on ESA get the extra Cold Weather Payment, those on Incapacity Benefit (which is related to the fact that claimants have worked and paid a stamp unlike Income Support) do not get it.</p> <p>Q4. Two rates should be the minimum to cover the wide range of needs for people with illness etc.</p> <p>Q5. Chronic incurable illnesses should be included in those exempt from re-applying. I have already given some examples of lung diseases, and arthritis but there are quite a few more, for example severe fibromyalgia and heart problems.</p> <p>Q6. essential activities are obviously eating and keeping clean as well as social interaction and some kind of recreation, even if this is just a free TV licence to watch TV, not to mention the ability to go outside the home from time to time and access to whatever disability aids that are on the market.</p> <p>Q7. Provision has to be made for the worst day or those who are ill or disabled will be left without the help they need. Doing this also frees up the disabled person to push themselves to the limit on a good day and stay as fit and healthy as possible.</p> <p>There is no point in assessing people for disabled adaptations they don't have and probably can never afford. The necessary government budget cuts are going to mean that more people have to go without, buy their own, or wait for a long period of time. Even if someone has a wheelchair, common sense would suggest that some people are strong enough to push it for miles and others need to have it pushed for them.</p> <p>Q9 It isn't just the difficulty of filling the form that causes problems but the stress of not knowing whether the latest rules will mean a serious reduction in income when the claimant is genuinely unfit for work and struggling to get around and do things for themselves. It should be possible to consult Carers for this even when they are family members.</p> <p>Q10 The current supporting evidence works well enough.</p> <p>Q11. Many Carers are not Healthcare Professionals and some have no contact with Healthcare Professionals on a regular basis as long as the condition of the Claimant is stable. This also puts further strain on overworked Healthcare Professionals who would be expected to meet with DWP for every claimant which will have a negative effect on the overall time they have to do the job they are paid to do.</p> <p>Q12. Some reviews could be carried out without the full process of medical</p>

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		<p>assessments etc, this is particularly where the condition is chronic and not going to get better.</p> <p>Q13 Some sharing of information would help this. For example, I know of a case when a Claimant was on both Incapacity Benefit and DLA, only one department knew of a worsening of their medical conditions resulting in an unnecessary Back to Work interview.</p> <p>Q14. How to deal with questions on, for example, their ability to do something when it varies from day to day and easy access to appeals procedures.</p> <p>Q15. Some people will not want access to advice and support so this should not be compulsory but after assessment, it would be helpful if Claimants were to receive a letter telling them what is available if they take it up, for example disabled aids that could be purchased, occupational therapist, further benefit advice. Obviously there will be some who are capable of doing a job of work but as this is already a compulsory part of ESA then it just doubles the workload to no effect to have it inbuilt into the DLA replacement.</p> <p>Q16. People do sometimes have to use DLA to fund disabled adaptations and items that will make their life a bit easier. Trying to legislate against it would be a waste of time. There is a limit to what can be provided on the national health. For examples, a motorised scooter or a higher bed. These are only provided for the most severe cases. The simplest way forward is to allow people to decide for themselves how the money is spent.</p> <p>Q17. Children have more complex needs in terms of the need to socialise and learn from other children as well as the health problems.</p> <p>Q18. DLA has been very useful in helping people access other services, some of the ones I know of include, blue badge or bus pass, Cinema pass so the carer can go free etc but this could be taken further to include free TV licenses for those with poor mobility and cold weather payments when not provided through any other benefit.</p> <p>Q19, No bus passes or blue badges which would remove mobility for many Claimants, fewer opportunities to go out and do something normal such as go to the Cinema. Many of the services which make those most ill would be removed making the quality of life much poorer.</p> <p>Q20. It may be possible, in certain cases to combine assessments for ESA and the new benefit. Certainly it would save duplication of reviews could be conducted through sharing information rather than doing the job twice.</p> <p>Q21. Be aware on the impact Government publicity of the reforms has on genuine claimants. It should go without saying that any assessments should have the option of doing it at home when necessary with interpreters on hand when required etc.</p> <p>Q22. It is rarely taken into account that many genuine illnesses can be adversely effected by stress and the current constant changes in benefit rules are causing a lot of worry to people who genuinely need Benefits. Assessments should not be carried out unnecessarily and great care should be in setting Targets which could end up with those in most need losing out on the help and support they need.</p>
EM24	07-Dec-10	<p>I am a wheelchair user who works for the DWP as a Disability Employment Adviser in Berkshire. I had polio in 1955 so have experience of working , bringing up a family etc as a disabled person. My current job also gives me daily contact with a wide range of people with a variety of health conditions.</p> <p>My observations are as follows I do not know if they are any help.</p>



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		<p>DLA is very hard to claim for many people, even with a support worker or other assistance. The detail and information required for a successful claim requires a high degree of literacy which many people do not have.</p> <p>It is difficult, especially when you are working hard to overcome an impairment, to concentrate on what you can not do when you want to celebrate what you can do.</p> <p>It is these difficulties which result in the confusing situation of customers with similar health conditions getting different awards or none at all. People can also be put in the unenviable position of working to improve their health condition, which could then result in losing a substantial part of their weekly income.</p> <p>A proper assessment of people's individual needs must be made, but it has to far more sophisticated than the WCA designed for ESA which is causing so many problems and is producing equally unfathomable decisions.</p> <p>The government is right that health conditions often combined with housing, social and environmental conditions all effect how much support any individual needs to lead an active and fulfilling life. Trying to put in place a benefit which will assist in achieving these objectives is not easy.</p> <p>As the WCA proved, it is easy to show that a large number of people are capable of 'doing something'. However marketing that 'something' in today's job market is far from easy.</p> <p>Clearly it is wrong that apparently people are receiving DLA who are not entitled, but I suspect just as many are not receiving it who should.</p> <p>The most common comment I receive from customers is that I am lucky because I have a visable disability, and therefore do not get the harassment they are often subjected to for being work-shy or lazy.</p> <p>Nearly everyone I meet wants to work either full or part time, their fear is being set up to fail : ie at the first sign of a return of a health problem they will be sacked . Putting at risk their home etc. If the new benefit offered some form of tapering or easy re instatement this would go some way to allaying peoples fears</p>
EM25	07-Dec-10	<p>I wish to make the following suggestions with regard to the current review of DLA.</p> <p>My remarks are related to the questions outlined and to those I wish to make a submission.</p> <ol style="list-style-type: none"> <li>1. Mobility and its costs. Discrimination by others to the disabled. Low wages paid to the disabled.</li> <li>2. I am of the opinion that the term DLA should be retained for the scheme - name changing is not required, it only leads to confusion especially amongst the elderly and those with limited education.</li> <li>3. The main costs that disabled face are heating and transport.</li> <li>4. The payments and DLA scheme should stay as it is.</li> <li>5. Annex 1 Table 3 should continue to be accepted reasons for immediate award.</li> <li>6 &amp; 7. No comment</li> </ol>

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		<p>8. No</p> <p>9. The application form should be simpler and as other evidence is requested to others - more emphasis be weighted towards GP and medical history.</p> <p>10. The claimants GP and medical history and a carer were available.</p> <p>11. If the information supplied by the claimants GP and medical records are sufficient to award DLA no face to face interview should be required. There are instances when face to face interviews can be detrimental ie such to claimants with mental problems</p> <p>12. A review of a claimant's entitlement to continue to have DLA should be assessed at least every 4 years, this should be made with regard to GP and medical records. Those claimants who have medical/ mental/physical conditions that it is known cannot change over their lifetime should be exempt from any future assessment.</p> <p>13. Until the claimant is in receipt of their State Pension Entitlement, they or their carer/guardian should be written to annually, to confirm that no change in circumstance have occurred regarding DLA entitlement. Failure to reply should then lead to the claimant to be required to be available for a personal interview inhouse or at home, failure to attend to such would lead to suspension of payment until compliance.</p> <p>14. I can only submit that the present DLA procedures be maintained.</p> <p>15. I can only submit that the present DLA procedures be maintained.</p> <p>16. DLA should be able to be used to make a one off payment for an aid such as power chairs/scooters etc.</p> <p>17. I cannot make any observation having no experience in this field</p> <p>18. On the confirmation of a DLA award the claimant should be given in writing details of other benefits etc that may be available to them.</p> <p>19. I can only submit that the present DLA procedures be maintained.</p> <p>20 &amp; 21. No comment</p> <p>22. I am aware that DLA has its problems, its detractors and those especially who wish to con the system. A more pro-active fraud staffing may be of more use to sort the problems of same than what appears to be a full frontal attack on the disabled.. I am of the opinion that the proposed 12 month waiting period is wrong - DLA is unlike other claims - needs must for those disabled - respect for those disabled is most important, this is why it is a scheme that should be independent of other benefits and their rules etc.</p> <p>DLA should be paid when the decision on the claimant award is made, in the first instant it may be time restricted eg. six month, nine months or a year until a further assessment is award as to the determination of duration applicable. Whoever dreamt up a 12 month waiting period is fully unaware of the problems and immediate needs of the disabled, their idea is wrong, wrong, wrong.</p> <p>I have experience of assisting claimants in making their claim for DLA. I am of the opinion that the DLA scheme is fit for purpose and should be maintained with a few amendments - these I believe I answer in my responses to Questions 12 and 13.</p>

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		<p>The problem of fraud which the DWP should pursue should be addressed not by changing a fit for purpose scheme such as DLA but to pursue with sufficient staff those that are the fraudsters.</p> <p>I am also concerned that publication of your consultation appears to have been "buried" in a bad news day on the 6th December 2010 ie snowmore important news -except in Northern Ireland where the Minister Attwood has ensured it got airtime on BBC/UTV and local press.</p> <p>I doubt you will get much of a public response but then does it count anyway.</p>
EM26	07-Dec-10	<p>I think it is downright callous and cruel to remove the mobility element from DLA for the disabled who live in Residential Care Homes. The so-called "savings" will be paltry. In return, the disabled will be confined to their homes with very few opportunities to go out, to organise affairs or go to the cafe for a chat. Their life-chances will be reduced. The con-dem Government cuts hit the most vulnerable, and very often and cause outrage. I implore you not to enact these cruel and callous cuts.</p>
EM27	07-Dec-10	<p>Hi as a blind person and helping to run the local talking newspaper for the blind, can I make a suggestion I made some time ago before this consultation started?</p> <p>Penetration of computers with blind folk is still quite low especially all those not able to work, so it might be a good idea to have a phone line for people to ring to do the form.</p> <p>Secondly, I do feel that at the moment there are so many changes going on that its getting hard for people to plan their lives, never knowing what funds they will have. At the moment many councils are rejigging their social care to, in effect push out those they do not consider to be critical. this is due in part to the inability to raise council tax due to government action. We also have restrictions on door to door transport as well, and although I do relise that there is a money squeeze on, many disabled people feel that they are being targeted all the way down the line and are thus taking a much bigger hit on their independence than perhaps was envisaged. there does, in my view, need to be some joined up thinking here to stop an impending disaster in funding of disabled peoples lives.</p> <p>I myself and organisations I help will consider the questionnaire and probably email it after the Christmas break. I feel starting the consultation when the first part of it is taken up by the Christmas/new year period is a mistake. maybe at this stage an extra few weeks should be added to the time so you get properly considered responses, not rushed ones.</p>
EM28	07-Dec-10	<p>You asked for feedback on the Government proposals for changing the benefits that are commonly received by those with permanent mental or physical disabilities. I have direct experience of the process with respect to Mental Health and only won an appeal because I insisted that the panel actually take evidence from a qualified psychiatrist. I have a daughter who we will call missX as it is not fair for me to recount her history using her own name.</p> <p>Getting anything out of Bexley has been a fight ever since MissX was "Statemended" more than 20 years ago. MissX was a registered disabled child but magically disappeared from the adult disabled list. Efforts by the social worker and ourselves have failed to right that error. At the assessment meeting there was almost no consideration of MissX's mental state but rather what she could do physically. Assessments are typically carried out by an occupational therapist who neither knew about or cared about mental illness. One major triumph was when MissX was allowed to go to Redhill residential College (██████) for 3 years and then a local day college for another two years but she still ended up, having been in the living skills process from age 3 to 23, unable to obtain a paid job. Having said that we have found her voluntary work for 4 out of 5 working days.</p>

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		<p>I interpreted the initial conservative press releases as a direct attack on those unable to work through mental or physical illness and responded to my MP, David Evennett (██████). His response was simply to say. I fundamentally disagree with the comments you have made. The Secretary of State for Work and Pensions is currently undertaking a complete overhaul of the benefit system to ensure that work pays, and equally that the most vulnerable members of our society get the support they need.</p> <p>Yours sincerely</p> <p>David Evennett MP Member of Parliament for Bexleyheath and Crayford I have just finished reviewing the discussion document cm ██████ My comments are attached as a PDF file.</p> <hr/> <p>Response to public comment document Disability Living Allowance Reform The new Universal Credit – which will replace a range of existing benefits with a single income-replacement payment – will finally ensure that people are always better off in work What about those who cannot get paid employment?</p> <ol style="list-style-type: none"> <li>1. Mental and or physical incapacity such that no paid work is possible Mental or physical symptoms that render it dangerous to the individual or others for them to be in a normal working environment or indeed unaccompanied anywhere.</li> <li>2. Recipients of higher rate DLA and MobA need assisted living so their combined allowance would have to cover the median private sector rate for that provision since few state run communities still exist. In my area (DA1) the cost of care is between £500 and £1000 per person per week. That is the need</li> <li>3. Inability to earn money for food and accommodation The cost of a shared able bodied carer Cost of a car with driver or taxis to get to voluntary work, therapy and discussion groups</li> <li>4. Flexibility is reduced for cases at the margins. Existing payment matrix is only 12 cells each with a rate – hardly complex</li> <li>5. Some mental and physical disabilities can neither be treated nor cured. In such cases this could be established at initial assessment. I would also point out that mental incapacity must be decided by at least one qualified psychiatrist and not a specialist assessor with little medical knowledge and, at best, a degree in some occupational related subject Right to appeal to a panel of qualified mental or physical specialists must be built in The named social worker of the individual being assessed must sign off the final assessment and ensure that the result is the ability of the individual to live safely and comfortably in suitable accommodation. If the individual is in a private care facility because there is no state facility then financial liability will continue even if the individual is hospitalised – the state must cover this cost as the price paid for outsourcing care to the private sector</li> <li>6. Assessment should start with need – how much does appropriate accommodation, care, travel and food cost and then take into account the ability of the individual to earn anything</li> <li>7. Monitor RPI, get GP to sign notes indicating change or no change, liaise job centre to find out if individual is in work or could be in work if work was available. In the latter case benefit will obviously have to be continued.</li> </ol>

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		<p>8. Stage one is for health and welfare to provide adaptations that will benefit the individual</p> <p>Stage two is assessment of the ability of individual with aids that have been provided</p> <p>Questions 9, 10 and 11 have essentially the same answer</p> <p>11. Claimant need fill out nothing if he/she has a carer. Carer or claimant to submit evidence of living expenses. Medical assessment from GP and appropriate specialist. Any occupational therapy reports to be reviewed by an appropriate qualified consultant.</p> <p>12. Unless GP notes indicate a change there is little point repeating</p> <p>13. Department asks for regular GP "sick" notes and possibly a rough breakdown of living costs.</p> <p>If the individual is in a care home run by private sector then that could be paid directly.</p> <p>15. Those eligible to claim will have a carer and the carer should act as advocate.</p> <p>16. Cost of approved aids and adaptations should be met in addition to PIP</p> <p>17. Children unlikely to be working or eligible to work. Children will often have a parent as main carer</p> <p>Children currently expected to live in parents' home forever as no provision for assisted living. When older than 18 young people should be found assisted living accommodation in a community where the disabled person can interact with peers .</p>
EM29	07-Dec-10	<p>1. That the condition or servity of illness/disabilty causes different effects upon the individual, some can be more noticeable than others. Treatment issues, poverty, It is also about the situation of the person e.g. working/or not. It is also about public persepction/image/opportunities and choices.</p> <p>....</p> <p>If a person is on state benefits of ICB, IS or other state benefit, DLA helps address the cost of living independantly e.g. gas/electric, travel, food, communication, clothing, bedding, cleaning materials etc.</p> <p>I suggest YES to this question. What the rates are to be and how the DWP will convert from old to new will be open to question?, given the reponse within the consulation of the complexity and the different SDA rates a new approach, understanding is acceptable for ease of implimentation and support.</p> <p>Disadvantages ?</p> <p>I suggest that the automatic rights listed under impairments, discriminates against the other conditions such as HIV/AIDS, Cancer, Parkinsons etc. and to comply with UK legaliastion this needs to be addressed to be more encompassing if it wishes to proceed on this line of approach. Alternativalty the system could set up a standard level of benefit for all of the different conditions. This would be done in dicussion with professional/charities/professional and disbaled people. Condition and treatment should also be taken into consideration.</p> <p>Create a main disabling condition tick box, were the condition is disclosed, this is then treated with priority and condition in mind, e.g. 6 months to live. Income notification.</p> <p>This relies upon medical training of those making decisions and a understanding of the conditions which will flucate. Information to be colated by professionals/charities and disabled people.</p> <p>None and No. e.g. someone who has a mobility stand to stand needs to keep hold to stabilize, how does some administor a task losing grip of a device to support, this also distracts from the additional support needed, which LA could use to get out of their responsibilities.</p> <p>██████ is anything to go by, NO. Also given some 10m people are disbaled within the UK and DLA only support some 3m+, answer that? List pre-condition tick box for summary/consideration.</p> <p>Relative consultant or GP.</p> <p>Depending upon the training and information available might cause problems, given the wide ranging conditions that will apply, how will the DWP</p>

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		<p>ensure the information is given to an appointment professional? Qualifications etc. Condition on the day.</p> <p>2 years standard and 5/7 years for indefinitely</p> <p>....</p> <p>....</p> <p>The current system of DLA by main disabling condition lets us know the types of people applying, successful with applications with DLA, this imbalance could be addressed by using this data.</p> <p>Aids and adaptations can be met through DSF, OT and other Government grants means which has a separate budget allocation. Charities and voluntary organisations have funds to provide additional support when the state feels it should not provide.</p> <p>Condition, life expectancy, family situation, poverty, support needs.</p> <p>DLA increases the SDA which raises income and helps address some of the additional cost that arise, in real terms is the current amount paid in line with current costs/CPI/RPI.</p> <p>As the current system stands it would deny people from community services and the ILF. Given the number on DLA and the numbers supported by the ILF, the system is failing!</p> <p>LA accept DLA/PIP as confirmation of condition/support than the independent FACTS criteria.</p> <p>Given the imbalance by condition which currently stands</p> <p><a href="http://benefits.tcell.org.uk/forums/dwp-quarterly-statistics-dla">http://benefits.tcell.org.uk/forums/dwp-quarterly-statistics-dla</a> should be taken into consideration.</p> <p>6 months life expectancy should be x 2 or 3 of standard rates, DLA could be awarded still but not in payment of income of £250K, a box could be added to the DLA form to suggest a person income and given the public restraints, income over this would not be payable but awarded in kind. Publication of independent person used, qualifications etc.</p> <p><a href="http://www.counselandcare.org.uk/category/policy/pdf/the-real-cost-of-qu...">http://www.counselandcare.org.uk/category/policy/pdf/the-real-cost-of-qu...</a> and <a href="http://benefits.tcell.org.uk/forums/disabled-peoples-costs-living">http://benefits.tcell.org.uk/forums/disabled-peoples-costs-living</a> be considered.</p>
EM30	07-Dec-10	<p>I am not sure if this is the right place to be voicing my concerns and worries. I have read the consultation document and am really worried about this process.</p> <p>I receive DLA after being turned down a few times. The appeal process was awful and caused me so much distress and am fearful of going through this again.</p> <p>I live with Multiple Sclerosis. I have had symptoms for 10 years but was formally diagnosed approximately 6 years ago. I see a consultant 6 monthly at Frenchay Hospital and it was equally distressing when I was told to give up work. I had had optic neuritis which has left me clinically blind in my left eye. I have recently had a relapse (6 months ago) which affected my walking and I now use a walking stick daily. Walking is very difficult. As I type this my arms ache and I am having to stop intermittently to rest. My daughter will complete this message for me. I drop things, forget things, am a danger to myself if out by myself, am a danger to myself and others in the home and the fatigue is debilitating and distressing. I live in my bedroom. After each activity I have to lie down and sleep. It's a horrible thing and although I try to remain positive it naturally gets me down.</p> <p>The thought that I may not qualify for this new benefit (P.I.P) frightens me and even though reassessment will not happen for another three years, I am already worrying about it. Financially, DLA has relieved much of my stress.</p> <p>MS is a progressive disease with no cure and I don't think people know enough about it and therefore assessment is usually incorrect. As well as MS, I have cell trait, Reynauds disease, vitamin D deficiency and cataracts.</p> <p>Can you give me any reassurances? My GP and consultant have already said that they will fully support any claim I make. Thank you for taking the time to</p>

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		read this and I look forward to hearing from you.
EM31	07-Dec-10	<p>There is no doubt in my mind, as well as thousands of other disabled people reading the proposed changes that most of it is just the work of Tory spin doctors trying to dress it up. I agree that forms must be made a lot easier to fill in. I would recomend that instead of paying so called health professionals large fees and then a bonus for everyone that they decide should have their DLA reduced are stoped. How can anyone who has never met the individual before really know all the many difficulties any individual disabled person has to cope with daily. Mobility, illness, care, mental health etc after an hours meeting. Surely all the imformation you need could be obtained from a simple form filled in by at least two persons who know and understand the person best of all their career, social worker, consultants, occupational thearpist and their own doctor. A easonable payment would be made to these professionals, cutting out the need to pay millions of pounds it will cost to set up and run this new system. Add to this the cost of constant reassessments proves that the Tories don't care how much it costs as their real aim is to go for the most vunerable and slash at least 60% off the DLA bill.</p> <p>I totally agree that their is a small minority of people receiving the benefit that are not entitled to it, but surely the cost of introducing and running this new scheme far exceeds what this minority of fraudsters cost the tax payer. I hope all involved in these changes will carefully consider what impact this is going to have on the disabled and re-think most of their idea's. Also where are these so called jobs for the disabled going to come from, I think most of the MP's don't live in the real world, I known several disabled people that have applied for hundreds of jobs over the years and when they state their condition in the application form they dont receive an interview. The times they applied not stating they where disabled, the employers told them sorry we need abled bodied people as they will be able to do more work for the same money. This happens all the time</p>
EM32	07-Dec-10	<p>Following viewing the consultation doc I have answered some of the questions listed as thoroughly as I can with regards to my personnal experience of living with a disability.</p> <ol style="list-style-type: none"> <li>1. financial/ emotional and physical to name a few. Financial..getting to work ie use of public transport or running a car. emotional, years out of work, becoming isolated, depression, lack of confidence. Physical, coping with physical demands of work, getting to work, fatigue. stamina. Barriers....suitable work, ability to perform tasks required, adequate help and aids to assist.</li> <li>2. Mobility aspect....to take account of varying nature of some disabilities. mobility issue is not just the walking part but managing tasks with upper limb problems as well. Care component..to take into account physical limitations and the nature of help needed as in the lower care component..ie help with preparing meals etc.</li> <li>3. Paying for help, not just to do with personnal care but every day tasks in maintaining a healthy and clean home to live in.. Certain medical conditions and disabilities make managing your environment difficult with assistance needed for this as well. Costs of all the aids, alterations and equipment needed ie lever taps..bathroom addaptions, ramps, clothing/footwear, running a car, wheelchair, mobility scooter, etc.. many of which have to be paid for privately. Expense of travelloign anywhere if you cannot mange public transport, taxis etc.</li> <li>4. not sure...I am concerned that those on the lower care component will lose out.</li> <li>4.(B) being placed in the appropriate rate or being excluded</li> <li>5. I would think that there is a place for automatic entitlement for certian conditions esp if supported by strong medical evidence.. for example i have Rheumatoid arthritis which has damaged the majority of my joints, is continuing to to do so with many operations already haivng been done and is unlucky to improve to a level beyond what i am currently experiencing.</li> <li>6. Getting up, dressed, managing day to day activities to a bearable level with</li> </ol>

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		<p>help when required, getting out and about ...shopping and help needed for that...looking after oneself and enjoying a reasonable quality of life.</p> <p>7. Have knowledge of how and which conditions fluctuate beyond the appearance of a person... to all extent and purposes to someone who doesn't know me probably thinks i have nothing much wrong with me until they get to see close up the extent of joint damage I have.. However, people I know still do not really know the difficulties I experience day to day.</p> <p>Also although surgical intervention has happened this isn't always a 'cure', for example i have had replacement MCP (knuckle) joints which hasn't improved function at all, and several other joints that have been operated on will never be a normal functioning joint.</p> <p>8. how can some be fully taken into account, if a person uses lever taps and bathroom aids these may not be available everywhere for them, if they visit family and friends. One example i can give is that i raise the level of the armchair/settee cushion at home but visiting elsewhere often need assistance to rise from others.</p> <p>also a mobility scooter is of limited use if the shops you visit block the aisles and access..</p> <p>8. (b) What exactly do you mean by easily obtain...all these aids and adoptions are incredibly expensive, not many people are eligible for the disabled facilities grants especially if their partner is in full time work. Having had to pay out for many adoptions and equipment has been a financial hardship.</p> <p>9. use layperson language and ask sensible questions and above all be fair, allow us to explain how our disabilities affect us day to day. Please don't use multiple choice fixed answers .</p> <p>9.(b) again use of layperson language.</p> <p>10. Doctors and Consultants reports/ full medical evidence/xrays if applicable. But be aware that although they have detailed knowledge of our disability they may not be fully aware of the affect on our daily life.</p> <p>Also family members and spouse/partners knowledge.</p> <p>11. first impressions don't always count. On first impressions i don't look too badly affected by my RA, I have even been initially 'disregarded' by some health care professionals until they see from my records the extent that I have been affected and the number of surgeries i have had to manage my condition.</p> <p>11.(b) don't know</p> <p>12. The likelihood of persons disability improving</p> <p>12.(b) Yes</p> <p>13. Give clear guidance about the type of things that need reporting and when.</p> <p>14. good idea....if it is clear the perosn needs a personal care plan then maybe do a referral to social services.</p> <p>15.don't know</p> <p>16. May be a helpful idea esp if a major adaption is needed that a disabled perosn has to finceance themselves and cannot afford, although consideration is needed if this then reduces the monthly income.</p> <p>17. don't know</p> <p>18. Extremely helpful as it is a gateway to the warm fornt scheme and blue badge scheme, this should be shown in the claim form or advice given at the same time.</p> <p>19. It would make things harder for us, it is difficult enough to access these without this link being severed. many people would miss out through lack of awareness of what is available and the knowledge and help in getting them approved.</p> <p>20.This could be infinite...the many different assessments that are done are a waste of many resources...care assessments/medical/benefit assessments all go over the same issues in different ways.</p> <p>21. The way individuals react and deal with their conditions, many people complain more about things and get more attention then others who are worse off and manage in silence. It is actually very difficult to be completley honest in how bad things can be....the syndrome of saying to the gp oh I am fine when you see him. many of my family really have no idea of what is involved with my condition.</p>



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		<p>22. I feel very fortunate to have had the help that I have had through the benefit system since being medically retired from work, and honestly have no idea how my husband and I would cope financially without the help we receive. My Ra has cost us thousands in adaptions/equipment/moving home three times in the last 15 years to cope wiht the deteriorating nature of my condition. There is also the cost of running a car which now has to be an automatic which inevitaby costs more. The proposed changes make me very nervous but i do understand that the current system has to change.</p>
EM33	08-Dec-10	<p>17 years ago, my driving introuction said "you having a walking problem ok you can use automatic padels" I was drive okay with padel for a long time 2 years ago my legs has changed started nervous and shaken to drive was so horrible feeling and very stressed, last year I crashed my car because of legs was nervous attack. I decided to use a hand control is much much better than padels and I do not have to worry and free stress driving. more comfrotable than padels. Im very happy. Honest I should use hand control in years ago but I was very angry with govertment because not proection for my safety. I'm very pleased that never got a sore back since last year so thanks for using hand control. I believe that carebal paisy is not suitable for foot padels. DLA motabilty need reform for application form for example are you carebal paisy walking? if say yes then automatic to tell the gargage sales "disabled need hand control only" Good reason is hand controls is good for emgergency stop.</p> <p>I believe who having a walking problem should be banned to use automatic padels because will be nervous and shaken when they are getting older, believe me its not safe for them to drive. I'm very worry about them caused will be an accident in further. Disabled who are carebal paisly walking problem or sore back better to use hand control is more safety than foot padels. I need a new health and safety for disabled drivers law because prevent an accidents in further.</p> <p>Please can you bought up to the parliament etc its very seriously matter. Good idea extra new motabilty assestment driver to make sure a person who can drive because disablded can be changes in further.</p> <p>Motabilty allowance rates unfair I believe that motabilty allowance rates are unfair for me okay would like to explaining you.</p> <p>Benefit told me that if you do not want a car then extra benefits but I would prefer need a car. Im paying my motabilty car and petrol but deaf people will keep money in their pocket. They shouldn't receiving lower or middle care motabilty allowance because already got a free bus pass and rail discount. Motaiblty only for seriously like walking problems, back pain, etc. Deaf have no problem with transport because they can write down pices of paper then show to the driver before get on the bus. who can long walking without health problem then no need to claim motaiblty allowance at all. I cannot walking more than 1 miles and cant lift my shopping bags etc etc is rights to claim motability allowance. Did you know that lots of disabled people already got a free bus passed but they got receiving motaiblty allowance its not right and not fair for me at all.</p> <p>new petrol allowance for motaiblty I'm paying £20 a week for my petrol and not much to going out because petrol are very expensive. Did you know that in america is very cheap petrol because automatic car is more expensive petrol than manual cars. Ireland and Austrillia already petrol allowance for the disabled but why not here. Petrol allowance is very important for the disabled people need to go out like visit friend, bowling and much to do something than staying at home to get bored and not healthy. If I want go back to work but problem is paying too much petrol like extra £20 a week and not much wages left I got. Duncan smith said "make sure their wages more money than on benefits (work pay). Its good for them back to training and jobs in further. If disabled people got receiving petrol</p>

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		<p>allowance from the govertment then they will be happy go to college, univerisity, jobs and going out for bowling, see a friends etc.</p> <p>I dislike the words is called "disability living allowance and motability allowance because is not nice name and make me label and very embarrssing. I would like to see change nice name personal independence payment, Im currently DLA but no necessary go to medical assestment because deaf will never become hearing and I was born carebal paisy walking problem will never improving for 35 years. Did you know that medical assestment cost £100 each, its wasting money if deaf go to medical assestment every year. Either DLA or personal independence payment should check to make sure who are deaf or health problem will never change to improving should be automatically for life awarded just save your money for medical assestment. Who are having a problem like mental health, sore back, fat people necessary medical assestment. I advice you not spending too much waste on medical assestments is waste taxpayers but you have to rethink the balance for example can improve (2 years medical assestment) or cannot change (for life awarded). Work and pension in Blackpool and all staff have to check their history files before they go to medical or not.</p>
EM34	08-Dec-10	<p>I run a website with a colleague where our intention is to gather evidence into the suitability and availability of education and care packages for people with Aspergers <a href="http://www.asteens.co.uk">www.asteens.co.uk</a>.</p> <p>I have many concerns about DLA and likewise about your Personal Independence Payment for people on the spectrum. The emphasis tends to be on what someone can do which for a physical disability is probably a reasonable approach but for developmental and mental health problems it all too often disguises the severity of the impairment. For example if I suffer from panic diorder and you ask me if I can work a cash till and talk to custommers the answer is yes, however if I feel trapped and panicy in any work situation where I cannot escape then in realiity I cannot work a cash till and talk to custommers.</p> <p>In our organisation we hear from people who are turned down for DLA when their children's needs are so extreme please see this example [REDACTED]. If one were to involve a health professional to assess the situation many of the deficits would not be picked up and GPs do not often know or understand the full impact of Aspergers on the child/young person and their family. Many of the problems our children have are invisible and variable and may not be apparent to the causal obseerver - if your new forms cannot assess the case cited and see it as a deserving cause then they forms and assessment is going to continue failing a significant group of people. Only 2% of our members felt that the current DLA form was appropriate to assess their children's difficulties.</p> <p>Filling in forms and facing assessments is unbelievably stressful particularly when one is already tired and has spent years fighting various systems so that one's child can receive a basic education and help to eualisie the playing field. All the time disabled people have to fight for what others take for granted and fill in stressful forms, they are being subtly discriminated against.</p> <p>For life long developmental and mental health problems I suggest one form is used (with sections specially designed for mental health and developmental problems) and reassessed again at age 18-20. I would suggest that one fully comprehensive form should be filled in by a specially trained person eg. social worker, mental health specialist, with rigorous training in the condition concerned. The child and parent can be present as appropriate and and possibly involve other professionals with knowledge of the case. This one form would automatically ensure that the person receives all the benefits they are entitled to. At present, some families have to fill in DLA, Carer's Allowance, Income and Employment support which means three lots of admin. This is not only phenomenally stressful but a waste of admin. time</p>

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		<p>Where people have life-long conditions, that either remain the same or deteriorate, they should not have to regularly re-apply. They should just receive an annual letter asking if anything has changed. For conditions that change, perhaps to reduce the chances of fraud, ensure that 10% of those who have claimed 'no change' are randomly selected and checked.</p> <p>Rather than the current form with its tick box criteria, which concentrates on only physical disabilities and what they can do, we should also look at what would happen if the care were withdrawn. The form should concentrate on what the applicant can't do and what happens if the care given is removed, because only then can you get a clear picture of the true range of needs and the actual amount of care being provided.</p> <p>Give DLA/Tribunal extra powers to make judgment calls. Where a case is complex or involves a rare disorder, specialist staff who have extra knowledge and training could be called in - such staff could be shared across regions. They could be consulted in unusual cases. Specific training to be given to staff who handle the developmental disorders and mental health forms (might I suggest my book as part of the package! 'Children an Teenagers with Aspergers - Anna Van Der Post)</p> <p>Single parents are additionally vulnerable and should be given prioritybecause without DLA they cannot get carer's allowance and with a child such as the one cited on the website the mother cannot realistically work full time. Oe of our questionnnnaire respondednts suggested</p> <p>'carers allowance should be automatically paid when DLA is confirmed. currently yet another form with same content has to be filled in.'</p> <p>It is essential that any system can be flexible enough to look at each case on its merits and that Tribunals can make decisions based on needs not on some arbitrary point system as at present.</p>
EM35	08-Dec-10	<p>Q1: Isolation, lack of transport, lack of communication with others, no facilities for their disability in local shops, public buildings etc, not being able to afford the cost of domestic help; lack of any day centre or club in their area where they could meet others.</p> <p>Q2: mobility and care components</p> <p>Q3: communication expenses : with their carers/health professionals: phone bills  Travel expenses; taxis to health appointments if they cannot manage public transport and have no transport of their own; ditto to any clubs or day centre they can go to  Disability aids around the home  Disability aids to help at work  Hiring people to carry out domestic tasks they can't do, like cleaning and gardening</p> <p>Q4: Not enough information to answer</p> <p>Q5: Some conditions should automatically get the benefit such as mental health disabilities, because the person might be unable to ask for themselves. The persons needs can often only be assessed by their health professionals and carer.</p> <p>Q6: Provision of items to remedy the lack of things in Q1</p> <p>Q7: Consult with their GP/other health professionals and their Carer</p>

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		<p>Q8: Yes, but you should also understand that aids and adaptations might not be usable every day for the disabled person. They may suffer intermittent pain and discomfort and not be able to use their aids every day.</p> <p>Q9: make sure their carers also get to see the claim forms.</p> <p>Q10: From their health professionals, carers and family</p> <p>Q11: For some disabled people the journey to the meeting in itself might cause pain, discomfort, distress, or make their condition worse. In this circumstance it would be better to get the information from the health professional and/or carer.</p> <p>Q12: re-assess once a year for long term conditions. You should rely on the persons GPs assessment re changes in their condition.</p> <p>Q13: Stay in regular contact with their health professionals and carers</p> <p>Q14: A simple reminder leaflet through the post; separate cover to their carer as well, even if in the same household.</p> <p>Q15: Yes, the benefit should be able to be used for anything, as DLA is now</p> <p>Q16: Make sure their carers/parents/ guardians are also consulted</p> <p>Q17: It would make life harder for people with transport issues and fuel poverty, because they/ their carers would have to re-apply to different government departments.</p> <p>Q18: all information you've got.</p> <p>Q19; disability is disability, sexual orientation should have nothing to do with it. Especially if by this question you mean that certain groups will receive preferential treatment in terms of getting the new benefit.</p> <p>Q20: Especially in the case of people with mental health issues: you MUST make sure that their health professional/ carer also gets a copy of their claim forms, invitations to meetings with assessors, any appeals etc. There is no point in using the human rights act as an excuse to deny people a benefit if they were too confused, drugged, in pain, in hospital, to answer the question at the time you sent it, on the grounds that only the person can be asked. You MUST keep the carers informed.</p> <p><u>In all your questions there is nothing directly about carers.</u></p>
EM36	08-Dec-10	<p>After reading the DLA consultation, I have enclosed my initial thoughts below. These are from my own perspective as a blind person currently in receipt of DLA. I am blind, and speak as a blind person, though have touched on the possible issues relating to those with other disabilities.</p> <p>I have written my thoughts, quoting parts of the consultation, then responding with my own thoughts on what I read.</p> <p>I have highlighted parts of the consultation with which I have issue, and some that I don't have issue with. These are notes, meant as a general comment from myself as a disabled person. Some of the questions asked in the consultation do not have relevance to myself, so I will restrict my comments to the points of which I have most knowledge about as a claimant of DLA and likely claimant of the new PIP.</p> <p>You say that: "For example, many people incorrectly believe that Disability Living Allowance (DLA) is an income-replacement benefit for people who are unable to work due to disability."</p>

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		<p>I am glad to see the consultation paper recognises this, as the chancellor of the exchequer failed to do so in the June budget, blurring DLA claimants in his speech with those who solely claim out of work benefits, therefore opening disabled people to the fire of the media as workshy. This is clearly wrong and a reprehensible mistake to make.</p> <p>You state that.“The changing approach to disability</p> <p>1.12. Since DLA was introduced in 1992, there have been significant improvements in medical treatments and in aids and adaptations that assist disabled people. Attitudes to disability have also changed. The introduction of legislation, for example the Disability Discrimination Act 1995 and Equality Act 2010, to protect the interests of disabled people and prevent discrimination has helped many disabled people lead more independent lives. It is now universally accepted that disabled people should have the same choices and opportunities as non- disabled people. “</p> <p>I would take issue with this assertion. Legislation is all well and good, but attitudes have not really changed, for instance, 65 percent of blind people of working age are still unemployed, getting access to information in an accessible format is difficult, and blind people can't access daily life without a greater level of struggle than fully sighted people. legislation, especially civil law, which can be all but ignored by a company with a good lawyer, does little or nothing for disabled people. the DDA is guidelines at best. How the government thinks disabled people should be treated in society , rather than mandating that level of treatment by backing the guidelines of the DDA up with criminal penalties for non compliance. Disabled people do not feel they have securable rights at the moment, as the law is not strong enough. A woman knows she cannot be discriminated against on the basis she is a woman, a disabled person cannot have that certainty. In the case of a disabled person, it's all based in what is reasonable to give them, which is a subjective test in my opinion. A woman however, has criminal law on her side.</p> <p>You say:The benefit can act as a barrier to work</p> <p>1.19. Evidence suggests that DLA can also act as a barrier to work 6, when it should enable people to lead independent lives, including having or getting a job. DLA is widely perceived to be an out-of-work benefit and receiving it appears to reduce the likelihood of being in employment, even after allowing for the impact of health conditions or impairments. There is evidence that people who receive DLA have lower work expectations. One reason for this appears to be that people fear they may have less money if they enter work. This is particularly the case for recipients of higher-rate DLA awards, who are often in receipt of a range of benefits.”</p> <p>I would hazard a guess the reason why people on higher rates of DLA have lower work expectations is because, in the majority of cases, their disability is so severe they have little chance of work due to the complexities of employing the most severely disabled. The attitude is based in realism, rather than a wish not to work.</p> <p>you say:1.19. “Universal Credit will reduce the complexity of the system, making it easier for people to see for themselves how much better off they will be in work. It will also ensure that all amounts of work will be more financially rewarding than inactivity and remove the current barriers to small amounts of work.” Why speak of universal credit when we are talking about replacing DLA? DLA is not income or work related. The two are mutually exclusive, as you state at the top of the consultation paper. DLA is awarded because of disability, not because of work status. This constant equation between DLA</p>

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		<p>and the new universal credit is erroneous in my view. Stick to the point please, which you state is reassessing all claimants of DLA to better meet their needs.</p> <p>You say:“We want to simplify the application process, creating a benefit and system that is more efficient, easier to understand, and identifies those most in need of extra support to live independently and participate in everyday life. We also want to ensure everyone continues to receive the correct amount of benefit.”</p> <p>I can’t argue with this point, other than to say, make sure the assessors are truly independent, and take all evidence into consideration. There has been evidence recently that assessors have not been carrying out their work thoroughly and with due care. The recent successful appeal rate of ESA claims should point to this failing in the current subjective, tick box assessment system.</p> <p>You say:““We hope that making the benefit clearer, alongside the introduction of Universal Credit and the Work Programme, will help many more disabled people to work and enjoy all the advantages that an active working life can bring.”</p> <p>Again you speak of work in connection to the new personal independence payment, though you have already told us this benefit is not an out of work one. Please decide which it is, and whether claiming it is possible both in and out of work. You say:  “Personal Independence Payment will be based on need not income and will be a more active benefit, recognising changes to individuals’ situations and taking account of the support that disabled people can access to help them live independently.”</p> <p>Constant assessment of claimants is going to be massively expensive and will put extra strain on those with mental health issues, or who have learning disabilities. Is this cost affective? Surely there have to be some exemptions, for instance, those who are totally blind, and, after a qualified ophthalmologists assessment, that blind person, who has been certified as having a condition of the eyes which will not improve with treatment, could be exempted for a period from constant assessments. You say:</p> <p>“Where possible, we will signpost individuals to support that may help them manage their condition..”</p> <p>Some people with certain disabilities would benefit from this, such as those with mental health issues, addictions etc. though managing a condition is a broad term which speaks of government not wanting to acknowledge the needs of people with complex disabilities the government would rather leave alone.</p> <p>You say:“We will ensure that the award continues to reflect the individual’s changing needs over time by building in periodic reviews.”</p> <p>Again more assessment  Constant assessment of claimants is going to be massively expensive and will put extra strain on those with mental health issues, or who have learning disabilities. Is this cost affective? Also, for those who have conditions which are unlikely to get better with time, reviews should be proportionate to the likelihood of a change of condition..</p> <p>You say:“The criteria on which DLA is currently based, on care and mobility needs, are subjective and unclear. They lead to inconsistent results and support which is not always focused on those who face the greatest challenges to leading an active and independent life.”</p>

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		<p>I can agree with this, re problems that blind people face getting middle rate care component of DLA at present. Even though case law says they are entitled to middle rate care component, some really have to fight to get this level of benefit.</p> <p>You say:“We want Personal Independence Payment to be a more consistent and more focused benefit. “</p> <p>Can't disagree with this point.</p> <p>You also state:“‘mobility’ as currently defined concentrates on an individual's ability to walk, not their ability to get around more generally. “ Yes, hence why the RNIB fought and won the right for blind people with the most severe sight impairments to get higher rate mobility component of DLA.</p> <p>You say:“Taking into account aids and adaptations</p> <p>27. We know that many disabled people use aids and adaptations to increase their ability to participate in everyday life. Currently, DLA takes account of some adaptations, such as prosthetic limbs, but not all, wheelchairs for example. We believe we should take greater account of the successful use of aids and adaptations as part of the Personal Independence Payment assessment, to ensure that support is appropriately targeted on those who need it most, and that the benefit reflects the advances made in this area. This might mean, for example, considering an individual's ability to get about in a wheelchair, rather than ignoring the wheelchair, as we do currently.”</p> <p>I agree with the thrust of this proposal, but would urge the government to think about the costs of maintaining equipment, not to say purchasing it in the first place. Also, if the ability to purchase equipment is taken away from the disabled person, they would become more disabled. For instance, if I purchase a cane with my DLA, and that DLA is removed because I am seen as not needing it because I can cope by dint of having use of the cane, and that cane breaks, what do I do then?</p> <p>You say:“We recognise that some aids and adaptations are provided by government while others might be paid for out of an individual's DLA itself. We are considering the best way to prioritise support in this situation.”</p> <p>I pay for my own computer with specialist software on it, on which computer I am responding to this consultation as it happens. Maybe a one off grant to blind persons, who are registered as blind for the qualifying period of this benefit, should get a grant towards computer equipment, screen readers etc, which would facilitate their communication needs? This currently doesn't happen.</p> <p>You say:“We also recognise the need to ensure that taking aids and adaptations into account does not discourage individuals from using them.”</p> <p>This means that, for instance, because I have a computer I work with here, I still have communication needs, as the computer needs updating with software to keep it secure, and periodic upgrades as computers break down beyond repair, or need updating due to changing technologies. This part of my life as a disabled person, is very expensive. I have to keep two computers in my house, one I use, and the other is a stand by machine, just in case the first one needs to go into repair or breaks down completely.</p> <p>You say:“Question 8 Should the assessment of a disabled person's ability take into account any aids and adaptations they use?</p>

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		<p>• What aids and adaptations should be included? Should the assessment only take into account aids and adaptations where the person already has them or should we consider those that the person might be eligible for and can easily obtain?"</p> <p>Depends what the definition of easily obtain is. A computer is easily obtained, though the screen reader to use that computer, in the case of a blind person wanting to use such technology, is expensive, and expensive training might be needed to use such software. Will the benefit help with those costs? Also, because a person has aids to their disability, it does not mean those aids will remain in good working order for life. Computers break, wheelchairs break, canes break, and disabled people need replacements now, not in three months time when an authority has cleared, approved, assessed and deemed funds to be available for the disabled person. You say: "Gathering evidence</p> <p>29. Using the best and most appropriate evidence will be essential to ensuring that the Personal Independence Payment assessment is objective. Disabled people are experts in their own lives and information they provide will continue to be vital. We need to gather this information in a way that is effective but simple for the individual."</p> <p>Yes I agree here. Trying to describe blindness and the affect it has on my life on a form is very hard, though is possible with some thought." You say: "Disabled people have told us, for example, that the claim form for DLA is too long and complex and can require them to talk about their disability a negative way, focusing on what they cannot do rather than what they can do."</p> <p>People who claim DLA at present claim because they are disabled. Most disabled people use adaptations to live their daily lives. Take those adaptations away, and they're sunk. A wheelchair user might employ a PA to help them in their daily lives, take that pa away, and they're more disabled than they were with the Pa's help. They employ the PA to assist them to lead as fuller life as possible. Disabled people are not able to shrug off their disability just because the government says it would prefer them to do so..</p> <p>you ask:Question 9: How could we improve the process of applying for the benefit for individuals and make it a more positive experience? For example:</p> <p>• How could we make the claim form easier to fill in?"</p> <p>Take the evidence of qualified persons in the field of the claimant's disability, for instance the CHI, certificate of visual impairment for people with sight impairments. The forms give indications of visual acuity etc. these should be adequate for a basic entitlement to the benefit in my view.</p> <p>You ask:"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>Good information, clear information, stamping on misconceptions of entitlement to benefit, as with the current DLA setup.</p> <p>You say:"30. We believe that advice from an independent healthcare professional, such as a doctor or occupational therapist approved by the Department, should be an important part of the new process."</p> <p>As long as the department's health care professional is truly independent, has no agenda other than the objective assessment of a claimant according to the</p>



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		<p>law, and also has a background in the claimant's disability. I would not like, for instance, as a blind person, to be assessed by someone who is qualified in bone disorders, for instance. As this person would not know anything about eyes, and visual acuity would mean nothing to them.</p> <p>You say:</p> <p>"In most cases, we envisage that this will involve the individual having a face-to-face meeting with the healthcare professional, allowing an in-depth analysis of their circumstances. But we recognise that there may need to be some exceptions – for example, in the case of terminal illness and those disabled people who face the most complex barriers. It will also be important that we consider information from healthcare and other professionals who work with and support the individual, such as their GP or social worker."</p> <p>Yes consider all evidence, everything, leave nothing out.</p> <p>You ask:"Question 11 An important part of the new process is likely to be a face-to-face discussion with a healthcare professional. • What benefits or difficulties might this bring?"</p> <p>Again, if the health care professional doesn't listen to the claimant, making arbitrary judgements on how they look, how they act, and the health care professional bases his or her decision or notes on their own preconceived notions of disability, a face to face interview could be problematic for some claimants. A blind person, for instance, might not, "look blind," according to the health care professional. The blind person might be able to make an approximation of eye contact though they cannot see, which though looking good, might give a misleading idea of the impact of their disability on their lives. If a blind person is more confident than the health care professional expects them to be due to preconceptions of disability, then this could have a negative impact on what could be a genuine and fulsome claim for benefits. Some disabled people only function well where they have defined coping strategies within restricted boundaries, IE, going to certain shops where they are known, or to certain places where they are known and accommodated. DLA, and this new benefit, is to help with those times where the established strategies fail, such as in a new environment, where the disabled person has to purchase help for instance. A face to face interview is only a snapshot of the disabled person, and gives no real insight into their daily lives in my opinion.</p> <p>You ask:"Question 15 Could some form of requirement to access advice and support, where appropriate, help encourage the minority of claimants who might otherwise not take action? If so, what would be the key features of such a system""</p> <p>This question is unclear to me, though might mean something to do with mental health issues, getting help with coping with depression etc, to mitigate the affect of a disability. I'd be careful with this conditionality, as forcing someone into it, can often lead to more anxiety. Though conditionality might be workable where drug addiction or other substance abuse is the basis of a claim for PIP.</p> <p>You ask:" How do disabled people currently fund their aids and adaptations? Should there be an option to use Personal Independence Payment?"</p> <p>Disabled people sometimes use loans, credit cards and other forms of borrowing if they can't access other funding streams. DLA is also used to purchase adaptations, though for big ticket items, DLA isn't enough money to purchase them in one go, and finance agreements are not often available for those on state benefits.</p>

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EM37	08-Dec-10	I suspect that after any "reform",there will still be many thousands fiddling it,and the numerous other benefits to which the fiddlers are"entitled". Welcome to UK....."Treasure Island"
EM38	08-Dec-10	<p>I am responding to this document as an individual. I sincerely hope that my voice is heard and taken into account.</p> <p>As stated in the consultation document, people with terminal illnesses are exempt from the reassessment process and will automatically be awarded the new PIP benefit.</p> <p>I think this 'exemption' should also include people that have medically diagnosed progressive incurable illnesses too. Multiple Sclerosis is incurable and there is debate as to whether it should be classed as terminal. Life expectancy of someone with MS is reduced.</p> <p>Critical illness is paid out automatically on diagnosis of Multiple Sclerosis, cancer and other illnesses that result in permanent symptoms and I think that payment of benefits should all in line, be recognised and be consistent in all cases of payment and awards.</p>
EM39	08-Dec-10	<p>I am a Disability Adviser for DWP working in Leigh JCP. Having briefly read the proposals for PIP , my major concern centres around the' in depth analysis by independent health care professional'. My experience concerning the personal capability assessment for people on ESA is that it is computer led and takes little account of mental health problems experienced by the customer. Surely the customer's GP and consultant will have a more accurate assessment of their needs.</p> <p>How this is done is very important if we are to get it right and current professionals who know the customer's medical history and current situation would seem best placed to providing this information.</p>
EM40	08-Dec-10	<p>here to my response as a disabled person in receipt of DLA - i not that you have NOT made responding easy - WHY no on line form to respond with ?? - why has the government NOT sent a paper copy to each DLA recipient for comment ?? - already we see discrimination against those who may not have Internet access - or may not be computer savvy - or is this part of the plan ?? if we as a group , do not respond then you will assume that we are happy and agree with what you propose ?? - PLEASE bear in mind that many of the organisations and groups consulted do NOT speak for individuals who may have no contact with them - whatever i respond as follows :</p> <p>1. in many cases total disregard of existing legislation - no enforcement of legislation - prejudice by people and employers against disabled people - and in many cases lack of money , as many disabled people live on or below the nationally defined "poverty" levels - the simple fact is that disability incurs extra costs that "able " people do not face - there are barriers such as transport that does ot cater for our needs - for instance - trains - i NEED my mobility scooter to get round - BUT i i wanted to go somewhere on a train ( bare in mind i don't drive nor own a car ) - then i may be able to get to a station - but as i cant take my scooter on a train - what do i do at the other end ?? - i cant walk far without it - so basically i don't go - same with buses etc - and as a non driver or car owner many social and domestic facilities are out of reach - as society is GEARED for car users not those WHO CAN NOT OR DO NOT DRIVE - again for instance - i am limited in shopping choices as the cheaper supermarkets are "out of town " - or a 16 pound taxi ride away - thus negating any savings to be made when on a limited income - like wise you preach about work for the disabled - again - transport costs - public transport NOT going near /to place of employment etc - need i go on ??</p> <p>2. don't fix what ain't broken !! - all this is going to do is penalise disabled people - cause stress and hardship for some - and REDUCE our limited quality of life - fine target the cheats - but leave the genuine claimants - who have</p>

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		<p>ALREADY been assessed and who's situation has not changed ALONE we don't need all this hassle !! - how many suicides will it take before you get the message ?? - its going to happen - you WILL push some over the edge with all this interference !!</p> <p>3. see my response in 1 above + some of us younger disabled people do not get any help with heating etc - which would be a great help if like me one suffers from chronic arthritis - the last 2 winters have been very difficult - BUT as i am in the age group ( 54 ) where i "do not fit the criteria" - i get NO help</p> <p>4. depends WHO is administrating it - there will as usual be too many "experts " telling disabled people HOW their condition affects them - and anyways this is all about saving money - not the needs of the disabled - does the government think we are all stupid ?? - we are disabled not DUMB !!</p> <p>5. MORE conditions should be automatic NOT less - all this "individual " thing will mean is abetery decisions by people who have NO idea of the "individuals " needs - don't forget some people are not ABLE to articulate their needs well - and may be intimidated by the proposed "reassessment" process - thus not giving best account OF their needs</p> <p>6. STOP giving lip service to all this !! - ENFORCE THE EXISTING DISCRIMINATION RULES and MAKE COMPANIES AND EMPLOYERS ACTUALLY AWARE OF THEIR RESPONSIBILITIES AND OBLIGATIONS TO THE DISABLED . as to activities ?? - see my previous comments</p> <p>7. educate and ensure that those assessing us understand that we ALL have good and bad days - just because we have a GOOD day is NOT an excuse to decide we don't need the same level of support - or need the financial support - DON'T use a short term "improvement " as an excuse to penalise us !!</p> <p>8. this again depends on IF you are for instance going to use the fact say that someone uses /needs a scooter or wheel chair as a factor FOR or AGAINST them - if you see an "aid " as a way of providing LESS support /financial support - then this in its self is discriminatory - what of those for instance who NEED a chair or scooter but cant afford them ?? - does having a false leg provided then negate their needs ?? - this is a very "open ended " question IMO</p> <p>9. make it shorter and simpler - stop asking the same questions many times in different ways</p> <p>10. ones doctor - they know our problems best - and it may help if assessors LISTEN to what the claimant is saying - not just go by a set of computer generated rules and standards</p> <p>11. will this BE medically TRAINED SPECIALIST in disability or some one under contract who has had cursory training and is working from a computer program ?? - HOW many of the assessors will be disabled themselves ?? and thus understand the needs and problems of the disabled ?? - not many i suspect - HOW can a NON disabled person JUDGE a disabled one ?? they have no experience of BEING disabled - they do not know what we face - again some people are NOT good at putting over their case /problems also if one has been already assessed - what is the point of keep reassessing them ?? - the GENUINE claimant 's condition does not usually change - probably only gets worse !</p> <p>12. again depends if this exercise is about saving money or genuine desire to help the disabled person - surly the government does not think we are ALL cheats and scroungers who will lie to keep the pittance we receive ?? - once</p>

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		<p>assessed we should be left alone and TRUSTED to be honest in reporting changes as now</p> <p>13. the ones that don't do this are the fiddlers - i refer you to my comments above - INNOCENT UNTIL PROVEN GUILTY has always been the rule - a simple SIGNED review questionnaire will be sufficient for most HONEST claimants - don't tar us all with the same brush !!</p> <p>14. clear - concise - and common sense !! - not a raft of government "mumbo jumbo " full of inconsistencies</p> <p>15. ha WHAT advice and support ?? - more paid contractors who are more interested in getting their money than helping people ??- had experience of this !! - we DON'T NEED rafts of "experts" trying to help us and costing a fortune - what you mean is "if you DON'T ask for help - then you obviously don't need it " - some people don't wish to have others interfering in their lives AND are quite capable of ASKING for help if required - AGAIN disabled does not mean stupid !! - + with all the cutbacks - will ANY HELP BE THERE ??- or will the stock response of "theres no money " become the norm ??</p> <p>16. they struggle !! in may cases or have to go cap in hand to charities - if you use any money for say buying a scooter for your mobility needs - then whats left to pay for taxis or public transport to enable you to get where the aid cant take you - see my previous comments on this - and don't forget - things like scooters /wheelchairs need maintenance - batteries etc - these don't come free !! - they cost money - money that some of us don't have as we are on small pensions etc and rely on DLA to be ABLE to even keep these things running - do you guys actually HAVE any idea as to the costs involved ?? - batteries 300-400 quid every 3 years or so - servicing 12 - 15 pound per hour etc +bits ( if obtainable ) need i go on ?? ) oh and don't forget insurance 60 -80 each year if one is sensible )</p> <p>17. well that's a no brainer !! - kids cant always speak up for themselves - again it a case of the assessors LISTENING to parents and doctors .</p> <p>18. VERY - don't mess with this - if this means LESS entitlement</p> <p>19. again would have thought this obvious - HARDSHIP AND DISTRESS !!</p> <p>20.as needed !! - if you want to save money - then cut out duplication of effort !</p> <p>21. a disabled person is the SAME be they black - white - gay - straight - a Muslim or Christian or whatever - whats this got to do with anything ?? if you start making concessions to one group it will alienate others -TREAT US ALL THE SAME - as people !!</p> <p>22. the REALIST in me says this is about saving money as part of the cutbacks - NOT about any REAL help for disabled people - this is NOT being cynical - DLA works fine as it is - again WHY FIX SOMETHING THAT IN THE MAJORITY OF CASES IS NOT BROKE !! - all this will do is cause anguish and distress to many GENUINELY disabled people - go target those who are openly flaunting the rules - people who can seemingly play sports - go on foreign holidays etc etc - those of us who ARE genuinely disabled cant do these things - heck most of us hardly leave our houses most days as we are in too much pain and discomfort caused BY genuine disablement - we find life difficult - PLEASE DON'T MAKE IT ANY MORE SO !!</p> <p>what ever the 3 hours it took me to type this will just be ignored anyways - but you asked !!</p>

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EM41	08-Dec-10	<p>my husband is on high care d.l.a and was awarded this for life in 1993. his illness is incurable and he went through several specialist doctors to get his award. he has constant medical consultations and is in constant touch with doctors and undergoes constant monitoring of his condition with hospital specialist. he has also now got diabetes. two questions a/ why does he have to go all through this again he will be 63 in 2013. secondly how can a government renege on its awarding for life which i still have a copy of the award for incurable illnesses. a society is judged by how it treats' it sick and elderly and to do this with the intent of saving money is a disgrace. all of my children and some of my grandkids work and pay taxes and think this is an utter disgrace.</p>
EM42	08-Dec-10	<p>As an investigator into all benefit I hope that the reviews will be robust and at least 12 monthly. I and my colleagues often investigate people whose health has significantly improved and have continued to receive this benefit for many more years, even though they are leading a full and active life.</p> <p>Also we have found quite a number of people with mental health problems who actually live alone and are raising children on their own but receive full rate care component, how can this be right?.</p> <p>Then we have households where 2 adults receive full rate care and then get carer's allowance for looking after each other, I do not see how they can need full care themselves and yet be "fit" enough to look after another person. There should be a cross reference in the benefits system stopping this from happening.</p> <p>I am fully supportive of this reform and it has long been needed. I see a large number of people, who seem to deserve the benefit, but have it refused, and yet I then see others, who do not seem to qualify, and yet receive it. The Disability benefits needs to go to the right people.</p>
EM43	08-Dec-10	<p>I am a parent of a 33 year old disabled person diagnosed cerebral palsy from birth. He works 16 hours per week and does not have the sustainability to work longer hours, he claims working tax credit and has a "for life" entitlement to DLA which in total gives him a yearly income that is slightly less that someone in receipt of Band B (AO) civil servant salary.</p> <p>For him, his father and I to be subjected to interviews / assessments in order to prove his entitlement to benefit would be extremely heart wrenching. We live with his disabilities every day we do not need constant reminders that he has these disabilities, he gets on with his life and has become a very social, outgoing young man, whose independency is limited, due to his disabilities, but catered for by people around him. It has been a long hard slog to get where we are now and remains to be such as the future progresses. I totally disagree that everyone who is receiving DLA should be subject to constant reviews as to their entitlement to the new benefit. I think there are certain conditions that would warrant a "for life" award to benefit as the disability will never go away, they just make the most of what they can do and don't dwell on what they can't. I hope that the new benefit will not penalise people like my son who actually tries very hard to lead a "normal" life.</p> <p>If the aim of this reform is to cut costs can you explain how assessing everyone on an ongoing basis whose condition will not alter for the better is going to be cost effective?</p>
EM44	08-Dec-10	<p>I am writing as an individual who was a social worker for 36 years, most of them working in acute mental health in hospitals and the community. For many years the forms were geared to people with physical disabilities but in recent years have been more relevant to sufferers from mental health problems; it is important that this is considered when re-designing the forms. I found that GPs often had little knowledge of what was expected of them in completing the forms and this was one factor in the application being refused; some dialogue between the DWP and GPs would be helpful. It always seemed to me that the frequency with which the first application was refused only for that decision to be overturned when a written request for the decision to be reviewed was expensive of time and money.</p>

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		<p>I am concerned that people in care homes are seen as not needing the mobility component. Many people need help with transport costs to visit family and go on social outings and this is not met by use of public transport. Ability to go to restaurants, shopping malls or to family occasions are expensive for those who do not benefit from free bus travel and are essential to avoid institutionalisation and to ease the financial burden on less well off family and friends.</p> <p>My final concern at present is that disabled people, especially those with severe and enduring mental illness are not disadvantaged by the fluctuating nature of their illness or that the review of use of aids and adaptations or other supports is not used simply as a way to save public expenditure for people who are severely disadvantaged by their illness.</p>
EM45	08-Dec-10	<p>As a registered blind person I am very concerned and anxious about the reform. I am proud that I manage to work and worry that the new benefit will be means tested.</p> <p>The mobility aspect is a great help and enables me to use taxis to get around. The benefit does not cover all my costs but helps.</p> <p>I worry the new system will involve lots of form filling</p> <p>In assessing the new benefit and who is eligible there are very clear conditions which result in a sensory impairment.</p> <p>I have to say this is adding to my anxiety</p>
EM46	08-Dec-10	<p>I am interested in the reform, as I work in a DBC, and also know someone with mental health problems on DLA/IB. These two points are made from a personal point of view:-</p> <p>1. <u>DLA before 65/AA after 65:</u></p> <p>I would make the point that it is extremely unfair, and expensive to the state, to make the cut off for application for DLA to be 65, so that if you apply a day before your 65<sup>th</sup> birthday, and are awarded, you carry the DLA entitlement over into the years after 65. Yet someone can apply for help after their 65<sup>th</sup> birthday, with worse conditions, in greater need, and only be entitled to Attendance Allowance! This is just not right or fair.</p> <p>If people in general do not need the full DLA allowance after their 65<sup>th</sup> birthday, then it should be ended on that date. Otherwise allow the application for more help after 65.</p> <p>2. <u>Mental health/addiction and responsibility/waste of resources:</u></p> <p>The person I know, to whom my father has provided a great deal of support, and I have also helped out, has mental health problems. He gets a bit under £200 a week, and it is usually gone by Mon/Tues. At the moment, he regularly says he is robbed on the day he gets his money, as someone who is short of money has found out what he gets and when it goes in. He then has no money for electricity, food, tobacco and bills. Even when he was not getting robbed, he would spend it by Mon/Tues. At one point, he would regularly buy an expensive phone at the beginning of the week, later in the week have no money, and sell it to get some money. This often happened week after week. The one time he had any real stability was in a hostel, but government policy ("Care in the community") means they move them on even if they are unsuitable for this. He also knows his rights, and wants his own place – yet is unable to manage his money, keep card and money secure, and provide for himself with this money.</p> <p>I would make the point that the money he receives is getting near to what I get as take home pay. What he receives is also tax payers' money, and what happens to it is like a black hole. It would seem much more suitable for him, and more efficient use of resources, to put him in a hostel, with board and lodging deducted at source, <u>before</u> he has access to the rest of the money.</p>

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		<p>That is, if a person shows they are incapable of managing responsibly the tax payers' charity, then they will be offered a hostel place as the only alternative, with no access to the normal benefit until they show they are capable.</p> <p>This would only work if the person's needs are taken into account. The person I know had drug problems, and in some hostels this can be where drugs are rife, and unsavoury people grouped together make it impossible for vulnerable people to be safe.</p> <p>The hostels would have to be mainly supervised, some with a higher proportion of higher trained staff to be able to ensure vulnerable people are not at the mercy of drug pushers, loan sharks, bullying etc, and discipline would have to be enforced.</p>
EM47	08-Dec-10	<p>Thank you for providing the opportunity to respond to the DLA Reform paper.</p> <p>I have just a few comments/observations to make which I hope you will find useful:</p> <ol style="list-style-type: none"> <li>1. Having the right people and the right processes in place to deliver and manage the benefit is key - it is lack of process and management technique which has assisted the explosion of DLA awards in recent years and "woolly, vague" guidance has not helped.</li> <li>2. Management of these people and processes is a key element to getting the awards to the right people</li> <li>3. Management of the end to end process is critical at every stage - we need buy in to robust management controls and an understanding of the consequences of non-compliance (there is none of this currently)</li> <li>4. A robust review and assurance strategy should be in place to build confidence that learning has been embedded and that all appropriate management checks are taken at the appropriate points in the process. There is no excuse to ignore guidance and make a lifetime award because it is easier and quicker. Targets and culture and behaviours need to be addressed and should support the Government intent and the correct delivery of this benefit.</li> <li>5. Face to face interviews between claimants and disability experts/champions to determine whether or not a claimant meets the criteria is key to get the right award to the right person.</li> </ol> <p>I hope this is helpful. I really do feel it hinges on a change in culture, behaviour and operational management techniques to get it right. This will underpin the reforms you propose to make.</p>
EM48	08-Dec-10	<p>In Confidence and only to be read and distributed by and to who it is relevant.</p> <p>I am submitting this feedback as an existing recipient of DLA and a sufferer of a long term , progressive illness , Multiple Sclerosis.</p> <p>During a review like this , which I personally have no issue with , there is the inevitable raising of stress and pressure on those with illnesses that are clinically known to be affected by stress. Please could it be emphasised that those already suffering from recognised long term chronic and progressive illnesses, be managed with some empathy.</p> <p>Please bear in mind the opportunity cost. i.e the hidden alternative costs that arise should someone lose their award and then become injured or progressively worse trying to seek additional income. By this I mean exacerbation of illness leading to hospitalisation and acceleration of symptoms. The default cost is to the NHS and the consultants and nurses who then need</p>

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		<p>to treat these patients. There is little point in moving a cost from one budget to another and / or further burdening the NHS.</p> <p>It is vital when assessing patients with Neurological diseases that the assessor is familiar with that area.</p> <p>General practioners see their patient much more frequently than a consultant. I may see my GP about MS palliative treatment once a quarter, my Neurologist will review me bi-annually. GP's are better placed to see the whole picture and have upto date info, consultants maybe out of date or simply snowed under with case load. Once they have diagnosed their patient they generally don't see them unless it is very urgent.</p> <p>For reasons of transparency and democracy it is important to know how well any system is working and costing. The cost of assessing people with obvious medical issues should be balanced up. The number of appeals and successful appeals should be in the public domain if it isn't already.</p> <p>I am more than happy to assist in constructive dialogue with any DWP person that would wish for more feedback,</p>
EM49	08-Dec-10	<p>The very idea of the coalition even thinking of reviewing children and pensioneers on DLA fills me with revoultion. I'm sure children on DLA would rather be running around and enjoying themselves like the vast majority of children can. Senior citizens, most of whom had probably worked a subntancial number of years before requiring the benefit, due to illness or becoming disabled, should be allowed some respect and dignity to what years they have left. The government should get their prorities in order. They ring fence oversea aid to the tune I believe of 50 million to Vietnam and 150 million to India alone, why not ring fence this benefit for your own vunerable citizens? The government have put the changes for consultation, then why not put out for consultation what the population think of oversea aid. No chance, as they already know at least 80% of people are against it. If the coalition want to save money let them start with scrapping oversea aid, taxing the banks, and the likes of Sir Phillp Green who rob the country in millions of pounds a year. Remember charity begins at home.</p>
EM50	08-Dec-10	<p>2. In your documentation you state that you aim to focus not on what the individual can't do but on what they can do. Wlth all due respect, it is exactly because of the things that disabled people cannot or struggle with, that these benefits help to overcome. Life long conditions should not be constantly reassessed, things like paraplegia or quadraplegia are not going to get better and reassessment is simply a waste of taxpayer money, which is simply unacceptable. Common sense should prevail here.</p> <p>3. That depends entirely on the disability. A "catch all" question isn't suitable. However, let us use physical disability as a mean example. Extra travel costs (taxi hire), payment for care and help. Occasional loss of earnings of partner, parent or guardian. Cost of adaptations to the home, car, family homes to ensure access. By and large - the very things that this proposal seems to wish to remove money for. Petrol - many wheelchair users have no choice but to drive everywhere and therefore use more fuel than average. Unpaid leave for medical appointments, wheelchair consultancy, physio, GP appointments and annual checkups. Statutory sich pay - many disabled people are prone to various infections or other conditions and therefore have to take more sick days than average, which will often mean having to go onto statutory sick pay. Extensions and downstairs bathrooms / facilities, which at the moment the current Disabled Facilities Grant is supposed to cover - but for those who are working and earning between £15,000 - £30,000 per year is entirely unaffordable due to the contributions necessary, which alread means that many disabled people are living in poorly adapted properties.</p>



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		<p>8. In the case of wheelchairs, which is an example you have used in your document, will you be taking into account the lack of accessible public transport, the ability of the wheelchair user to wait for public transport outside in adverse weather conditions, the lack of accessible disabled parking bays and the cost of having someone escorting them for practical reasons like carrying shopping or help accessing a inaccessible building? In short the use of a wheelchair should not have a negative financial affect on a disabled person any more than a stair lift should have an affect on an elderly person. The very idea is ridiculous.</p> <p>4. The current three rate care system, two rate mobility system is in my opinion, not overly complicated. It is simply poorly explained to the public. I suspect that as a result of the compulsory reassessment you are going to see a dramatic upsurge in Judicial appeals and many people who are currently on middle rate are going to be unfairly financially disadvantaged as a two tier system is obviously less flexible than a three tier system.</p> <p>5. As I mentioned above, it seems obvious that reassessing people with life long conditions such as paraplegia or quadraplegia as these conditions are not likely to change, so people with these conditions should automatically receive these benefits. More flexible application and reassessment processes should be put into place for people with mental health problems. The application and appeals process is extremely stressful.</p> <p>22. I myself have Aspergers Syndrome and I currently do not claim benefits. The reasons for that are simple, under the current scheme I wouldn't be entitled to them. I know this because I am familiar with DLA law and my partner sits on the local judicial appeals panel. I am unable to drive and I am unable to use crowded public transport due to sensory issues. I mainly use taxi's and the good will of family and friends for transport and I also rely on the latter to help me with shopping. My condition causes severe depression, insomnia, sensory pain and almost constant anxiety as well as social interaction problems. Although I work - I work stereotypically from home as a website designer and earn very little. I survive on less than £200 per month earnings. By any definition, I am not a functional member of society. If by some miracle I did qualify for benefits under your new scheme I would face constant anxiety about whether your random independent specialist giving me my reassessment would cancel my benefits or not probably based on a twenty minute appointment and little to know understanding of my condition - A point that I believe the National Autistic society has already pointed out to you.</p>
EM51	08-Dec-10	<p>agree with the changes.</p> <p>A lot of people have learnt what to put into forms and what we call' play the system'.</p> <p>Most of the DLA is not spent on disability needs but on living standard, life style.</p> <p>We have a lot of people who have mobility cars but never transport the children. The children are transported by Educational taxi due to the SEN.</p> <p>We have families who have way over £2000 benefit a month, just claiming DLA for children, one parent and claiming also carers allowance.</p> <p>I am not a Tory voter, but these benefits have gone out of hands during the Labour government.</p>
EM52	08-Dec-10	<p>1. The problems that we face is disabled people that we have problems accessing public transport outside of London, we are treated as second-class citizens went trying to take part in activities this could be even sporting</p>

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		<p>activities, or gym-based activities which we are advised to as part of our own physiotherapy based programme of exercise to try and strengthen and give relief to existing painful conditions. Sometimes these therapies can be rather expensive and there are also other bureaucratic hoop is that we have to go through in order to satisfy certain criteria. Even though we may have notability car we do not always wish to drive into London as this is very tiring and the game is very expensive. Yet in a way we are considered to be the poor man/woman within society and we do not all have this disposable income that keeps being mentioned as on a constant basis. As a disabled person with a long-term condition who is in receipt of disability type benefits I don't think that the money we are given covers all of our activity-based costs yes I'm already on a personalised budget due to the nature of my disability. People who are on a higher rate of disability such as myself because I'm affected by my mobility should be entitled to other type benefits regardless of whether you have paid enough National Insurance contributions which are treated as a way of discriminating against disabled people. Access is a big issue and often the way that we are treated as disabled people.</p> <p>2. I think the current process doesn't need to be updated however upon reflection I do not agree with some of your proposals, such as using your own GP to give evidence about your condition and in my case I would have to use a consultant rather than my own GP as they tend not to believe what I have to say. The main issue I would say which could cause me a problem is speaking face-to-face with the professional, as I tend to be rather dyslexic and I find the whole process very tiring and stressful which is due to my condition.</p> <p>3. The extra costs that we face as disabled people are related to the issues of having to put fuel in two armoured mobility cars, which as you can imagine can be rather expensive if we have to visit places because we cannot access public transport. Someone like myself has to purchase different hand creams and antibacterial creams including loads of non-adhesive gauze, because my legs tend to split and believes rather heavily, also a constant supply of wet wipes and antibacterial wipes, specialists Prince which are not available on the NHS, or if they are usually worn out within six weeks to about three months, wheelchair access is including spare wheels tires or cautions. Food costs and associated other costs including heating and electricity costs. Additional costs including personal assistance to boost our additional income is we are given by social services with the purchasing or supplying of a personalised assistance to give additional assistance as and when required. Computer aided equipment to help in the writing of documents such as this.</p> <p>4. It may help having to rates for each particular component however this is dependent on what type of process you are going to put in place and how this would be applied to the disabled or individual that would be affected by the whole process, sometimes we need to know because when we are in purchasing a car for notability we have to use some of our care component or if not all to how the purchase would the advance payments.</p> <p>5. When considering this question I think this would depend upon the condition for example if the individual has a condition that is not going to get any better or any worse then they should be automatically entitled to the benefit and yes they should be based upon it the individual needs and requirements of the person, however it should not be used as a way of not giving them any entitlement to which they are entitled to under the disability discrimination act or the equality act 2010.</p> <p>6. Accessing the community, communication with people outside of your natural family which includes access to leisure Centre-based activities including gym, including a range of other activities which are essential to the person who needs independence or wants to be independent without having to rely on</p>

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		<p>others. People who have mobility problems who have to use the use of a wheelchair.</p> <p>7. What you have to remember in this point is that just because somebody is bad one day it doesn't necessarily mean they are good the next three days as it takes time to get over activities and extra stress which can be caused by the activity, which often leads to a spell of chronic fatigue, this means that somebody cannot take part in their usual activities or if they try and take part in the usual activities this can lead to further complications.</p> <p>8. They should take into consideration aids and equipment such as wheelchairs, powered chairs, motor ability car</p> <p>8.(b) Motor ability car, sticks, shower and eat including stalls grab handles toilet assistance specialist pillows, expensive wheelchairs.</p> <p>9. You could actually do this by having an easy to read version of the application form for people who have learning disabilities and are often not taken into account when trying to claim money. For people who do not fit in that category yes you can have an ordinary form but have a tick box process and an additional form at the back in which the individual can go into a bit more detail about their actual disability and how it affects them on a day-to-day basis.</p> <p>9.(b) You can make the information available in an easy to read format, speak in English and not government speak and make your booklet is easy to get hold of update your website all of the time and not just when you feel like it, have helpline number with helpline people know how to speak to the general public or disabled people, have trained people who are not patronising like most of your staff are.</p> <p>10. Often the best person to provide this type of information is the individual themselves as they know their condition usually better than the actual consultant or GP or as prereleases stated if you do not get on with your GP a physiotherapist or the consultant who you've originally sought the first place.</p> <p>11. The main issue could be that the healthcare professional might not believe a word of you that you're saying or a fatal condition does not exist when in actual fact you know that it does, so what we actually need is a non biased the healthcare professional who is not being paid to get people off the benefit rather than to help them, also somebody who understands what it is like to have a long-term condition where your outlook on life is not wonderful. Also not to judge an individual on the activities they do take part in as this is often seen as a way of saying I'm sorry you don't fit the criteria, when in actual fact this is what has been advised by your consultant physiotherapist.</p> <p>11.(b) This could also be seen as an invasion of privacy, such as religious preferences, diversity and equality issues.</p> <p>12. Personally I don't think there should be any review is carried out on individuals with long-term conditions, such as people with Hypermobility syndrome, or degenerating condition that such as the one I have just mentioned, this is because we had to go through enough stress and anxiety when dealing with individuals within the medical profession. This is because we have to fill in endless pieces of paper which had totally unnecessary and if we are to have reviewing process they should actually take place say every six to 12 years with a tick box process and additional help if required when trying to fill in the form.</p> <p>13. People do not keep the Department informed various reasons that could be down to trust and confidentiality, also that they find the whole process humiliating which is something you have to try and discourage and this can only be done by having trained and appropriate staff who are compassionate and have the skills of empathy which is severely missing within the</p>

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		<p>Department. Often people feel that if they report a change this would go against them and they will lose their benefit altogether, especially when they have a mobility car, often people also finds that if they report a change they had to go through endless forms a day and again and also have to get additional evidence from a medical professional which are not easily to get hold of.</p> <p>14. People need to know what the whole process is and what type of information you are looking for and how, they also need to know how long the process is likely to take.</p> <p>15. You need a section within the form that is not patronising and does not repeat itself as there is too much of that in the current system gain you need an easy to read version of people who have major difficulties filling in government forms.</p> <p>16. If we are fortunate to get awarded the higher rate mobility then that goes towards the purchasing of a vehicle or motor ability scooter and say we should need a specialist wheelchair we have to access this through access to work or go to a specialist charity, however this only helps when you fit the criteria and some wheelchairs is very expensive indeed and yes there should be a means where the individual can purchase the items they need to meet their needs on a day-to-day basis.</p> <p>17. Again you should make your documents child friendly and also if a child has a mobility problem do not have this ageist policy whereby if they are under the age of 16 they do not qualify for higher rate mobility and instead get higher rate care component and lower rate mobility as this is an ageist policy which has to go and you should be asking them things like on a scale of one to 10 how do you feel and get them to describe how they feel the pain or the problems are that they are having, use the advice of specialist organisations within the voluntary sector who know a little bit more about certain conditions than professionals or GPs as they deal with it all the time and also use the parents as their knowledge is second to that of the GPs as they had to deal with the pain and aggravation of dealing with a disabled child 24 hours a day 365 days of the year.</p> <p>18. If we are as individuals to be entitled to climb the benefits under this past sporting arrangement, then we should automatically be given them on the basis of the information that is within the new benefit application process. This could also be helpful when applying for personalised budgets through social care as I have always argued that the whole process is totally unfair and biased to other people who live on their own.</p> <p>19. This would have far reaching implications meaning that people would not be able to use appropriate levels of money or benefits to access the range of treatments and therapies and specialist items they would need for their own personal well-being in accordance with their own conditions.</p> <p>20. The simple answer to this is that you could remove the bureaucracy that is often poor in supply by bureaucrats/civil servants who have no idea what a disabled person actually goes through, you could also speed up the process of how you in form some on whether they have been successful or not instead of letting them hang around three months knowing what was happening all what was not happening.</p> <p>21. Your proposals could have a number of far reaching implications for all different equality groups within society and it is hard to look at that without looking at my own equality group who example I have a learning disability and a physical disability, but my learning disability has not been looked at were assessed properly. Another thing I would like you to consider even though you might not wish to consider is that while the individual is waiting for an outcome</p>

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		they could at least be given some money to tide them over based on the information that has been given.
EM53	08-Dec-10	<p>As a visiting officer for PDCS, I undertake many home visits to children in receipt of DLA for appointee action as they approach 16 years of age. The vast majority, in the region of 95%, are children diagnosed with "ADHD". During the visit, I make a point of asking the child questions to enable me to establish their care and mobility needs.</p> <p>The majority of these children attend mainstream school, travel there (either by public transport or on foot) without the need for assistance and enjoy a normal social life out of school.</p> <p>It is most apparent that there is no care, and certainly no mobility needs for these children yet most receive middle rate care and low rate mobility.</p> <p>Two examples :</p> <p>Lad in Lowestoft in receipt of middle rate care and low rate mobility left the house after my visit on his moped to spend the rest of the day and evening with his mates in Lowestoft town centre which, according to his mother, was a regular occurrence and</p> <p>Girl in Norwich in receipt of high rate care and high rate mobility uses her DLA to buy and keep horses!!</p> <p>It is quite obvious to me that the DLA is not being spent for care or mobility assistance and is being paid in it's millions to provide these children with extra pocket money for the purchase of the latest hi-tech gadgets, playstations, xboxes etc etc.</p> <p>In cases where facts as described above are reported, may I recommend that an immediate review takes place to determine whether such payments are appropriate.</p>
EM54	08-Dec-10	<p>I would like the specific needs of people on the autistic spectrum to be included within this review. I have long believed that DLA and Mobility Allowance receipt primarily concern those with physical disabilities, and these people form an important group. However, the effects of ASD can severely limit the affected individual, in terms of both their ability to function within " mainstream" life, and I also feel that mobility is a serious issue for many autistic people ( in that many may be able to walk, but often in the wrong direction, at fast pace and often, entirely out of control ). I also feel that in many of these cases, the intelligence of the autistic person is inconsequential, as autistic behaviours can severely affect a very intelligent person, and I would like the new system to acknowledge that fact, and understand that autism is, in itself, a very life limiting condition, regardless of the intellectual ability of any individual. Therefore, social functioning should be given more emphasis, and intelligence less.</p> <p>I would also like to see the amount of carers allowance increased, as the current amount of £53.90pw is insufficient, and in no way reflects their value to society in general, their families and their value to the state ( carers save the government £££'s ). Many have had to abandon careers and subjugate their own needs and wishes to perform a role that they would otherwise not have chosen. This subject needs review.</p>
EM55	08-Dec-10	<p>1. There have been many technological advances made for blind and partially sighted people and this is probably true for people with other disabilities. Unfortunately, equipment, training and support is extremely prohibitive due to cost and the fact that suppliers of these services and products are serving a niche market that inevitably incurs additional costs and a pricing mark up to cover research and development. It is clear that barriers will remain where disabled people do not have the means to pay for these products and services. However, if they are paid for out of personal savings or income, the person</p>

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		<p>has little or no dispensable income to be able to make full use of them.</p> <p>2. Only that the payment is direct to people's bank account as is the case currently.</p> <p>3. I have outlined briefly that the additional costs are incurred in equipment, training and services. For example, a Trekker Breeze is an excellent satellite navigation tool for a blind person to independently travel on foot or public transport, cost £550. Software to enable a blind person to use a mobile phone £150 and you are restricted to use on expensive mobiles. Training in any equipment purchased is extremely expensive at a minimum of £100 per day. Looking at TV in the home, Sky are selling a box that tells a blind person what channel they are watching, £70, and you still can't make use of the EPG or other facilities when you have paid that.</p> <p>4. I am comfortable with 2 rates for each component. However, I feel very strongly that the new benefit will be wholly unfair as DLA is if it does not use common sense for some disabilities and apply a consistent approach. I am totally blind and receive lower rate mobility and care. Other totally blind people receive the middle care component, an extra £150 per month. Furthermore, a large number of "blind" people and partially sighted people receive the middle rate care component. My wife is also totally blind and has been rejected twice for middle rate component. A totally blind person faces exactly the same issues as the next blind person. It is not an individual judgement between them unless there are other factors other than their blindness. The benefit should distinguish between totally blind persons, estimated at 4% of the registered blind population, and those with residual sight as the problems faced are different. However, it is wholly wrong that two totally blind people should be awarded differing levels of support based purely on their blindness as their disability. I feel that I have been discriminated against since tDLA was introduced and very much hoped that the new benefit would put this right once and for all. I'm extremely disappointed not to see this in the proposals.</p> <p>5. Yes, most definitely. As described above in question 4, total blindness, blindness with some useful residual sight and partial sight are conditions that are not individual. It should not be argued that blindness affects one person differently to another if they have the same level of blindness, only other factors should have an effect. I would implore you to put this right for the new benefit.</p> <p>6. Most essential support will include support in the home and support in undertaking the activities that non-disabled people would take for granted. The ability to travel independently without the stress and fear of getting lost, support to be able to shop and take up leisure activities and importantly, support to help people obtain and retain work.</p> <p>7. The onus should be placed for the beneficiary to inform you when circumstances change and a full review of the case should be undertaken.</p> <p>8. In the case of blind and partially sighted people it would be ridiculous to try and take into account what equipment they have or what is currently available because technology is still advancing at a rapid pace and so equipment requirements will change. Note some of the indicative costs above. Any blind person should have sufficient funds to buy new adaptive equipment that will allow them to lead independent lives.</p> <p>9. The form should have "killer" questions that mean a claimant doesn't have to complete further for certain conditions such as totally blind, profoundly deaf. I think this society is advanced enough now to know how these disabilities debilitate people so let's not make people fill in forms just to state the</p>

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		<p>bleeding obvious and make them feel the worse for it.</p> <p>10. There are existing documents taht record some disabilites such as the BD8 and the like. Use them instead of wasting public money spending time that is not cost effective and shold arrive at the same conclusion "the claimant is blind".</p> <p>11. I have no problems with a health official interview but it really shouldn't be necessary for the more definable claims such as those for totally blind people. However, if a face to face is necessary, health officials should be consistent nationally. A person that is totally blind in any part of the countrny should receive the same allowance as any totally blind person in any part of the country. Let's have fair calibration please.</p> <p>12. Review should be no more frequent than annually and in the case of a totally blind person, shouldn't be necessary.</p> <p>13. Provide an annual renewal where the claimant has to declare that nothing has changed from their initial application.</p> <p>16. The allowance should be significant to allow blind and disabled people to save for their adaptionns but in reasonable timescales rather than introducing the complexity of one-off payments.</p> <p>20. Any information already available such as BD8 registration, etc.</p>
EM56	08-Dec-10	<p>I have grave concerns in the following areas:</p> <p>1) To have an assessment by an independant healthcare professional or doctor as they will have no individual knowledge of that disabled person and are making an assessment based on: a snapshot in time of that disabled person.</p> <p>2) Some disabled people experience variable and fluctuating conditions that vary from day to day and from week to week and so can not be accurately assessed from objective criteria.</p> <p>3) The consultation seems to be a cost cutting exercise that will deter some people from applying due to some people will find the process too intrusive and humiliating.</p> <p>Look forward to a response</p>
EM57	08-Dec-10	<p>I am emailing in response to the DLA reform document as the parent of a 16 year old girl who is currently in receipt of DLA. As she is unable to respond personally due to lack of understanding and severe learning difficulties I am doing so myself. My daughter has been in receipt of DLA most of her life so I understand the implications of any changes made to a disability payment made to parents of children with disabilities.</p> <p>I am pleased to see that there is to be no change in the way that the new benefit will be paid to those with a terminal illness. My father applied for DLA when he was diagnosed with cancer and having the fast track system for this helped my parents enormously and they would not have been able to deal with the full forms needed to apply without this.</p> <p>The length of the current DLA forms are a nightmare, they break my heart every time my daughter's DLA is renewed, having to go over and over all the thing she isn't able to do that a child of her age can usually do independently. I am pleased that the forms will be simpler to fill in but I do hope that in the case of an application for a child that the parents do have the chance to explain fully the impact that their childs condition has at home. My daughter has far more</p>

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		<p>problems at home than the professionals see at appointments. Kids are often on their best behavior at appointments and anxieties and behavioral problems aren't often seen by someone who briefly meets a child in an artificial situation.</p> <p>I notice that the current way of stopping benefit when a child is in hospital for 84 days is to be continued and I am disappointed in this. We haven't had a year when my daughter went over this limit but came close to it a couple of times. I feel strongly that this is grossly unfair on a family at a time when costs are likely to rise greatly. I know a lot of families with disabled children and I would estimate that at least 85% of them stay with their child when they are in hospital, many continuing the day to day personal and medical care of their child simply because hospital wards don't have the staff to give children with disabilities the care they needs. Many of these children have 1 to 1 care 24 hours a day at home and at school, some even more than that. There is no way that hospital wards, even in specialist childrens hospitals have the staffing levels to deal with complex children. My daughter was in hospital for 10 weeks after she was born and needed round the clock medical care for nearly 3 years. In those 10 weeks I spent the first 4 weeks at her bedside and the following 6 weeks I spent just 2 nights at home with my husband and other daughter. I needed to stay to learn to care for her as well. I often had to wait to leave the ward to take meals because nursing staff were too busy to be able to watch my daughter. I know from recent experience things haven't changed. The cost of travel is only refunded to those on low income and hospital food costs a fortune, I would ask you to PLEASE reconsider removing the payment of the new benefit to children or to increase the time allowed before it's removed.</p> <p>We recognise that some aids and adaptations are provided by government while others might be paid for out of an individual's DLA itself. We are considering the best way to prioritise support in this situation. We also recognise the need to ensure that taking aids and adaptations into account does not discourage individuals from using them.</p> <p>I think this needs very careful thought as a lot of parents end up self funding equipment for their children due to long waits for equipment or unsuitable equipment provided. I know in some areas parents can wait for several months just for an appointment at a wheelchair clinic before a chair is even considered. Then another long wait for it to be ordered and then arrive. We had to hire a suction machine for my daughter from a charity as there was not one available at that time and we needed it before she could come home from hospital. Often there are such long waits for equipment of any kind so parents understandably buy them themselves rather than make their child wait for something that is going to improve their life.</p> <p>We are also considering how we could share information from other assessments which disabled children undergo, for example to determine special educational needs, and whether or not we should take into account a child's support needs if they are being met from public funds by another institution, such as a school.</p> <p>I am quite shocked at the second part of above statement. I can understand that if a child has special educational needs as assessed by the LEA then that assessment would be suitable to be used to determine an eligibility for the new benefit. However, if a child's needs are being met or not via school that makes absolutely NO difference to the home life of that child outside of school. If a child has a good care package in school that's great, but that care ends when a child is out of school the same as any school provision does for any other child. A child with a disability brings many extra costs to a family even if they don't need extra outside care or equipment. Children with autism and learning problems often need special diets and extra clothing just as a quick example.</p>



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		<p>Although my daughter will be over 18 by the time the new benefit is in place I feel that as the parent of a child with a disability can help with this consultation and pass on informed experience.</p> <p>I would like to end in saying that a reform of DLA is long overdue. Decisions are currently made by people who often seem to have little or no understanding of a lot of medical conditions and how they can impact on everyday life for someone with a disability. The forms rely on the person filling them out being clear and precise in their answers and basically saying the right thing. Decisions being made on the basis of an informed assessment using both professionals who know the person as well as other professionals should cut down on the number of people claiming to be more disabled than they are and using it to get out of working.</p>
EM58	09-Dec-10	<p>I am responding as an individual who is in receipt of the lowest level of the care component of disability living allowance and who is in full time employment. My disability is that I had my left arm amputated following cancer. I do not have any prosthesis due to the extent of the amputation.</p> <p>1. The main barriers that prevent disabled people participating in society and leading full and active lives are that society is not yet set up to accept disabled people living full and active lives. Disabled people should not have to rely on government benefits to help overcome the barriers in society but until society fully accepts disabled people then the extra money provided by the benefits is the only means that disabled people have to overcome the barriers that society places before disabled people.</p> <p>3. The main costs that I incur are the costs of: purchasing ready made food stuffs as I am unable to prepare meals from scratch. The cost of purchasing clothing and having this altered to fit. The cost of purchasing aids and adaptations that help me to overcome some of the difficulties encountered with only having one arm. I do not meet the local authority criteria for services and therefore unable to access aids and adaptations from them. I am forced to purchase these myself i.e. electric can opener, veg peeler, spork, one handed tray etc. I also have had to have my car adapted to be able to drive safely with only one arm. This costs over 2 thousand pounds every time I change my car. I have to pay for this myself as I do not receive mobility allowance.</p> <p>4. This will depend on the eligibility criteria for the new two rates for each component. For those like myself who currently only receive the lower rate of the care component will this mean we will no longer be eligible?</p> <p>5. All claims should be based upon the needs and circumstances of the individual applying. However there are some impairments like the loss of a limb that will never improve. Should people in this situation have to suffer the indignity of having to be reassessed on a regular basis or can the benefit be granted for life.</p> <p>6. Personal Care, food and drink, dressing, bathing, access to work.</p> <p>7. Individual's should be able to request a review of their circumstances.</p> <p>8. Aids and adaptations should only be taken into account if they are readily available and free of charge. Many disabled people use their DLA to purchase their own aids and adaptations.</p> <p>9. The criteria for entitlement to the benefit should not be based upon the amount of time that a person requires support. It should be based upon the severity of the impairment.</p> <p>10. The individual themselves are the best source for evidence of ability. In my case I have not seen my GP in over 14 years because I'm not ill. I simply have</p>

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		<p>a significant impairment due to the amputation of my left arm and shoulder.</p> <p>11. I would welcome this as my own impairment is visually very obvious.</p> <p>12. As mentioned above some impairments will never change. i.e. the loss of a limb. Why insist on reviewing these cases.</p> <p>13. Make it easier to contact the department, Telephone and email.</p> <p>14. Yes it would.</p> <p>Advice on other benefits access to aids and adaptations, home improvements etc.</p> <p>16. I have used my DLA payments to fund adaptations to my home and car due to my disability. I have had to save up for these over a number of months. It would be great to have the option to have the money in a lump sum to fund future adaptations.</p> <p>17. You should consider only the extra support that the child's impairment requires and not the support that all children require.</p> <p>18. I have only used my DLA to gain access to the warm front scheme to improve the energy efficiency of my home. This has been a great scheme. I would be willing to access other such schemes if they were available.</p> <p>19. In my instance it would mean I would not be able to afford the energy efficiencies done to my home. I would continue to live in a less than efficient home and would continue to pay more out on heating etc. This would keep me in a circle of poverty.</p> <p>21. Under DLA, some people received their awards for life as it was recognized that their impairments would not change. Are you now going to demand that those people reapply for this new award?</p> <p>22. Disability Living Allowance supported disabled people to live their lives as normally as possible. The new benefit is called Personal Independence Payment. Does this mean you will only receive this payment if you are dependent on someone else for your support?</p> <p>Many disabled people currently live very independent lives. If their benefits are cut this will result in a decrease in independence and could result in increased poverty.</p> <p>I am a fiercely independent disabled person. I use my DLA to fund the aids and adaptations that make living with one arm bearable. If I lose this benefit I will be forced to fund these aids and adaptations from my take home pay resulting in a significant loss of earnings. I will seriously have to consider if it is worth going to work in the first place. I may be better off not working and claiming more state benefits.</p>
EM59	09-Dec-10	<p>I have read with interest your consultation paper. As a recipient of DLA I rely heavily on the mobility aspect and also have some need of the care aspect.</p> <p>Having had a serious back injury some 30 years ago I now find that I need the financial support that DLA provides, despite having continuing to attempt to forge a career.</p> <p>I have fought hard to achieve my present employment position and without the DLA components I would not have been confident enough to continue to try to keep working.</p> <p>I am pleased to see that you do not intend to make this means tested as I probably would not qualify as I earn just short of £40k in my present role. However I have had to reduce my hours as my health deteriorates and have other health issues that are slowly reducing my ability to earn.</p> <p>Therefore DLA is a financial assistance that I feel is important to me and other disabled people. It allows us the freedom to continue to work - I have never found receipt of DLA to be a barrier to work - and to maintain my mobility. I use the Motability scheme and would struggle to continue to be mobile without it as the funds I don't have to use from my income I use to assist in providing aids to</p>

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		<p>allow me to try to have a 'normal' life.</p> <p>I agree we have a claim culture in this country and we need to overhaul the system but please do not penalise those of us who genuinely need the help at the expense of those who may just be claiming everything they can and do not contribute to society.</p> <p>Without the components I would have to consider whether I could continue being employed, paying tax and NI, as without these components I would have to radically rethink my life.</p> <p>My life is tiring and stressful already - please do not move in haste and penalise those of us who are genuine claimants.</p> <p>I fully support all the government aims to reduce the burden on the tax payer as there are areas that really do need overhaul - I hope that the legal aid and other benefits that are handed out will also be subject to scrutiny as it really does annoy me that I continue to try to work with a disability and yet I see people regularly being 'given' benefits without putting any effort in.</p>
EM60	09-Dec-10	<p>The Federation of Private Residents' Associations (FPRA) is a not-for-profit advice, support and lobbying organisation for private residential leaseholders, tenants' and residents' associations and residential management companies, including those companies where the leaseholders together own the freehold of their own residential block. Our comments therefore are from the perspective of private residential leaseholders and the residents' associations and management companies that they have formed to run their residential blocks. We were a participant in the Review Group on Common Parts, and consulted by the Office for Disability Issues concerning the proposals to legislate for disability-related improvements to common parts of let residential premises contained within the proposals for the Single Equality Act.</p> <p>The majority of residents' associations and management companies are run by volunteers from the body of tenants or leaseholders who give of their time freely and it is this type of organisation on whom duties under The Equality Act 2010 falls in their role as "landlord and manager". It is therefore essential in our view to minimise the burdens and complexities of the Disability Living Allowance and provide clear and unambiguous advice to supplement any changes.</p> <p>Code of Practice</p> <p>In terms of the proposals in respect of common parts, we consider that providing a statutory Code of Practice will be very important. The requirement on landlords to act reasonably in deciding whether or not to meet a request for a disability-related alteration will be very relevant to our members.</p> <p>Potential Difficulties</p> <p>Whilst we welcome the extension of the rights of disabled people, we have identified a number of potential difficulties associated with introducing the Equality Act in respect of common parts. These include conflicting demands from various disabled residents with different disability needs (for example visibility-related alterations may not be compatible with mobility-related alterations), the need to comply with fire safety and other regulations which apply to common parts and control matters such as emergency exit routes (Regulatory Reform (Fire Safety) Order 2005) and the actual practicalities of installing and maintaining the disability-related alteration.</p> <p>An audit of all other legislation affecting common parts and its relationship with the proposed changes should be carried out to identify and address potential conflicts and difficulties.</p>

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		<p>We consider that with each of these potential difficulties there are also potential liability issues for landlords/managers and this needs to be recognised as do the consequent financial impacts. For example, the introduction of apparatus on to stairways may impact on insurance costs for landlords both in terms of occupier's liability and fire safety risk.</p> <p><b>Costs to the Disabled Person</b> It follows from the above, that the disabled person requesting the alteration must be required to meet all reasonable additional costs to which the landlord/manager will be subjected as a result of the alteration. The removal of the alteration and/or any making good to the common parts needs to be explicitly included in the proposal as being potentially required by the landlord/manager. At present only reasonable maintenance costs are mentioned in addition to the actual cost of the alteration itself. There are potentially additional insurance costs, consequential additional health and safety costs, cleaning costs, energy costs and so on. These additional and consequential costs must all be able to be recovered from the tenant requesting the alteration so that they do not fall on the other leaseholders to be recovered from the general service charge account.</p> <p><b>Ownership of the Alteration</b> The landlord/manager retains ownership of the common parts and grants rights to the tenants to use those areas in common with others. Office for Disability Issues' stated that the landlord and tenant should be able to negotiate whether or not an alteration should be treated as a tenant's fixture. We are very concerned about this and hope that it does not form part of the final legislation in respect of common parts. The landlord/manager needs total control over all the common parts because of all of the obligations and liabilities that exist in respect of those areas imposed either through legislation or under the lease. Of course, there would be nothing to stop a landlord/manager offering back the alteration (e.g. a stair lift) to a tenant who is leaving the property where appropriate or practically possible.</p>
EM61	09-Dec-10	<p>I am in receipt of the higher mobility element of DLA following a failed knee operation two years ago; I have been receiving the higher rate care component for my mental health for the last ten years for eight of which I was in full or part-time work.</p> <p>I agree with you that DLA needs reform and share your assumption that genuinely disabled people are just as concerned as the government as to how the present system is implemented and also how it is perceived in society. In particular, the fact that the benefits system is a fragile house of cards needs to be addressed. Amongst other things, claimants will endeavour to stay on the highest rates of DLA because without it, other benefits and entitlements would collapse around their heads (#).</p> <p>However, some of your proposals are predicated on false assumptions, for example that disabled people have fewer barriers to entering the workplace when this is simply not true as I know from my own experience over the last decade. DLA is perceived as an out of work benefit because people who are disabled cannot find or stay in work, so on that particular point the consultation has turned reality on its head and this appears to show a lack of understanding.</p> <p>I do not have a political agenda, in so far as I am neither an active member of any political party nor any other campaigning group, and I would like to volunteer my services as an active "consultee" on these reforms. I am able to travel to London (outside of rush-hours) to attend meetings if required and can give the DWP as much of my time as it needs.</p> <p>These reforms will not work unless the DWP lets genuinely disabled people shape the outcome.</p>

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		<p># In my case I do not need a "top of the range" 5 door hatchback from Motability paid for by my higher rate mobility component but I do need some financial help with transport and I definetly need a Blue Badge; as the latter depends on reciept of the former my consultant and I have to ensure that I receive the higher rate. Also, if I were to notify the DWP of a slight reduction in my mobility needs they would automatically re-assess my mental health and, as actually happened to me earlier this year, I would risk going from the higher rate of care to nothing overnight. Based on this experience, you will not be surprised to hear that I am unlikely to contact the DWP again until the current entitlement expires even if my mobility needs were to lessen during this period.</p> <p>Consultants and GPs know that their patients may need some help and they also know that unless they state the patients case very strongly the patient will not get any help. This is why the DWP feel that they cannot trust patients' own doctors. Doctors are not in cahoots with their patients it is just that they, as highly intelligent people, understand the arbitrary nature of the present decision making process and therefore know that unless they state the case strongly their patients will suffer financial hardship.</p>
EM62	09-Dec-10	<p>If and when it affects children, how many of these so called 'medical assessors' will know what autism and other such conditions look like in children, how variable they can be, and how to assess them, since diagnosis is so hard to get? How will you make this applicable to adults to begin with? again, autism is very difficult to diagnose in adults and yet can wreak havoc.</p> <p>We are very, very skeptical of your medical assessors and assessments' ability to judge these conditions correctly. it stinks of taking invaluable support away from people with disabilities - which is a poor way to cut the budget.</p> <p>Why not stop the claimants with 5-10 children and no jobs from claiming all that insome support and child benefit, instead?</p> <p>I am American, my two autistic children are dual citizens, and the reason we choose to raise our children in the UK versus the USA is because of how the UK looks after its disabled, by providing free-to-the-end-user healthcare which is not dependent upon how much money you can produce up front, and the benefits and services available, which again are not means tested or dependent on up front cash.</p> <p>The UK is in danger of losing its compassion, its superiority over America, and risking becoming just like the so-called Land of the Free, where no one can afford to be healthy.</p> <p>Don't do it. Dont take our benefits away. the amount we parents save the government by caring for and raising our disabled children is a staggering amount of money - why take away our paltry sums given as compensation for the disabilities?</p> <p>Seems that's the one thing Labour did get right...</p>
EM63	09-Dec-10	<p>1. Many things such as wheelchair access, sensitivity to loud noises, inability to read social cues making them vulnerable, naivety, not being aware of potential dangers or threats in the outside world as they often retreat inside their own worlds. Communication difficulties, being able to express themselves adequately if they are upset or in pain.</p> <p>2. Looking at mobility issues and medical/social/dependency issues separately.</p>

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		<p>3. Learning skills the able-bodied take for granted, for example learning to drive (if appropriate), skills to gain independence, they may be unable to maintain their own property and need to pay for DIY and decorators, need for special equipment eg. negotiating stairs and baths. Special adaptations to be able to prepare their own meals safely.</p> <p>4. Shouldn't think it will make that much difference.</p> <p>4.(b) Yes, I am concerned that in this cost-cutting climate those claimants on the medium rate will be lowered and those on the lower rate of benefits may lose them altogether.</p> <p>5. Yes, life-long incurable conditions such as cystic fibrosis, chronic degenerative disorders.</p> <p>5.(b) No.</p> <p>6. There needs to be more communication between the various professionals concerned. eg. a Doctor diagnosing a condition should be able to access information regarding flagging a person as needing help, communications between medics, occupational therapists and those involved in processing benefits need to be much better.</p> <p>6.(b) Better communication regarding which services are available, good transport and mentoring, 'buddy-ing', retaining houses set up for disabled young people to learn independence in a safe environment. Placement of safe houses near bus pick-up and drop-off points, with a phone number that can be called in the event of a disabled person being stranded.</p> <p>7. Again closer links with the medical profession, a computer link where information from the medic can be uploaded in the event of significant deterioration/improvement.</p> <p>8. Yes if these incur extra cost, maybe a grant could be made available.</p> <p>8.(b) Wheel chairs, artificial limbs, guide dogs, anything that is necessary as a direct result of the disability.</p> <p>8.(c) Both. Also if there are aids or adaptations that would make a big difference to a disabled persons quality of life that are not easily available then every effort should be made to make them more available.</p> <p>9. The claim form needs to be very detailed, but it could be made easier if communications between the medical profession and other involved professionals was better. The medical part of the questionnaire should be verified by the diagnostician and physical needs be verified by for example a occupational therapist.</p> <p>9.(b) TV ads, leaflets sent in the mail, perhaps the medic making the diagnosis could have some leaflets to hand-out.</p> <p>10. The information needs to come from the person, the person's carer(s) who know the day-to-day difficulties.</p> <p>10.(b) The information needs to be verified by independent means, eg. medics, occupational therapists, physiotherapists, other professional care workers.</p> <p>11. There are many forms of disability the independent person needs to understand that particular disability. Some disabilities are straightforward eg.</p>

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		<p>blindness but some have complex implications such as autism.</p> <p>11.(b) No, provided that the disabled person was able to have a carer with them who was also able to contribute. Conditions where communication disorders are part of the problem would require this.</p> <p>12. Again if there was a system by which significant deterioration or improvement could be flagged by the medical profession.</p> <p>12.(b) Yes, some conditions may improve with time, whereas chronic degenerative conditions will deteriorate with time.</p> <p>13. Send out questionnaires periodically?</p> <p>14. Advice about accomodation and it's maintenance, transport and access, social groups, support groups (being able to meet others in a similar situaion).</p> <p>14.(b) Yes.</p> <p>15. Some grants are available, but there should be greater clarity regarding entitlements.</p> <p>15.(b) Yes, if this would enable them to be independent.</p> <p>16. The impact of the child's disability on the family as a whole. For example many parents are single parents and have more than one disabled child and are unable to work because of this. Other parents can't work as many hours as they need to because of inadequate after-school care (particularly for 11-pluses). Parents have also been denied promotion through not being able to take on more hours or not being able to move to another area because the facilities weren't available. If the parents don't choose the school the LEA thinks they should (because they feel it's not in the child's interests) they get no help with transport. Therefore the cost of transport falls entirely to them.</p> <p>17. These other services and benefits need to have a much higher visability.</p> <p>17.(b) Make these services more visable, better communication, leaflets, TV ads.</p> <p>17.(c) This would have a devastating effect as (for the reasons outlined in the answer to question 16) many of the families are low income and really need these services.</p> <p>18. In general terms the extent to which their disability impacts on leading a 'normal' independent life. Their needs, equipment and/or adaptaions reuired to achieve greater independence.</p> <p>20. You need to be very careful not to withdraw benefits from the most vulnerable and in need. A 'one size fits all' view of disability is not going to work. The spectrum of disabilities being looked at is huge and peoples needs wide-ranging and complex.</p>
EM64	09-Dec-10	<p>I am writing in response to the consultation on the reform of DLA. As a carer for someone with a mental illness, I was particularly concerned about the proposals.</p> <p>I am concerned about the assessment time for the receipt of the new Personal Independence Allowance - potentially disabled individuals could be waiting for up to a year before a payment is made. This is a long time to manage without support, and if someone is genuinely disabled they will be incurring these costs during this time, with no additional means to pay for them.</p>

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		<p>One of my main concerns is that the vital role of carers, many of whom are unpaid, is ignored in the proposals. In my own circumstance, DLA has allowed me to stay in work, as it has allowed me to support my wife without physically being there every day. Consequently, the cost to the public has been significantly lower - if I was not in work, I would be in receipt of housing benefit, out of work benefits and a much higher level of child tax credit for my children. This also links to the potential new delay until the start of receipt of payments - in my own case this could have led me to having to stop work for that period - which potentially could have resulted in me finding it more difficult to get back into work once DLA was being received.</p> <p>In addition, it has already been well established that the help provided by carers significantly reduces the impact on the public purse - help that would otherwise have to be paid for. I think the reform of DLA is another opportunity to re-assess this vital role of carers, since, as my own case proves, supporting carers adequately can help reduce the benefits bill.</p> <p>Q10 &amp; 11 &amp; 12 - I am concerned about the requirement to have a face to face assessment. For many mental disabilities, people often end up leading chaotic lives, and may be suspicious of being 'assessed' or simply find it difficult to communicate with a stranger. I have trouble getting my wife to a GP, let alone someone she hasn't met before in an 'assessment' situation. As a result the face-to-face part, people may be put off applying, or give up on an application just because they find it difficult to face that situation. Its not that I disagree with the need for a proper assessment, just that this needs to be proportionate and sufficiently flexible in the method of assessment to cater for the wide variety of personal circumstances.</p> <p>One alternative might be to learn from the Common Assessment Framework (CAF) that is being rolled out in children's services. This allows any qualified individual (GP, doctor, social worker) to follow a standard assessment that all professionals will recognise. This would lead to a greater reliability in the completion of forms, since professional integrity of the person assessing would avoid fraud. A two part form - one by the individual, one by a key professional along these lines might be more productive, and avoid the need to to-and-fro between benefits assessors and professionals.</p> <p>Question 5 &amp; 6 &amp; 8 - I am concerned that the focus on the impact that a disability has on a persons life may put those with a carer at a disadvantage. Carers can significantly reduce the impact that a disability has on a persons life, and at no cost to the tax payer. However, it would be unfair to put disabled people with carers at a disadvantage because of this. In my own example, the round-the-clock care is provided by myself and my wife's family, with no cost to the taxpayer, and as a result, impact is minimised. Under the new proposals, because the family has minimised the impact, my wife would be worse off. As a result, you could simply encourage the 'better off on benefits' syndrome, where people can be better off on benefits, because the perceived impact is better - if my wife's condition had resulted in us both being unable to work, the impact would be assessed as greater.</p>
EM65	09-Dec-10	18 & 19. Applicants would need to forward their form to a medical professional to complete a section who would then forward to ourselves for assessment. A number of authorities also carry out assessments by OT's rather than involve other professionals. Therefore the process would be a slower one for these applicants.
EM66	09-Dec-10	<p>I would like to make some comments on your proposals to change DLA to a new benefit.</p> <p>I don't understand why you should want to make such changes as from the kind of questions I have read they seem pretty much the same as the DLA questions as they stand.</p>



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		<p>From my own experience I have had many traumatic events. I became ill in 1997 and started claiming Incapacity Benefit; my first claim for DLA was in 1999 which I was successful. The following year I re-applied for my Incapacity Benefit.</p> <p>I then was retested for DLA and incapacity benefit every 3 years up until this year when my DLA was awarded for life. That was 4 applications for DLA in all. During the whole time I saw three DWP doctors and attended two Tribunals. The longest application took 18 months due to clerical errors. The Tribunal panel showed a complete lack of knowledge in pain and my conditions, the DWP doctor even suggested I take all my medication in one go as I am prone to forgetfulness, I felt very alarmed and wondered if I was in fair knowledgeable hands.</p> <p>After my experiences I was so relieved that the final award had been made as the stresses experienced throughout these years have only made my condition worse. Getting expert help is not as easy as people think. My recovery time from these 4 applications left me quite ill indeed. I would like to add that in-between the DLA and IB applications I also had to deal with spot checks from Housing Officials, Social Security Officials, plus all the added appointments with OTs, physios etc in efforts to keep good health.</p> <p>My health is not improving, by my stress and anxiety were slightly improving, but the very thought of having to go through yet more applications fills me with dread, stress and now more anxiety.</p>
EM67	09-Dec-10	<p>I am writing to urge you, as Minister for Disabled People, to recall the Public Consultation on Disability Living Allowance (DLA) reform, and to cease work on reform of this benefit, due to serious flaws in the consultation paper. As such, the consultation questions are deeply skewed and any answers will be likely to support wholesale reform. This is both unfair and unwise, and will cause hardship for many disabled people. 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 "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 <u>no evidence</u> 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,</p>

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		<p>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.</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>

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		<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 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 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.</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 rebranding 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</p>

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		<p>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 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</p>

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		<p>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-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 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, and to the DLA Reform Team in your department. I am also forwarding this letter to Hywel Williams 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</p>

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		<p>compilation of the DLA reform consultation paper. I await your reply.</p>
EM68	09-Dec-10	<p>5. people with a progressive condition such as motor neurone disease, or secondary progressive, or primary progressive, multiple sclerosis.</p> <p>18. DLA as a passport to other benefits is extremely useful, and should be kept, to cut down the immense stress and difficulty in doing things, for severely disabled people, especially for those with a progressive condition, which will never improve.</p> <p>19. The implications for it not being a passport to other services and benefits, is the extreme stress, caused unnecessarily by the points i made in Q 18 and it being too difficult for them to apply from scratch, or reapply and be left without critical help or the services they depend on..</p> <p>I am completely opposed to any data sharing, as so many mistakes about me have been made, doing this, in the past.</p> <p>I am also opposed to private companies doing any assessments, as there is a complete conflict of interests, when they are judged and paid for getting people back into employment. For some of us, including myself now, that is impossible unfortunately.</p>
EM69	09-Dec-10	<p>I am writing to pass on my comments on the proposed changes to DLA, as it is becomes Personal Independence Payment. As a disabled person, who is in receipt of the full amount of both the mobility and care components of DLA I feel I am in position to comment the proposals.</p> <p>While I fully understand that there are concerns about the cost and complexity of the current system, I am not sure that the direction proposed is the right one. To infer that equality legislation will make it easier, and cheaper, for a disabled person to live is incorrect. Both as the law as it stands has no real teeth and is not effecting a change at the same rate as the schedule for these proposed changes, and because even when they do finally allow disabled people to be able to interact in society in the same way as able bodied people, this will have almost no effect on the extra costs incurred by disabled people. In fact being able to enjoy the same access to the world will probably involve more costs.</p> <p>The proposed new assessments of all claimants will put a huge strain on many disabled people, who already feel under attack by this governments witch hunt towards people who are claiming benefits due to disabilities. My DLA award is a benefit that was passed after vigorous assessment, by medical experts as I understand they all are. It is a benefit that is almost impossible to gain through fraud. I am confused as to why those people who have already been through the vigorous assessment process in the past will have to be re-assessed, especially as this extra cost could be used towards maintaining the benefit itself, or al least the proposed replacement. It just seems a huge cost to appear to being doing something to the public, around an issue they do not really understand. In my case, I cannot walk and use a wheelchair full time so obviously am entitled to the mobility component. The care component was awarded as I have periods of server pain, and during these need full time care. These are totally unpredictable and have no time scale. But these are episodes. So during the periods of less pain, I need less care. The reason why I awarded the full care component is the doctor who assessed me felt it was fairer to consider my care at it's highest level.</p> <p>It appears that in your new assessment guidelines this would not be the case. I know that there are many disabled people like myself, who conditions are not a constant. It is hugely unfair to even consider penalizing us to save money. Especially as the cost of providing full time professional care as required would</p>

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		<p>be much higher to the social services and the state. The mobility component is used by a huge number of disabled people and their families to allow them access to a Motability vehicle. I myself have one. IN fact Motability is one of the biggest purchasers of fleet vehicles in the UK, and is essential not only to the users of their service but to the UK car industry as a whole. To even threat to make a change to how this benefit functions will not only effect those of us who are in receipt of it, but will send chock waves through our ailing car industry. Let's not forget that however much the government would like to think the Equality Act is leveling the playing field, our public transport system is still very inaccessible. Many disabled people have to have a car just to be able to get around. Many of those cars need considerable adaptations, like my own car.</p> <p>To claim, as it does in the proposal document, the DLA needs reforming as the public does not understand it makes no sense. It seems to freely admit that this change is purely for a mixture of public perception and financial saving. I am pleased to see it will remain as a universal benefit, will not be means tested and will continue to a means of allowing support for disabled people. However to claim that improved aids and adaptations can in anyway make life cheaper and easier for disabled people is disingenuous. These aids are highly expensive, and can be out the reach of the very people who these changes may effect. As for the claims that disabled people have the same choices and opportunities as able bodied people, I feel we are a very long way from achieving that. The Equalities Act has only been in force a short while, as any discrimination is still only an act against the person and not the state, so there has been very little change in the day to day experiences of most disabled people. Definitely not enough of a change to mean we do not still incur extra costs to live. To use the need to simplify the system as a tool to cut the of people entitled is a shameful act. We live in aging society and this will obviously lead to an increase of the number of people claiming such a benefit. Also medical advancements mean that many people who would have died, either when they became disabled or ill or shortly afterwards, now can live until old age. I myself was beloved to only have short while to live when I was 15, yet I am now 45. To cut benefits because people are living longer is as equally shameful.</p> <p>When I was awarded both parts of my DLA it was still Attendance and Mobility allowance, and you were awarded them for a set period. I was awarded for life, as my condition was going to be stable. Yes I have outlived my diagnosis, but my condition is the same. However to claim that people get awards that do not reflect the prognosis of their condition is untrue. The assessment I went through was very vigorous, and this is the story I have heard from everyone I have met who has tried to claim DLA. In fact it is considered a very difficult benefit to gain. It is much more likely that there are more people out there who are entitled, and the amount DLA currently costs the treasury is less than it really should be.</p> <p>The desire to move away from automatic entitlement for certain conditions is a mistake. Many of these conditions make life very difficult already and having to go through a claim and assessment process will add to that difficulty. Not what this kind of benefit should do. Stopping the Mobility component if a recipient goes into hospital will cause serious problems for those people using Motability, will only lead to more fraud as these people will have to lie about hospital stays to prevent them from loosing their vehicle, which they may have used to drive to the very hospital they are staying in. If you have a car through a disabled child or family member it will mean that if they go into hospital the family may loose the car they need to use to make hospital visits.</p> <p>The claim to want to stay true to the social model of disability and then to plan to make these changes show a total lack of understanding of the social model. These types of pressures are exactly that barriers to inclusion that the social model explains as what disables some people. DLA was designed to be an</p>

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		<p>attempt to level the playing field, and any replacement should continue to do this. The new rolling assessment process may have the desired effect to save some money but will also be a new barrier to inclusion. The stress alone of having to attend continuous assessments will add a new disabling element to the lives of disabled people. The idea that the ability to plan a journey or communicate will effect the level of award is terrifying to someone like me. As you can tell, I have no problems with my mental abilities, yet due to physical limitations have been awarded the high rate care component. To imagine that my ability to talk and think will act against any benefit is shocking, and I can see no reason why this should be so. These new areas of assessment seem to mean that only people with server learning disabilities may be entitled to full PIP payments, and this is just blatant discrimination. While I do not wish to be negative towards those people with learning disabilities, and they should definitely be awarded any DLA/PIP payments, surely to be able to fully comprehend how you disability impacts your life should not be a barrier to gaining benefits designed to try to ease that impact. To say that this idea around the assessment needs to be halted is an understatement. I am also unsure of what the legal situation would be around such a move. It does seem to say if you can understand you disability you can't get help.</p> <p>To even consider that by using a wheelchair to get around somehow makes us as mobile as people who can walk is so stupid I am stunned that it is even mentioned. Wheelchair does not mean we can get around easily. Apart from the huge cost, normally of around £1500-£4000 per chair, the world we live in is so far from being fully accessible that this change is wrong, stupid and offensive. More than that, people who use wheelchairs do so due to conditions that have more impact than not walking. Spinal injury leads to chronic pain, incontinence, spasms, and loss of sensation that can cause pressure sores. It was a pressure sore that caused the death of Christopher Reeve, so I think it is clear how serious that can be. Oh and of course, if I don't use my chair I can't get out of bed, and so will need full specialist care 24/7, and that will incur a huge cost to the treasury.</p> <p>The plan to use an OT to assess entitlement is equally ludicrous. In my case, to fully understand how my disability impacts my life, you would need to be a fully qualified Neurosurgeon, and would also need input from a pain specialist, a Orthopedic Surgeon, and a incontinence nurse. To expect an OT to grasp the full impact of a disability I expect will only lead to more fraud, not less. OT's are trained to provide aids and adaptations and to find ways of over coming some of the bigger physical limitations, but have no real knowledge of the intricacies of illnesses and disabilities. The best way forward would be gain information from the medical team dealing with each claimant, and not have one person just run a series of set questions. This is the only way it can be assured to get the benefit to those who really need it. The rolling assessment that is proposed must be of a long enough period as not to put extra pressure on claimants, should still allow for very long periods between these assessments if those who carry them out feel it is required.</p> <p>The carer's allowance, which my wife currently claims, is so woefully low that is an insult. She had give up a £500 per week job to become my £50 per week carer when we married. I feel that there should be a greater payment to anyone who is a carer who is caring for some one who is in receipt of the care component of DLA or PIP. That way there is not the huge change in circumstance that we had to endure. Getting DLA has not lead to us gaining all of the benefits we are entitled to, but this is not a reason to consider such a dramatic change in the system. Instead it should mean that more should be done to ensure entitlement is understood. The idea on sharing information with other government departments might seem a good one, but what are the safety of information considerations and there must be questions of confidentiality. Some of this information will be medical and so must be kept secret.</p>



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		<p>On the issue of social care, DLA allows people like myself and my wife to be able to stay out of the care system. We prefer to build care systems using family and friends as we feel this is better for us. It also saves the country considerable sums in personal care, and allows me the dignity I desire. I hope that people who make this choice do not end up being penalized as we are not tied up in the local authorities processes. I feel it would be an act of discrimination to force me to have use state provided care to qualify for PIP, and would definitely impact on my life in a negative way.</p> <p>So after my long comment on the proposals, which I apologize for but feel it is necessary as it is of such vital importance, I will answer the questions posed in part five of the document.</p> <ol style="list-style-type: none"> <li>1. The barriers that exist in society are many. The biggest is environmental accessibility. Where I live many buildings are totally inaccessible, as is the transport system. The social attitude towards disabled people has worsened in the past few years and we are now seen as as scroungers. In someway this has been facilitated by documents like this. Of course environmental access means that there are barriers to work, as we cannot get jobs of we cannot get into the building. Then of course there are work practices. Who would employ someone who may need time off when their disability requires it? Especially at a time of rising unemployment. Before we can change the benefit system so dramatically these barriers have to be confronted.</li> <li>2. DLA does not cover the extra costs that disabled people face, but goes towards them. I feel that any replacement should also do this. DLA is not really open to fraud as claimed, and any replacement should try to understand this.</li> <li>3. The extra costs can be anything. Having to drive leads to the need to have a vehicle, and pay for fuel. There may be costs around personal care, and hygiene. Special equipment and the need to always be accompanied should also be considered.</li> <li>4. The idea of only having two rates will lead to many people loosing out. Any disabled people may not be entitled to the high rate but still need a considerable amount of assistance, yet two rates will not cover this.</li> <li>5. I feel that automatic entitlement takes the strain off people already dealing with serious conditions and so should stay.</li> <li>6. To ask what activities are important to living an everyday life, shows how little disability and the social model is really being considered in this proposal. Is it my chronic pain, my inability to walk or my incontinence that effects my everyday life more? At different times that have a greater or lesser effect, yet they obviously all have an effect. Isn't it best to have an assessment that states if your disability includes a problem then you instantly are entitled? That way it makes the assessment process easier and less intrusive, allowing the applicant more dignity.</li> <li>7. Fluctuating conditions are already taken into consideration and any awards are made by with the help of medical experts who explain how a disability may proceed. So surely the best way forward is to continue to use this system?</li> <li>8. Aids and adaptations are not part of a disability. My wheelchair does not mean I am equal in ability to someone who can walk, and so should not be considered. To want to do so goes against the social model.</li> <li>9. I do believe that improvements to claim forms are essential as are improvements in information. More details of entitlement should be available and systems should be created to ensure that all people are in receipt of all benefits they are entitled to. That way the desire to ensure people declare</li> </ol>

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		<p>changes is equal to the desire to ensure full receipt of benefits.</p> <p>10. The evidence should come from any medical professionals that are involved in the claimants care, and this information should be given the most consideration. Then there should be input from social services and other health care experts, but the actual impact of disability and illness is best understood by those trained to do so. Trained doctors and surgeons should have the final say in how a disability can impact a persons' life, and their opinion should be used to make the final decision.</p> <p>11. I am amazed if DLA is awarded without a face to face meeting, as I know I had one. However it must be with someone with the highest level of medical knowledge and not someone like an OT.</p> <p>12. I feel that if the assessment is made by a medical practitioner, with input from the medical teams working with each applicant then the period of reassessment will be set fairly. However as I was awarded my benefits for life, just being reassessed undermines this. It is essential that there is the ability to make awards for long periods as well a shorter ones, for those people who have little chance of their conditions changing.</p> <p>13. To promote the reporting of change, I feel that there should be facilities to add medical information around the change to avoid benefits being stopped quickly. I also feel that if someone finds their conditions lessens then drop in benefit should happen slowly, This would take the shock of a drop in income less and make it less frightening to report changes. I also feel that there must be mechanisms to move quickly if a conditions changes for the worse, which never seems to be mentioned.</p> <p>14. I feel that before anyone can undertake a reassessment, there should be a series of documents that need to be filled out. If they are not the claimant will be notified and the assessment moved until all the relevant information has been received. Then way people will not find themselves unprepared and will not loose out due to misunderstanding.</p> <p>15. I do not believe that are a high number of people who do not seek to find advice and support. People like myself who have found a way of running their life without the input of a series of government bodies tend to do so by choice, and should not be forced to do so. They should be advised of what they can claim and what help is available but not penalized for a life choice.</p> <p>16. I do feel that adding an ability for PIP to help with one off payments would be a benefit to anyone claiming the new benefit and this is great step forward.</p> <p>17. As a child I was refused mobility allowance, only to awarded it years later with a back payment. I have always felt that supporting parent of disabled children will lead to those children being able to enter into society easier and will end up with disabled people finding it much easier to play a beneficial role on the future.</p> <p>18. I have always felt that more should be done to ensure all entitlements are known by those how might be able to claim. Of course more should be done, and any moves to improve knowledge of entitlements that would allow disabled people to have more independence should be applauded.</p> <p>19. PIP must be a passport benefit, as DLA is now. This MUST not change.</p> <p>20. The awarding of the Blue Badge could be combined with mobility assessments. This would lessen the beaurocracy and stop the growing BB fraud. I do feel that information of a medical nature must be kept secret but what entitlements are awarded could be shared.</p>

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		<p>21. Disabled people are from all other equality groups and so any changes will impact them equally.</p> <p>22. I would like to add that I feel it is shame that the government feels it can target the disabled when it is cutting benefits. Yes there is fraud but this is an illegal act already and should be addressed. But to change so many benefits that are essential to real disabled people in the name of cutting fraud and expenditure shows a lack of understanding of how disabled people live in the UK today. While the new equality laws will eventually lead to more inclusion the have a long way to go, and until they have an effect disabled people are at a considerable disadvantage. More should be done by government to create an equal society for disabled people before trying to cut their benefits so radically.</p>
EM70	09-Dec-10	<p>Reading the consultation document there are a lot of references to the DWP 'Decision Makers' and their role in re-assessing disabled people presently in receipt of DLA.</p> <p>Given the contents of the recently published WCA Independent Review by Professor Harrington, together with evidence exposed in my own research report: Atos Healthcare or Disability Denial Factories, now attached, can you please be definite as to the type of Decision Makers you are proposing to use for the reforms of DLA?</p> <p>In other words, do you intend to proceed with the present totally unacceptable system of using basic grade administrators who, by their own admission, are totally unqualified to assess medical reports? Incidentally, they breach the £100 million per annum DWP contract with Atos Healthcare by failing to access all other detailed medical evidence, so they simply "rubber stamp" any opinion offered by an Atos Healthcare staff member, ( as confirmed by myself and Professor Harrington) or do you intend to appoint fully qualified Medical Administrators, as future Decision Makers, to conduct responsible evaluations of all the medical evidence presented by the disabled claimant?</p> <p>Those of us who intend to respond to the call for evidence need to know the answer to this question before presenting our detailed evidence.</p>
EM71	09-Dec-10	<p>My husband is 64. He has been claiming Disability Living Allowance since he took medical retirement in 2000. He has secondary progressive multiple sclerosis.</p> <p>When he retired he was semi mobile but was partially dependent on a wheelchair because he had difficulty walking. Now he is totally dependent on a wheelchair as he has no mobility below the waist. He is able to stand but is unable to move his legs.</p> <p>For the last three years he has had a Motability Wheelchair Accessible vehicle that is paid for with the mobility element of the DLA.</p> <p>For the last 9 years he has also paid for regular physiotherapy sessions to help slow down the deterioration of his condition. Once we got the Motability WAV and the DLA income was reduced, the payments for these therapies had to be funded from our Savings. He currently pays about £110 a week these.</p> <p>Some equipment is supplied by Social care services and wheelchair services, but a few items we've had to supply ourselves. We travel around the UK staying in hotels to visit family and friends and need portable equipment to take with us to assist with transfer to and from wheelchairs. This has had to be self funded. We have also supplied equipment for the home that could not be supplied by social care.</p> <p>We also occasionally need to pay to have some help from a Home care agency, to help with his personal care. I have medical problems of my own and occasionally need help.</p>

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		<p>I also claim the Carer's Allowance, which is dependent on my husband receiving the DLA.</p> <p>Can you please advise what provision will be made for people like my husband in 2013/14 when he will be 67/68. Will he continue to get the DLA and will I still continue to get the CA. Both provide a vital income for us to provide for his care.</p> <p>We can ill afford to lose either</p>
EM72	10-Dec-10	<p>I am responding as a blind individual. I use the word blind to describe myself as I have no light perception. I am one of a very small number of people in this position.</p> <p>I am very concerned about the proposals that have been put forward. 75 percent of working age blind people are not in paid employment. In my case, my DLA is used to help me fund a number of things that make me more independent, which I do not think the new system will cover.</p> <p>1. If I can choose where I live carefully, I can access public transport. It is not possible to access public transport in many areas as many roads are simply impossible to cross when you can't see. This means that one of the key ways of making me more independent is actually to subsidise my rent. I therefore urge you to look at accommodation for disabled people in more depth. While I may not need wider doors for my house, there is no way for me to get an accessible heating control. They are getting harder to use, and many landlords insist on cookers with complex controls that are much harder to use than old ones.</p> <p>2. DLA has subsidised all my computer needs. If I hadn't bought a new MacBook recently, your online PDF would have been virtually unreadable. People do not understand how difficult it is to get basic information when you are blind, and computers are not subsidised. You must allow people to buy a computer that meets their needs through DLA or an equivalent system every three years.</p> <p>3. I cannot walk at all outdoors without my long cane. While my legs work, without the cane, I have no idea of any changes in surface etc. This is where recognising the fact that all blind people will need canes, mobility training etc is vital, and why I believe lack of vision should be a passporting issue. I do not believe that all registered blind people need the same help I do, but all totally blind people do.</p> <p>There are a number of key opportunities that are being missed here, and I give examples below.</p> <p>1. There is no mention of exercise or physical fitness in your consultation. Disabled people need the ability to get and stay fit, for all the same reasons that others do. Whereas we can get personal assistants or gym memberships in some parts of the country, I find I am unable to commit to a regular schedule as I have the sleep pattern problems suffered by so many blind people, and also balance issues which mean I need to exercise when I can and for how long I can. Therefore, again, it would be more helpful to allow people through one system or another to get extra housing help so we can live in an area where we can extensively walk safely, or have space for some exercise equipment. This would actually be cheaper. For instance, to use my local gym, I would need to pay a gym membership, pay for somebody to come round with me as the leisure centre doesn't have enough staff to help, despite legislation,</p>

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		<p>pay to be driven or taken there and back in a taxi as using public transport is not feasible. This could easily cost £30 per session, so for a good level of fitness, up to £480 per month, or an extra £50-100 per month for an extra room in a rented property. Surely it is more important to keep people fit in a way that meets their needs than to insist on doing it the mainstream way in cases where that way doesn't meet the need!</p> <p>2. Often we could get around if the local environment were made more accessible. Could there be a way of incentivising councils to ensure all roads can be crossed by people who are blind, deaf, or in wheelchairs? So many do not have controlled crossings and are so busy that you cannot hear any gaps in the traffic. Zebra crossings where cars must stop are the very minimum useful to us.</p> <p>3. Enforcing the equalities act could be very expensive for many blind people. Bus companies are among the worst for compliance. They often won't tell us when we reach the stop we want. Some won't even stop their bus to tell us what number it is to let us board, and we can never prove anything as we just didn't even see it go past!</p> <p>4. I believe that disabled people could come together and live in communities where we can provide most of the employment. We can do training, differently disabled people can help each other with different tasks, and we can live in accessible housing. Yes, this is expensive to set up, but would reduce PIP needs radically, along with disability unemployment.</p>
EM73	10-Dec-10	<p>I am deeply concerned that many people will see this as a means to cut even more from a disabled person's budget. I use my DLA mobility payment to purchase my wheelchairs, and maintain them, and to purchase other accessories as they become available, to enhance my quality of life. I include the use of taxi fares into this as our local bus services leave a lot to be desired, and, I believe, discriminate against those of us with disabilities. The 'care' component is used for many other things like extra cost of heating, my cervical collars as well as a whole host of smaller things to make me more comfortable.</p> <p>I can only see these 'cuts' as a way of reducing funding and moving people onto the much lower ESA etc. I am all for people who are able to work, however this is the wrong time to carry out this agenda as so many people are out of work and disabled people will not be able to compete in the jobs market. Furthermore, I believe, P.I.P's will cost a lot of money to bring in, and I expect the number of appeals to ATOS decision to grow significantly, costing the government a lot of extra money, and heaping lots of distress onto many people with disabilities. It is hard enough to get DLA in the first place, please do not distress people further.</p>
EM74	10-Dec-10	<p>I am a physically disabled person who is the father of a SLD young adult.</p> <p>I would ask, how can a severely learning disabled person with ASD and complex communication and social interaction difficulties be expected to attend a consultation with a health professional without being subjected to significant stress? Attending a consultation would result in stress caused by a change in routine and could lead to violent outbursts, possible harm to the assessor and the individual being assessed.</p> <p>I would argue that individuals with complex and severe learning difficulties are highlighted during the application process and reports from professionals (social workers, educators, doctors etc) dealing with the individual would mean that the learning disabled person does not have to go through the trauma of an assessment. Your new criteria need to be flexible enough to identify the severely learning disabled especially those with ASD and to allow for careers and professionals to contribute to assessment on behalf of the disabled individual.</p>

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		<p>For my own part I am person who has been awarded DLA indefinitely and is disabled by a combination of rheumatoid polyarthritis, spondylitis, asthma and a history of depression and stress related mental illness. I am only able to get about at all because of a combination of pain killing medication and cytotoxic drugs I would argue that the stress of medical assessment and the possibility of losing benefit is unjust and potentially the cause of both further physical and mental ill health. Under current rules I believe that anyone with active and progressive arthritis is exempt from further medical examination/assessment. I would hope that this continues to be the case.</p>
EM75	10-Dec-10	<p>Q11.and q 12</p> <p>I think consideration must be given to special training for the people carrying out the face to face interviews and the reviews when the claimant has mental Health problems.</p> <p>Difficulty in engaging is often a problem for these claimants, as is a denial by some that they even have a Mental Health problem.</p> <p>It would be quite easy for such claimants to talk themselves out of a benefit to which they are entitled. (some might not even claim at all for the same reasons)</p> <p>I feel therefore that a special category of interviewers should be specially trained to deal with claims from those with mental health problems.</p>
EM76	10-Dec-10	<p>Further to your consultation process....</p> <p>Recently I have taken over the management of the Blue Badge scheme for Lancashire County Council.</p> <p>Last year we renewed 18,000 badges, issued a further 9,000 new badges and as a result we now have nearly 73,000 badges in circulation in Lancashire (28,000 of which are directly as a result of a DLA assessment).</p> <p>As with all BB services we get regular complaints from the public about what they see as misuse of this service by those who they deem, or in many cases know (neighbours, friends and neighbours etc), to be more than capable of getting around without a blue badge and, unfortunately, in the vast majority of these cases we find we are unable to take any action at all as the Blue Badge holder is in receipt of higher level DLA and is therefore considered automatically eligible for a badge, as per the DfT Blue Badge guidance.</p> <p>Regarding the questions below we would welcome any measures that you could introduce that would help us to ensure blue badges go to those who need them most – those that the DfT describes as having 'permanent, substantial disabilities (either in walking or in BOTH upper limbs) and who are unable to use public transport'.</p> <p>We see the DLA as an excellent passport to the BB service and certainly want that link to continue but would really welcome any tightening up of the scheme that limits this much needed service to those who really need it by ensuring the criteria for assessing the DLA is more closely to the criteria for granting other services i.e. BB's.</p>
EM77	10-Dec-10	<p>How real disabled people be discriminates against like this I have MS which is gettin worse day by day and all this stress is goin to add to this, i think for these Medicals you need people with experience of these conditions which they clearly don't</p>
EM78	10-Dec-10	<p>I am writing on behalf of Hft – a charity which supports Adults with Learning Disabilities.</p> <p>Within Hft are a number of “Speak Out” groups (“Speak Out” groups are for people supported by Hft to talk about issues that are important to them). A few weeks ago we asked the groups for their thoughts on the plans to cut the mobility component of the Disability Living Allowance. Hft thought that you might be interested to hear some of the comments:</p>

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		<p>“Speak Out” North Oxford</p> <p>We all discussed the proposed benefit cuts especially the cuts in mobility for those living in registered homes and how this would affect us if the cuts happened for people living in supported living. Below are some of the comments:</p> <p>██████ – “that would be bad, people wouldn’t get out, people would be angry and frustrated”</p> <p>██████ – “My granny needs more care, these cuts will affect her. If my benefit was cut I would not be able to visit my family in Coventry or friends in Leeds”</p> <p>██████ – “I would be cross and upset, if I walked in the rain I would get wet, I wouldn’t be able to visit my Mum or go anywhere special”</p> <p>██████ – “I wouldn’t be able to go out”</p> <p>██████ – “I cannot walk far I would not be able to do my shopping or go to college or any activities”</p> <p>██████ – “I wouldn’t be able to get to work, I would have to quit my job”</p> <p>██████ – “I would be angry and upset, I wouldn’t be able to see ██████ in Stratford, I wouldn’t be able to see ██████. I would get soaking wet in my chair in the rain”</p> <p>██████ – “I will complain, it is wrong especially for people who cannot walk”</p> <p>All think that the planned cuts would be bad.</p> <p>“Speak Out” Leeds</p> <p>The group thought this was not fair at all on people who live in residential care as this will restrict what they can do and to get out and about. They also raised concerns that is this going to effect people who live in supported living in the future or if not now. They were very worried about this and what effect it would have on their lives, they would very restricted in getting out and about and getting involved in the community.</p> <p>They also felt that something has to be done with the local MP to fight the corner for people with learning disabilities they were happy to go to the local mp and to join mencaps campaigns. They feel annoyed about this cut back and feel that it will stop them doing things they like to do as they wont have any money to do anything in the community . Also they feel that it will be like turning the clock back to how it used to be people with learning disability will be out of the way as they have no money to get out and about and this will effect their lives very much.</p> <p>They do feel very strong about this and they are worried that it will be people living in supported living next and would like to assist to inform the MP who wants to introduce the cut backs of the consequences of her action if she continues with this cut back. They want to write a letter to their local MP to take to parliament to inform her of what she is doing and how bad it will affect people lives.</p> <p>“Speak Out” Kent</p> <p>We discussed the proposed government changes to DLA in the Speak Out Kent meeting on Saturday. There was a mix of people from both supported living, and Residential services. All thought the changes were unfair, and decided that instead of writing as a big group, they would rather send one letter from each house. The 2 houses in Kent that are residential Services are possibly going to send one letter from each person, and also sign the online petition. People are still deciding if they will invite the local MP to come and talk to them about this matter.</p>
EM79	10-Dec-10	<p>With reference to the consultation document issued recently, please note that I am responding as an individual. My responses to the various questions listed in Section 5 follow below.</p> <p>1. Progressive legislation means that the barriers are less than they used to be. However, they still exist, in part because of lack of consideration of the</p>

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		<p>needs of disabled people: there is a tick box mentality as opposed to a proper thought process. As an example, my (disabled) wife and I had to check out of a four star hotel where we had booked a holiday because the access arrangements for disabled people were laughably inadequate. An extract from our letter to the head office of the hotel company follows below.</p> <p>"Near to the time of our treatments (2 pm) we planned to go to the Spa. We asked at reception how to get there – bearing in mind that I am disabled and have poor mobility – and was told that there either some steps or a path along the front of the hotel winding down to the Spa. As I cannot walk far, I decided that I would slowly attempt the steps. Fortunately it was not raining as there were 30 steps and no hand rail (as shown in pictures 1-4). Eventually we got to the back of the Spa to encounter a locked door with a number pad: something we had not been told about. A window was slightly open near to the door, so I shouted to someone inside to let us in. We were totally ignored until someone came down the steps carrying towels. This person let us in.</p> <p>"At this point I was extremely upset due to the pain and discomfort I was in from having to get down the steps. I was also extremely angry that I was not informed that the hotel and Spa is not accessible for disabled people. I asked to speak to the manager and was told that he was not in but that the Deputy Manager would be in at 6 pm. I insisted that someone in management come down to talk to us. Meanwhile my husband asked the young woman in the Spa how disabled people are expected to get into the Spa. She said that there was a back way and took him to see where it was and how the path came down from the hotel (pictures x-x).</p> <p>Eventually a young lady did come down from the hotel to talk with us, saying that she did understand our plight – to which I said she had no idea what it was like and requested that the Deputy Manager come and see us as soon as he arrived that evening.</p> <p>When Mr [ ] came to see us, he tried to empathise. We said how disappointed we were that we had not been told how inaccessible the Spa was to disabled people and that if we had known, we would not have booked five nights there. We asked Mr [ ] to show me the disabled route out from the hotel to the Spa in my wheelchair. He did take on this challenge with difficulty.</p> <p>The problems that the hotel and Spa have are as follows:</p> <ol style="list-style-type: none"> <li>1. There is no signage for disabled people to know how to enter the hotel.</li> <li>2. The disabled route into the hotel is not adequate (as seen in picture x), and is obstructed by traffic cones, bags of concrete, rubbish and a fire escape.</li> <li>3. There is no indication within the hotel of how disabled people are to find the the route out (i.e. both to the spa and to the outside): in practice, one has to go out via a door marked as an alarmed fire exit and pass through parts of the hotel normally only accessed by the staff.</li> <li>4. When out of the hotel and embarking the path route to the Spa (and thank goodness it was not raining), one first has to go down a fairly steep slope to the main path (picture x). This path is wheel chair friendly, albeit lengthy. The next hurdle is a right turn onto a gravel path – with a steep drop (see pictures xx). Then in the middle of the long gravel section is a bench parked in the middle of the path: just as well I had someone pushing me who was able to move it.</li> <li>5. Towards the end of the path, nearer to the Spa the gravel changes to become larger pebbles. It was at this point that Mr [ ] could not push me any further. I therefore did not get to the Spa via the disabled route.</li> </ol> <p>This is totally unacceptable and extremely tokenistic towards people with mobility problems."</p>



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		<p>In addition, certain fixtures in the hotel room (towel rail switch; radiator thermostat; window handle) were so positioned as to be difficult for an able-bodied person to use, let alone one with disabilities. I have not quoted the name of the hotel since they have undertaken to remedy the situation. However, the fact that these problems occurred at all (and, I repeat, in a four star hotel) speaks volumes.</p> <p>3. This depends to an enormous extent on the nature of the disability and the amount of support which family members are prepared to give. For example, someone who is deaf might not incur any extra costs at all since the NHS provides hearing aids and batteries free of charge. At the other end of the scale, a blind, mentally incapacitated paraplegic will need round the clock care and a multiplicity of special facilities.</p> <p>4. Any reduction in the number of different rates will make the benefit easier to understand and administer. Whether or not it will provide appropriate levels of support depends upon where the line is drawn. In all such situations, there will be hard cases which fall just on one side or other of the dividing line and it needs to be appreciated by all involved that the payment of benefit on a set scale implies a measure of rough justice.</p> <p>5. All claims should be based on individual needs and circumstances. In particular, the mere fact of a terminal illness having been diagnosed - whilst tragic for the sufferer and their loved ones - does not necessarily imply any extra costs. My second wife died from cancer, having received a terminal diagnosis some five weeks before death: we claimed the DLA because we were entitled to it, but I cannot honestly say that we incurred any extra costs at all. If anything, our costs were less during the period leading up to her death (the DLA helped with the funeral costs but that is hardly its purpose).</p> <p>8. Yes, all aids and adaptations should be taken into account, whether already obtained or easily available, but only to the extent that these have or will be provided free of charge to the disabled person. That is, if a charity provides a disabled person with an electric wheelchair, this should be taken into account, but not if the disabled person pays for it themselves. One does not want to have a situation where self-help carries with it a financial disincentive.</p> <p>9. The form needs to be a lot shorter with more use made of flow charts and tick box answers. Consideration should be given to making the process electronic (for example, the disabled person provides information which an interviewer immediately inputs into an electronic claim form).</p> <p>10. The key evidence will surely be that from the medical practitioner most familiar with the claimant. I am unconvinced that the evidence of social workers will be particularly helpful: this is after all an allowance for disabled people (i.e. those suffering from a medical condition).</p> <p>11. An interviewer trained to ask the right questions to be able to determine eligibility would be a significant advance, though it must be recognised that there are people who find any sort of interaction with officialdom fraught with difficulty. I think that all would accept that it would be pointless to interview those who lack the mental capacity to respond meaningfully.</p> <p>12. I suggest that a review should be carried out after 12 months and then every three years. It is essential that this review does not merely duplicate the original claim process (i.e. the applicant should not be required to fill in an original claim form again - as happens at present - but the review should focus on what has changed).</p> <p>13. I think it unrealistic to expect people to report changes in</p>

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		<p>circumstances. The very nature of some disabling conditions means that there will be periods of remission interspersed with ones of greater severity and it is pointless (and costly in administrative terms) to expect each such change to be reported.</p> <p>16. Disabled people currently fund aids and adaptations out of their own resources, family funds and donations from charities as well as official sources. There should indeed be a facility to use PIP to meet a one-off cost.</p> <p>17. The fact that children grow and that equipment that was entirely suitable when purchased can rapidly become obsolete is an obvious one to take into account.</p> <p>18. I confirm the usefulness of DLA in granting access to other services and it is essential that this continues.</p> <p>19. If passporting was not available, both disabled people and the bodies that administer other services would be faced with additional inconvenience and cost.</p> <p>22. Beyond doubt, the process needs to be less bureaucratic. At present, it is a paper-based nightmare.</p>
EM80	10-Dec-10	<p>I would like to register my views on the proposed reforms of DLA to PIP.</p> <p>I am totally against any changes to DLA as i feel you are intending to replace this benefit hard won benefit with a lesser one, and force disabled people to go through yet more hoops when they will be unable to.</p> <p>People on Indefinite decisions should be honoured as you are not given this decision lightly. You must be a genuinely disabled person with genuine support needs.</p> <p>The person i care for uses his DLA for the purpose it is intended for namely care and mobility, without it he would not survive.</p> <p>I believe the government and the DWP want to save more money by making the most vulnerable people suffer, and if you take away a person's security you are harming them in a most destructive way.</p> <p>At present if a person's circumstances change and they find they can work, then the onus is on them to inform the benefits agency, i believe that the vast majority are on DLA because it would be impossible for them to work again, and they should be left alone free from harrassment and given the support they require both financially and care wise, this is a sign of a civilised society, not one that picks on the most vulnerable, because they can.</p>
EM81	11-Dec-10	<p>I am in receipt of Disability Living Allowance. I am male, 62, single, live in a rented flat, and move around by wheelchair. The specialist said There is no treatment There is no cure It will get worse It isn't fatal</p> <p>I was granted early retirement, and slowly was approached to serve on various Monday to Friday 9 to 5 committees, including Health. I serve unpaid and voluntarily on all these, including the St. [REDACTED] Disability Network, and the Social Inclusion (Mental Health) Network. I step up to the St. [REDACTED] Council organised Physical and Sensory Disabilities Partnership Board and further up to the LSP sub group on Healthier Communities.</p> <p>However, this is my personal response to the survey.</p>

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		<p>1. It's tough out there. Access to trains is antiquated compared to Europe and the USA (we use very very steep ramps to push us onto trains, many buses do not have working manual ramps, kerb edges from pavement down to the road more of than not have a lip that prevents a wheelchair rolling smoothly from pavement to road and across to pavement, the timings for pedestrian lights give one very little time to cross the road, and many buildings/shops do not have easy access for wheelchairs nor suitable disabled toilets, and disabled toilets are rare and not well signposted easily.  You go out if you like a challenge.  The world is still 9 to 5 and if you have carers or meals on wheels, you have much less free time.  We have many accessories to help us around the house, but we have to leave them behind when we leave the house.  Signage is usually too small for the visually impaired and relies on wordage rather than clear signs to help the visually impaired, those with learning difficulties, and tourists.</p> <p>3. I am referring to going out. In my case, taxis rather than wheeling around for public transport. There are free disability bus services but they are very limiting. Many venues charge full price for a ticket for you and for your carer so because I have free/cheap travel, I have to attempt alone.</p> <p>4. Some days are better than others, and I should not be penalised for not being 100%. Having two rates per component is not a problem. It is drawing the eligibility line between the two, when there are so many differences between disabilities, abilities, and the handicaps/challenges we face.</p> <p>5. All FIRST claims should be based on the needs and circumstances of the individual applying, and should be supported by a GP or Specialists report. Automatic entitlement should remain if the medical opinion is that the condition is effectively permanent, bearing in mind the claimant has a responsibility to notify and changes.</p> <p>6. It is so difficult to define "full and active" because we are all so different, and our environments and access to culture/sports are so different. Some people are happy to sit in front of a computer, playing games or building websites or researching. Others need more sociable lives, even if just sitting in a shopping mall and watching the rest of the world go by.  The GP is probably best at assessing their patient.  The ability to stay warm, to eat and drink and visit the toilet, to wash and to go to bed and get up from bed, and to switch our TVs and radios and music centres on and off are probably the most essential daily tasks.</p> <p>7. I am a wheelchair user. I am lucky because the rented flat where I live has doors and space wide enough for me to move around, and because the housing association built two permanent ramps to enable me to leave the flat. Three of the four blocks are inaccessible to me. I just feel that taking aids and adaptations into account is discouraging. My wheelchair will last a heck of a lot longer if I minimise going out. Aids and adaptations have to be encouraged.</p> <p>8. Normally NO. One needs to consult with a variety of medical opinion, carer's organisations, etc.  It is a personal freedom that we can choose to use or ignore aids and adaptations. Some days we struggle more with them or have a day without them. Who is to define "easy to obtain"?</p> <p>9. There are a mixture of experienced people out there, working for the Council, a carers or volunteers group, CVS, and the GPs. If they can understand the claim form, and can be involved in completing it, it will be more reliable. Their</p>

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		<p>understanding to be clear about what it is for and who is likely to qualify will also improve its reliability.</p> <p>One has to accept some cases are much more complex than others, so there should be plenty of space for the third party assessors to explain as best they can.</p> <p>10. The opinions of the medical and council services etc providing assistance or doing the initial assessment. Ability to do what? Leave your formal response</p> <p>11. It depends on the "healthcare professional" 's experience. I am a member of our Social Inclusion (Mental Health) Network and appreciate the different needs of physical and mental handicaps. I would assume that a candidate has already met with some healthcare professionals, so it should not be necessary to involve someone who has never met the applicant. If there are extenuating circumstances in which it may be inappropriate to require a face-to-face meeting with a healthcare professional, then surely an expert medical narrative as to why should suffice. Leave your formal response</p> <p>12. GP choice/advice</p> <p>13. IF the healthcare professional reports a permanent or terminal condition, that is one category. If not, then a confirmation of no change from a GP or service providers such as Meals on Wheels should suffice. A GP should be aware if his patient goes into hospital for an extended stay.</p> <p>14. They need to talk with a professional familiar with them and their circumstances, not a telephone helpline or civil servant, .</p> <p>15. Any potential claimant should be known to a healthcare professional. Someone with mental health problems may need more help than others. But submitting a claim should not be mandatory.</p> <p>16. In theory I should get a wheelchair voucher. I first asked for one two years ago and still none has arrived. I have bought them out of my own income. The Council assessed me when I was first referred to them and they fitted suitable accessories such as grab rails for no charge. The Council currently provide my Carers and Meals on Wheels and send me a four-weekly bill.</p> <p>17. My taxi drivers occasionally mention the runs they make taking children to special schools, some being out of the Borough. This kind of expenditure must be continued to be fully subsidised. Leave your formal response</p> <p>18. My DLA entitlement statement from the DWP has been acceptable to get me a free MerseyTravel travel pass, my Adult Disability Rail pass and my carer's cinema pass. These clearly encourage me to travel about, which has helped me develop a sense of independence and a confidence in the relative reliability. Airports and rail are generally very good. Taxi drivers are usually quite helpful. Some surly Bus drivers and out-of service equipment on buses that carry an "easy access" and a disabled sticker are a problem. This is dictated by the frequency and thus the time you have to wait for the next bus. Organisations in my home town like Shopmobility and DASH (Disability Advice St. Helens) should be listened to. They have many years front line experience.</p> <p>19. A document setting out the entitlement to the PIP should be simple and a photocopy/electronic copy should be acceptable. Sharing the DWP data with</p>

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		<p>appropriate partners should be simple in theory, but the greater priority of sharing info about children at risk shows how flawed this approach can be.</p> <p>20. A GP usually refers a potential or existing patient to a specialist. That specialist can easily be traced and confirmed with a Google search. All the different assessments can be reduced to two, the opinion of the GP/Local Authority Assessor as to what is needed and the opinion of the Specialist.</p> <p>22. Yes. You sent me a letter about the Winter Payment and also one about the Christmas bonus. You did not send me one about this "public consultation". Everyone who may be affected should have the right to respons, even if the vast majority do not take up the offer.</p>
EM82	11-Dec-10	<p>I have read the DLA reform consultation document, and wish to add my comments.</p> <p>The process for claiming boarder payments is not very Lean, (I work for DWP and am familiar with Lean).</p> <p>For example although many benefits can be claimed online, DLA boarder payments cannot.</p> <p>When my autistic son stays overnight at home (he is in a residential setting), I complete the relevant form, which is then posted to Warbreck House. Once approved, £13.66 is credited to the bank account, and a 6 page letter, with customer service booklet and reply paid envelope is sent out, this contains a 2 page form for subsequent claims. It seems like a lot of paper, postage, administration for one overnight stay (my son normally only stays about 1 night every 4 weeks so claims are submitted immediately rather than awaiting until we have a couple of overnight stays to claim for). Will it be possible for these claims and notifications to be sent online? I have made a similar suggestion to a PDCS lean team.</p> <p>I am aware that DLA, and its replacement Personal Independence Payment, are not Income Related Benefits, but are benefits "which will contribute to the extra costs of overcoming the barriers faced by disabled people to lead full and active lives."</p> <p>My daughter has a condition called Galactosaemia, <a href="http://www.galactosaemia.org/index.php/eng/About-Galactosaemia">http://www.galactosaemia.org/index.php/eng/About-Galactosaemia</a> which means that she has to have soya, rather than milk based margarines, ice creams, etc. these are considerably more expensive than the dairy ones they replace, yet I know that this is not provided for in DLA, can consideration to the impact of dietary conditions on weekly shopping bills be considered. My daughter (for whom DLA is paid because of the impact of her conditions on other areas of her life) also currently has a calcium supplement (Osteocare), which is prescribed free of charge, however once she has left school this will have to be paid for, will Personal Independence Payment consider the costs of medications/prescription etc.</p> <p>Finally, the consultation document states "We will, therefore, take into account DLA's role as a passport to other support as we design the new benefit." My autistic son is entitled to lower rate mobility, but this does not entitle him (or us on his behalf), to a Blue Badge, although the award of the mobility component is an acknowledgement of him have more difficulties getting out and about than someone without his disability. Is it possible for the DWP to liaise with the Department of Transport to make the lower rate of mobility also a passport to a blue badge?</p>
EM83	12-Dec-10	<p>Please find below my replies to your questions in the consultation document.</p> <p>I would ask you to excuse any small typing errors as because of my disability I have problems with my hands.</p> <p>1. There are many of these the moment which include:  poor access and disability awareness in most public spaces  the design and layout of shops and commercial buildings  the greater costs for disabled people in getting to places, having to travel with</p>

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		<p>an assistant etc, the higher costs of adapted vehicles. The poor medical services for people with long-term chronic conditions</p> <p>2. The mobility component of disability living allowance is essential for me keeping any social life outside of my own house. Without this I would be almost completely isolated from other people. The access it gives to other disability assistance is key, i.e. disabled Railcards, blue badges etc</p> <p>3. With a condition like mine which is degenerating there is a constant need for new adaptations and assistive devices. Occupational therapists provide a few of these but most of them are ones I have to buy personally. My condition also has dietary implications (gluten and lactose intolerance) which mean that I cannot use most ready meals and as I can no longer cook for myself this means extra costs in terms of food and food preparation. Care provided through social services only meets the bare minimum requirements of survival and personal hygiene. For me to have a reasonable quality of life I have to pay somebody to help me with things like trips out, trips to the hospital, help with physiotherapy exercises, and practical help around the house.</p> <p>4. My answer here depends very much upon the assessment used to decide which level a person would receive. If the assessment is holistic and fair then I would be perfectly happy with just having two levels. If however the assessment does not do this then a lot of people could see a reduction in their income which they depend upon to function normally.</p> <p>5. Some terminal conditions should carry an automatic entitlement (certain types of cancer etc) as the time it takes for applications to go through with government departments would be severely damaging to their well-being.</p> <p>6. The reason given for disability living allowance was to enable people to be active in society and it is clear from earlier legislation that basic care needs should be met separately either by the NHS or social services. To enable people to live full and active lives they should have access to all the services and facilities to which everyone else has access. This should include social, work and family life. At the very least this should include not being left isolated in their homes and being given at least the choice and opportunity to be able to shop and socialise. Those least able to take part should be given personal choices of activities they would like to take part in and the support to make this a practical possibility.</p> <p>7. There are some simple things which could be done here, on the forms for application possibly have two columns for the answers, one for when the condition is moderate and disability at its least and the other for when the condition is at its worst. The medical professionals doing the assessment need to have a familiarity and understanding of the specific condition of the person they are assessing. The consultation paper suggest GPs as having an input in this process, not all GPs know enough about some of the less common conditions and they are not always the best people to write reports.</p> <p>8. As the consultation paper says "the successful use of adaptations", which is a very subjective question. For instance many people are successful with wheelchairs around their own home but put a hill in front of them and they are unsuccessful. It is only sense to include the fact that a person uses a wheelchair, or has access to a guide dog, and it would be ridiculous to assess them "as if" they had them if they did not in fact have them. It is important here that the assessment looks at the situation somebody actually lives with, as the waiting lists for some adaptations are very long. As an example it is possible to be on the council waiting list for a house to be adapted</p>

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		<p>for a period of years. They may be eligible for a grant for adaptations but this does not mean they will receive it in a sensible or reasonable time. In this part of any assessment I would favour only including basic adaptations such as wheelchairs, prosthetics, crutches. But I have a big problem with the terminology of "successful" use as this is a subjective judgement depending on the variability of medical conditions, location and even weather conditions.</p> <p>9. The present DLA application form is a very good way to get depressed about disability if you are not depressed already! It forces people to focus on what they cannot do. Also the form is restrictive in its questions and does not give people the chance to express clearly how the disability affects them. The questions need to be more open, and getting medical evidence in a timely way is very often difficult with the NHS system.</p> <p>Simplifying the system for applying would be the first step to people understanding it more clearly. Also more positive information about the benefits would help, a lot of people are scared of being labelled frauds when they should qualify because they do not see how they have lost abilities overtime.</p> <p>10. The consultation document refers to GPs specifically and these are generally good but not always the best. The best supporting evidence to get a clear assessment would be by medical professionals who are trained to have a real understanding of the specific disability they are assessing. This could be Consultants who specialise in the particular condition or Occupational Therapists</p> <p>11. The difficulties with this are that some conditions vary from day to day, not all healthcare professionals know every condition, some people with disabilities have difficulty communicating the problems they have (this especially applies to some psychological conditions or physical conditions that affect the cognitive processes). The benefits of this would be that the medical professional may see some problems the person has not put on the forms, and could clarify some answers on the application form which may be unclear.</p> <p>11.(b)Where it is absolutely clear that the person applying meets all the criteria from the evidence and the application form or the nature of their condition means that the stress and worry this would cause would outweigh any benefits.</p> <p>12.This should vary according to circumstance, if someone for example had lost both legs then there is no need for further evidence or reviews, but if it was a condition where surgical intervention has occurred which could cure you or reduce the problems then it should be reviewed post surgery.</p> <p>12.(b)For some people there will be no need of reviews, thus saving the cost of doing the reviews. This should apply to a permanent condition where change is not going to happen. For conditions that can degenerate and change (such as EDS, MS, etc) reviews could show a need for more support. Reviews for conditions that can improve and or be cured reviews should take place more often to reduce the incidence of fraud.</p> <p>13. There needs to be a better balance between threat and understanding. Many people are honestly scared of dealing with bureaucracy and more form filling. They fear that a small change in their condition will lose them all their support. Making the system simpler would be a great start.</p> <p>14. The criteria needs to be simply explained in plain English, a guide to the form explaining what information is being looked for in each question, and an explanation of people's rights and what will happen next.</p> <p>15. It would have to avoid patronising people, as most people do not enjoy living limited disabled lives and have pushed every avenue they can to get help. For many the advice and the support is simply not freely available. It may</p>

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		<p>be an idea to link the assessment with an assessment by an occupational therapist that is there not to assess for the benefit but to see how they can help people cope better.</p> <p>16. Disabled people are sourcing their funding from anywhere they can get it! This includes their families supporting them, charity fundraising, grants from charities etc. People should be allowed to use their personal Independence payment for a one-off cost but the many disabled people this is not an option as it is already being used to pay for care and other essential things.</p> <p>17. Parents of disabled children have a massive struggle and in assessing the children the support needs of parents must be included.</p> <p>18. DLA has been good at getting access to other services such as disabled parking badges, disabled rail cards and VAT exemption on certain items. Perhaps giving everybody who has been granted DLA a simple card like a credit card to prove their entitlement would simplify things. One major problem is with the Motability scheme and those who wish to drive from their wheelchairs. The initial payment on the Motability scheme for most vehicles of this type is beyond the means of many disabled people who are unable to work, thus denying them the ability to fully take part in normal life.</p> <p>19. This would lead to a lot more form filling, wasted resources in government departments, and people missing out on what they are entitled to.</p> <p>20. The assessment for disability living allowance is seen as separate because it is not dependent on contributory benefits. This is a distinction which should be maintained. It will be beneficial to share information for entitlement to some other services but since it is different in its nature from other benefits the assessment itself should be kept completely separate from that of contributory benefits.</p> <p>21. Most disabled people would still love to be working if they were capable of it as DLA certainly does not compensate for a salary. There seems to be a focus in all current government documents on disability about getting people into work when many disabled people would love to be capable of working. Disabled people even when they do manage to get jobs are often earning far less than the average. There seems to be an assumption among those designing these policies that most disabled people are capable of work. I am concerned that those identified as facing "lesser barriers" will not get the support they need especially as other sources of support to help disabled people into work have recently been cut. If the assessment is primarily focused on physical disabilities then it is only focusing on one set of the barriers that prevent disabled people having equality. It has to also include those with psychological and mixed disabilities.</p> <p>22. There are many good things in this consultation which could work well. At the present time some people get awarded disability living allowance and continue to receive it after they have had either corrective surgery or treatment which effectively removes the disability. This element of fraud needs to be dealt with so that people who are honestly and really disabled can get the support they need without stigma. Some phrases however do give me severe concern including the mention early on in the document of "affordable", which suggests that budget cuts are the real motivation behind these reforms. Also the concept of "successful" use of aids and adaptations, which is as subjective as the current assessment of DLA claims and also depends very much upon variables which can change rapidly.</p>
EM84	13-Dec-10	<p>My name is [REDACTED], I am responding as a disabled individual. I have Primary Progressive Multiple Sclerosis and I am in receipt of DLA (Higher Rate Mobility and Lower Rate Care).</p>



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		<p>I feel it is relevant to mention that I am in full time employment.</p> <p>I believe there is no disputing that some people who are currently quite rightly and legitimately receiving DLA will find themselves no longer eligible for an award as a result of the new policy aims.</p> <p>In light of this I would like to suggest an additional rate level. As well as the "higher rate" and "lower rate" of mobility there could be a "Nil Rate". The "Nil Rate" would have no cash award but would act as an acknowledgement that the claimant is disabled and does have a mobility issue but is outside of the "greatest need" category. The "Nil Rate" would then be used to "passport" the person to other non financial support. For example, a "Nil Rate" claimant would be eligible for a Blue Badge or the City of London Red Badge. It would be used to justify Reasonable Adjustments in the workplace.</p> <p>Another benefit of having a Nil Rate would be to avoid the potential stigma of losing DLA and appearing to have been fraudulently claiming. The media and Government have made public reference to fraudulent claimants and it would be very easy to point at the reduction in cost as a victory over the scroungers and dishonest claimants. However fraud has been found to be something like 0.6% and yet the reform will hope to make a 20% reduction. This will be a very large number of people who would be cut out and faced with appearing to have been frauds.</p> <p>Without a DLA award the disabled person would have to prove they are disabled to every organisation from which they are requesting a concession. This would put additional cost on the organisations and the GPs/healthcare professionals. The Nil Rate would mean a single assessment, periodically reviewed, would be all that is required. It also keeps the person in the review system and at a later date may qualify them for an award should their need require it.</p>
EM85	13-Dec-10	<ol style="list-style-type: none"> <li>1. Lots of things but accessibility has to be up there at the top.</li> <li>2. All of it.</li> <li>3. Fuel, heating, medication, home help and maintenance...the list is endless.</li> <li>4. Easier to run and understand yes, but also easier for you to make people who would have qualified before suddenly not qualify depending on where the criteria for the reduced groups would fall.</li> <li>5. All claims should be based on individual needs.</li> <li>6. a, Make sure that GP's and Hospital staff advise the patient to make a claim where applicable and b, mobility.</li> <li>7. Regular updates from GP's and Consultants which are all on file (computers) and can be easily shared with other departments.</li> <li>8. a, No. b, None and c, Neither.</li> <li>9. a, Refer to medical records and b, Medical staff.</li> <li>10. Medical records and staff.</li> <li>11. If all of the above were done or implemented there would be no need for any independent assessments/meetings in the first place!</li> <li>12. Would very much depend on whether the disability is deemed to be permanent or not.</li> <li>13. Medical.</li> <li>14. a, Form filling and b, Yes.</li> <li>15. a, Privately or lease depending on the aid of course and b, Yes.</li> <li>16. Extra care, clubs and activities resulting in extra travel expenses etc for the parents.</li> <li>17. a, Very and b, More hassle, stress and the possibility of more people to say no to something they know they should already get anyway.</li> <li>18. Any medical information relevant to the claim.</li> <li>19. None.</li> <li>20. Seems to be a lot of information about a new scheme which is not really any different to the current DLA. There are no real hard facts about the</li> </ol>

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		changes so it is impossible for anyone to say how they really feel about them because no-one can tell at this stage how any of these changes are likely to effect them. The summary of my own opinion is that any disability claim should be backed up by the medical profession. To me, that is common sense and easy to keep track of any changes.
EM86	13-Dec-10	These proposals are cold hearted barbarism. The changes will create such a lot of suffering for some of the weakest people- If i was involved in all of this, its certainly not something i would be proud to announce as i meet my maker.
EM87	13-Dec-10	<p>I am writing as a mother of a son whith Aspergers syndrome, OCD and Dyslexia.</p> <p>As you are thinking of changing DLA I felt I have to write and take this opportunity to change things now before its too late.</p> <p>I would like to 3 main changes:</p> <p>1. The form needs to include mental illness and disability. I would sugest that the government liases with the voluntary sector as these are the users representatives who really know what the conditions involve. Groups I would sugest to talk to are MIND and NAS - The National Autistic Society.</p> <p>2. What the benefit addresses: DLA as it stands mainly focusses on the physical and mobility needs of the aplicant.. it was not worded in a way to account for mental health needs. For example it might ask can you walk 200 yards? Physically our son can walk 200 yards down an open road, but if there were lot of people he would be worried that he might get touched then have to wash, then he would be panicked to find somehwre to wash, or he may have to use his water container to rinse his hands or clothing, then he may be woored that people will see him and think its weird, and that he might get teased. So asking can you walk 200 yards is not enough!</p> <p>3. The form is also very very depressing, as it has to focus on the bad sid of a persons disability, the negatives, difficulties, daily struiggles and challenges. These are the things that parents and carers deal with every day. To get by we have to not focus on these, we have to put them to one side and focus on the good, the small, few or different achievements - of which we are very proud. So the way the form is worded needs looking at by someone who is a qualified counsellor, as well as being in simple language. I know several people who have taken 6 months to a year to apply, some give up as they cant face the form! Thse may be the most needy people in our society. We do need to be careful that we dont give money to people who dont need it, but I feel we need to balance this with a form that can be accessed and is not too off putting.</p> <p>I am glad that the word disabled is being taken out of the form, when our son became 18 and had to sign the form he said to me 'but I arent disabled' and I explained that it was just what the government has called the form.</p>
EM88	13-Dec-10	<p>I am currently in receipt of DLA (middle rate care, lower rate mobility) and have been sinc el suffered a massive nervous break down at the end of my University degree which resulted ina diagnosis of bipolar disorder (I had been suffering with poor mental health followign an attempted rape in my first year - this had been exacerbated by a number of other factors including severe family illness which led to a major breakdown). In addition to this I have a number of mobility issues with reduced mobility and pain in my upper back/ left side due to a traumatic birth and dyspraxia I have a number of secondary issues and problems but these are those that are of primary relevancve to the DLA).</p> <p>I am in full time employment and have been for a number of years - despite my disability. Part of this is due to the assitance and stability provided by the DLA. I am concerned that the new proposals will disadvatnage people like myself as there is a greater focus of "aids" which seem to be very much focused towards</p>

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		<p>permanant physical disablement. While having a number of physical issues - including near permanent pain and tension in my upper back - my main disablement to leading an entirely normal life is my mental health.</p> <p>Currently the DLA allows me to be able to afford to keep an emergency phone, to enable contact whenever necessary with my doctor/ parents - which is massively important at time of acute mental distress, and to afford to run a car - which means I can take a more active role in social activities as due to my mental health I am prone to extreme agoraphobia and a tendency to avoid leaving the house after dark.</p> <p>To alleviate pain I am able to afford to have massages (not readily available on the NHS) with my DLA money.</p> <p>All of these things allow me to lead a relatively normal life - and subsequently hold down a highly demanding fulltime job as a journalist.</p> <p>I am seriously concerned that with changes to the DLA - these will not be the sort of aids and help that you will be willing to offer - and that the focus of your attentions will be on aiding those who are unable to work rather than those of us - who with the help of DLA are able to be fully contributing members of society.</p> <p>Without the assistance of the DLA - I would need regular attention from social services and the community psychiatric team in a way that I currently do not. Could you please ensure that people like me are accounted for in any proposed revisions to DLA? People like myself - with serious mental health issues and learning difficulties can rapidly decline if access to appropriate facilities are not available - since mental decline can happen almost overnight relying on appointment systems within the NHS is not always appropriate. Usual physical aids are clearly not appropriate and I suspect concerns for the mentally ill to be able to readily access social facilities or immediately contact help via communications systems will not be the sort of aids you will consider - I urge you now to look at them and the plight of people with mental difficulties if the current system were totally reformed. For soem it may be appropriate to organise services and care through the NHS and social services and inbuilt disability aids - but for many the current system is far more effective.</p>
EM89	13-Dec-10	<p>Hello there, as a recipient of this benefit, I am horrified that the review is starting off from the premise 20% must be saved, especially as the proposals seem to suggest that we need to make the system more bureaucratic, with an independent doctor doing the review, which in turn will see administration costs rocket.</p> <p>I have MS. I use DLA to keep myself well. It pays for extra things such as walking aids, the odd taxi to pick my children up if I cannot possibly walk to the school etc. Any tiny bit of support to avoid fatigue can keep me away from hospital and becoming even more of a burden. Any review causes concern and stress, and this in turn can lead to relapses for MS sufferers. Please bear that in mind before you launch any more changes or consultations!</p> <p>To lose DLA, or see it targeted at people more seriously ill than me, simply makes it harder for me to function and contribute to society. For me, that would mean losing a benefit for a year or so, until the very act of taking my benefit away tips me into crisis, and needing even more of the same benefit and others, whilst destroying my life and that of my family.</p> <p>I resent the inference that the disabled are somehow scroungers or that the vulnerable and poor can be split into "deserving" and "non-deserving". The coalition encourage this view, and it is wrong. It is right and proper that we all make sure everyone contributes to society and does not get money they are not entitled to, but this includes corporate tax dodgers as well as benefit fraud.</p>

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EM90	13-Dec-10	<p>I am a visiting officer with PDCS and visit customers of all ages. I fully support the DLA review and I understand it is still under consideration if children and pensioners will fall for re-assessment. I would strongly recommend both categories are reviewed with the introduction of PIP for the following reasons:</p> <p>The majority of young people I visit in relation to DLA is based on an award due to ADHD/behavioural disorders. I would say 95% of visits for under 18 are made up of ADHD/Behavioural disorders. Usually the award is middle care and low rate mobility, around £66 per week and then of course CA awarded in most cases to one parent. Most of these children are in mainstream school. Most are able to socialise with their friends independently using public transport to get into town/city. There are rarely any costs attributed to ADHD so the money is usually spent on PC games/CD's/Designer clothes/Holidays etc etc. I have had specific cases where one lad was saving his DLA money so he could set up a business when he left school (pretty good for someone who needs a lot of attention during the day and guidance when out and about!), another lad who advised he used the money to take out his girlfriend, a mother who advised she ensured the money was used for her son and demonstrated how she had purchased a mini motorbike for her son with the money. In some cases teaching assistants are assigned at school, a cost that is not met from the DLA money, but another cost to the taxpayer. In view of the basic principles of DLA being an extra cash award to contribute to extra costs incurred due to the disability - with ADHD this is an absolute farce - there are no extra costs to the individual - we are just lining their pockets to buy the latest clothes and gadgets - if school transport is required it is met by the school - no costs are relevant to the ADHD symptoms. All minors are in need of parental control/support and it may mean that a child with ADHD/behavioural issues needs more support - but surely that is just part of parenting? It cannot be compared to those children we see who are physically/mentally disabled and clearly do need on-going support from parents and will continue to need support throughout adulthood. The low rate mobility is based on needing someone to be with you to make sure you are safe and need help when finding your way around places you do not know well - the latter is surely true of most minors is it not? Would we expect a minor to go to an unfamiliar place on their own? Yet these same children get to school independently and socialise independently so I can never understand the mid care and low mobility award. One lad receiving such benefits was actively approaching all local shops for part time employment, all off his own back.....</p> <p>Likewise I have visited pensioners in receipt of high care or mobility awards yet have been incredibly mobile, and one such customer had his own business taking videos, he lived in a first floor flat with the steepest stairs I have ever seen and had no problem getting up and down the stairs or getting out and about to video people playing sports. Another lady awarded high rate mobility holds a part time cleaning job for an elderly lady.....as far as she is concerned she still has fibromyalgia and so she feels that is why she gets the benefits.</p> <p>So, yes I believe these 2 age groups do need to be reviewed and serious consideration to actual costs incurred due to the disability taken into account for the award of PIP - I would really hope to see that only in the most extreme cases of ADHD/behavioural disorders would the award be applicable, and cannot see how on earth this can be justified if in mainstream school.</p> <p>A regular review needs to be carried out with the new benefit - customers who are currently awarded DLA do not fully understand any improvement in health needs to be notified - they just see they still suffer from the condition/illness so believe they merit the award. I think that no DLA/PIP claim should be awarded</p>

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		<p>without a face to face interview. I believe it would be a good use of Visiting officers to be trained to carry out the assessments and given the ability to decide the award at the visit. It is easy to observe people in their own environment.</p> <p>Finally, I believe that there should be a formal system in place so that if a visiting officer from PDCS identifies potential incorrect award there is a formal system in place to give regard to the comments from the VO and a review is carried out face to face.</p>
EM91	13-Dec-10	<p>Am copying this to MP &amp; National Asthma Campaign for their information.</p> <p>Re DLA consultation paper and my thoughts as a person with severe asthma who still works but part time as my health is not good enough to work full time. Whilst at first view you could easily be forgiven in thinking I could do a full week but this wouldn't last long. I'd be unable to keep all my medical appointments if I worked full time much as I'd like to.</p> <p>Medical equipment purchased by self eg portable nebuliser to allow independence and ability to leave house is not considered nor is its maintenance. This in itself increases ones ability to do things. Had I not of purchased it I could very easily have been medically retired or spent long spells on incapacity benefit.</p> <p>Cleaning is currently not considered by DLA nor is shopping for needs. A lack of cleaning at a high level could make health condition worse in case of allergies etc and to do it oneself has on occasions huge risks but so vital too. Reduced working week means needs are lessened but would immediately increase sick leave and care needs if increase of hours. Hence not true picture of needs at current basis.</p> <p>Please listen to specialist nurses and consultants where long term conditions are situation. They often give a much clearer view of needs and prognosis than individual who can exaggerate or totally underestimate and this may reduce need for extra assessments by atos, extra medicals or appeals which cost and increase stress.</p> <p>I like this statement in consultation document "We believe that now is the right time to reform DLA, creating an affordable and sustainable system that will support disabled people to overcome the extra barriers which prevent them from leading full and active lives." DLA isn't an out of work benefit as seen by so many to be but support to enable people with a disability to take part in life be that work or whatever. My DLA &amp; WTC have allowed me to work 4 days a week and pay my bills though am still worse off than if I worked a full week. I'd certainly like to do that but would soon be off sick with increased needs for assistance if I did and with hospital treatment on a regular basis I'd be taking leave at least 13 days a year in order to try and stay well and without adequate breaks I'd yet again be risking my health and increasing my needs.</p> <p>To simplify the forms would be fantastic as they are so daunting and difficult to fill in accurately if not used to the wording etc e.g. experience of working in health or social care. Also as a disabled person you adapt without even realising it to overcome the difficulties e.g. purchase of pre-prepared vegetables, cook extra on good days so you don't need to cook on the difficult days. Purchase slip on shoes instead of laced ones even though the alternative may be better. I've worn sandals in winter if unable to do up or put on winter shoes. Whilst I can often do many things it can be a considered choice, is it going to create pain, make me ill immediately or for days after and is it a case of pride I'll do whatever and suffer later as too proud to ask for help as feel such a failure or nuisance to others if I do.</p> <p>Consider variable conditions and extreme ends of the spectrum and how</p>

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		<p>several lesser issues joined together can make a bigger impact than when each are looked at separately. A specialist nurse etc may be of more use here to make accurate decisions.</p> <p>Mobility type payment needs to be thought at in line with increase in petrol costs etc or maybe a discount at source for fuel eg vat exemption. This could actually work out cheaper in provision for those who do few miles but not limit those who need to drive etc to get to work and therefore contribute to society. Sometimes it could be easy not to attempt to do more with current system of mobility needs. E.g. a physiotherapist can suggest an exercise programme of walking when you can. It would be easy not to do this if it's seen as contradictory to mobility needs and being unable to walk far. What it does do if you attempt it on the good days is prevent you slipping further down the scale and therefore needing more support. Also it does need to be carefully tackled as use of a wheelchair could make it easier in some circumstances to get around it could actually make a person "give up" trying to walk and then risk a slow decline in overall health as it can be a case of "use it or lose it" in abilities.</p> <p>I think a health or social care person who has actually observed person and their needs could be really helpful BUT it needs to be someone who really knows the situation. For example a physio who has treated you for a year and knows how things are hidden or just not mentioned can be great, same with a specialist nurse. BUT a doctor who has never met you before or knows little of how disability affects you cannot have a realistic view. I'm certainly good at hiding difficulties from people by a huge variety of tactics most of which I do without even realising I do it. The opposite would also be true in that to act with severe difficulties when they are milder for an hour or two during assessment hence yet again it's difficult to get a realistic long term assessment for so many conditions.</p> <p>Please acknowledge that DLA application is stressful and difficult especially when struggling in daily life. Hence please do not do unnecessary reviews of payments etc.</p> <p>The current situation of having to notify DLA when you go into hospital is impossible for emergency admissions or when very unwell with respiratory difficulties. I've rang up when I came out and starting to make a recovery and given the required dates. I really felt bad that I couldn't comply with the rules so please allow a little flexibility here. After all we don't want our families having to do this for us always. It's a dignity and independence issue for me.</p> <p>Payment. I would find it much easier if that could be monthly as in the world most bills etc are either weekly or monthly. I personally don't have anything that works on a 4 weekly plan.</p> <p>There needs to be a realistic view on chance of good recovery given enough treatment and support or unlikely regardless of help. Perhaps known professional who support person could give a considered response to this.</p>
EM92	13-Dec-10	<p>I have a long term chronic mental health problem. I receive middle rate care and lower rate mobility DLA. I have a key worker and also need support from other mental health and medical services.</p> <p>I feel as if I cannot face scrutiny, more medicals and forms etc as I have had so many in the past. I am now aged 63 and feel as if I really have had enough.</p> <p>Will I have to go through this new process or, because of my (genuine and enduring) mental illness, will I be all right? Other people in my situation may feel the same but I really cannot handle more after the major struggles for DLA I have had so far. I was eventually awarded DLA indefinitely but I needed a lot of help to get it and was very upset about it. Although I am subject to bad bouts of ill health I was able to relax a bit about finances once, some time ago,</p>

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		<p>my DLA award was indefinite.</p> <p>Although I understand that you cannot give an individual response at this time I am anxious to say how stressful this is for people who suffer as I do - you cannot see the disability but it really is crippling.</p>
EM93	13-Dec-10	<p>I am a retired law lecturer and widow with a son who is on the autistic spectrum(diagnosed in his late thirties with high functioning Aspergers Syndrome and now 45). None of my family have ever been on benefits of any kind until my son was diagnosed. I have supported my son all his life and paid for numerous courses to try to get him into employment. He has suffered rejection after rejection. After trying agencies who paid basic wages to unqualified support workers and paid themselves handsomely in agencies fees, I determined to find my own support worker and succeeded in acquiring one where the direct payments are paid to her and she gives an excellent support service to my son.</p> <p>I am aware and, indeed, have lobbied for the Autism Act, a private members statute which I believe comes into force this month. I believe that more should be done to give people with this disability ,training in social skills to enable them to find employment The education system falls short in this and in utilising the innate skills that many people on this spectrum possess. For example, being aware that my son had skills in technical drawing he was enrolled on a Computer Aided Design course and he completed 2 years of this course obtaining a distinction in the second year. I was informed that year 3 was industry recognised, but unfortunately my husband died in my son's arms at the beginning of the third year and he did not complete the third year. I was told that he needed two more terms to complete this course but he was shunted off the course because of some silly criteria about disability support. This has had a devastating effect on him. He needs to work but his lack of social skills is preventing this.</p> <p>Any reform of the law should take cognisance of the need for an Aspergers team in each local authority where essential skills can be taught and cognitive behaviour therapy by qualified psychologists could assess the problem. Too much money is wasted on administration and diagnosis and not enough on helping the disabled person educationally and socially into a more fruitful and healthy lifestyle.</p> <p>We have been largely disappointed by organisations who purport to provide a service for people on this spectrum who take large salaries for Chief Executives and Directors at the head of such companies and yet provide low paid support workers who do not even have the basic skills to even understand let alone help people on this spectrum. My son's life has been a nightmare until I intervened with legal action and the threat of judicial review.</p> <p>I intend to write a documentary for Panorama to show the devastation and injustices which go unchecked for these vulnerable people and I hope that the proposed changes are not just a mask by way of a new name to cause further distress to those who are less able to cope with it.,</p>
EM94	13-Dec-10	<p>Because there are so many of them in the national population, deaf and unsighted people, whether totally or partially affected, form a powerful lobby for considering their benefit needs. Because the survivors of laryngeal cancer are so few, very little consideration is given to the needs and problems of the unvoiced neck-breather. Yet to lose spontaneous speech is no less a serious disability than losing sight or sound. For a laryngectomee to be awarded DLA, a large measure of good fortune is required; the majority of applications appear to be refused as a matter of course and a substantial number have to go to a tribunal, no mean ordeal for someone whose personality has recently been devastated by the permanent loss of their primary means of communication.</p>

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		<p>There was nothing wrong with the published aspirations of DLA; but the practice seemed to be in the hands of functionaries at the DWP whose decisions might have been decided by the toss of a coin or the state of their livers. There is very little consistency of equal awards being granted to equal conditions.</p> <p>Recently the DWP have started sending doctors working for an American company, ATOS, to assess the condition of applicants. The huge majority of cancers are 'rare' and the chances of these roving doctors having the necessary knowledge to offer a useful assessment of many of them is remote. Specialist knowledge is required which GPs do not have yet the submissions of clinical staff who know the patients are dismissed.</p>
EM95	14-Dec-10	<p>Please could you put my point across regarding the Reform for DLA.</p> <p>These plans are clearly not needed, why change the name, just keep the name the same, because it will confuse people and it can cause upset and stress.</p> <p>When you talk about the <u>working age</u> it clearly should be for <u>18years old to 60 years old</u>, the young people do not want to work and you should be looking first of all the once claiming job seekers and housing benefit, these people do not want to work (why should they when they are getting their housing paid for them).</p> <p>Also I would like to point out that when someone is told they are disabled this comes from a professional person (Doctor / Consultant), by doing these changes you are undermining the professional people. It is bad enough trying to get there heads around there problems, but with all the changes it will cause more illness from stress.</p> <p>I ask please re-think about it, there is clearly other things you can change, try to cut crime and getting people out of gangs into jobs etc. There are plenty young people who clearly do not want to working claiming job seekers people age 16 – 60 years old, you clearly should be targeting more young people who are not working, for a example all those young people who have been protesting about fees, someone of them do not work, well make them work if you have the power.</p> <p>You must please leave the disabled people along please do not change because it will cause a lot of heart ache and upset and stress and to much stress and more illness from it all can cause DEATH!!!!!!.</p> <p>PLEASE HAVE A HEART AND RE-THINK!!!!!!!!!!!!!!!!!!!!!!</p>
EM96	14-Dec-10	<p>Im getting more angry and angry everyday and thats without the ACQUIRED LOSS OF HEARING.. Now I agree with some of these changes, as Once upon a time I had hearing aids, and then other things came up I became pretty ill and now disabled.</p> <p>Now I really dont think that Hard Of Hearing or those with hearing aids really need D.L.A or P.I.P s it will be called..Ive been there and done it why they need i will nevrr know, that why I never claimed, because I didnt think and still dont think that H.O.H should get it. BUT ACQUIRED DEAFNESS is worst disability apart from those who lives ar at risk.....ACQUIRED DEAFNESS is so so difficult, cant hear people, no Communication..</p> <p>Born Deaf is also different kettle of fish they are brought up to live with it, but they still Deaf..But Acquired Deafness and Tinnitus is so so AWFUL...</p> <p>1 BECOMES RECLUSE away from everyone, no B.S.L....no lip reading..some of us have balance problems..... Now from what Ive read in past we got D.L.A</p>



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		<p>because of someone standing up for us, it is loss of Bodily function....remember that...</p> <p>But its more than that for ACQUIRED DEAF, WHOM NOBODY STANDS UP FOR....I had Cochlear Implant that FAILED you know...I wont go into detail thats not what Im here for..But how do you think I felt, CANT HEAR WIFE ANYMORE BUT SHE IS MY EARS AND DRESSES BOTTOM HALF OF ME...Cant HEAR my children well young men, and CANT HEAR my GRANDCHILDREN..Tinnitus drives me mad, balance throws me over...</p> <p>Im speaking for all ACQUIRED DEAFNED PEOPLE....Please please think of ACQUIRED DEAF.</p> <p>I have a Blind friend who prefers to be blind than Deaf, he can Communicate with others, I cant, Ive lost friends, my friend may not be able to see a film but he can hear it, I have trouble getting sub titles..Take this year CHRISTMAS..I havent seen 1 XMAS film yet with sub titles....</p> <p>My friend can listen to Music If he had tinnitus as well he could mask it, I CANT..</p> <p>I see this on old D.L.A form&gt;&gt;&gt; 80% Deaf and 100% Blind get high rate D.L.A .</p> <p>but there is NOTHING ABOUT Deaf, and I also saw something about Deaf being hardest to employ on records somewhere..Dont know where but saw it.</p> <p>I WISH THAT SOMEONE SOMEWHERE IN HIGH AUTHORITY COULD GO DEAF FOR A MONTH AND SE ALL THE BARRIERS WE COME UP AGAINST...</p> <p>I WAS ONCE ASKED TO GO TO JOB CENTRE PLUS FOR INTERVIEW, MY WIFE ANSWERED PHONE AND EXPLAINED I NEEDED "SPEECH TO TEXT REPORTER" We dont do that that say, this was few years ago now, I wanted that interview so people could see how difficult it is, but its long gone now....</p> <p>I knew my hearing was going and never thought much of it you know..MY GOD ITS SO DEPRESSING AND BARRIERS I COME UP AGAINST....</p> <p>BUT ANYWAY ISNT IT TIME THAT D E AF WERE PUT ON THESE FORMS, WHY WHAT HAS STOPPED DEAF OR ACQUIRED DEAF FROM GOING ONTO FORM, ITS HIDDEN DISABILITY, DIFFERENT FROM BEIONG BORN DEAF AND ACCEPTING AND LIVING WITH IT, BUT DEAF STILL THE SAME BUT HARDER TO COME TO TERMS WITH..</p> <p>I FOR THE LIFE OF ME CANT UNDERSTAND WHY NOT...</p> <p>ACQUIRED DEAF, LOSS OF BALANCE, TINNITUS, ETC ETC ETC..IM SPEAKING FOR DEAF FORGET MY OTHER DISABILITIES..</p>
EM97	14-Dec-10	<p>This is my response to your consultation about proposed changes to DLA. I am writing as the mother and carer of a 12 year old boy who has Downs Syndrome and hearing loss and who is in receipt of high level care and mobility.</p> <p>I firmly believe that DLA should remain a non-means tested benefit. Disability affects all people across all income groups. More poor people receive DLA but are they disabled because they are poor or poor because they are disabled? I suspect the latter, with an element of "knowing how to play the system" in some areas.</p> <p>There is a very high level of concern amongst the charities supporting disabled</p>

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		<p>people with a high level need that the proposed changes to DLA are a smoke screen to unleash devastating cuts on the most vulnerable people in society. I appeal to you not to do so and to engage some high profile PR to win the large charities around.</p> <p>I would urge you to very carefully consider the impact of the proposals on these very vulnerable groups. DLA is often used to passport to other essential services. Inappropriate downgrading of DLA would be devastating; a cruel and unacceptable additional burden to these people.</p> <p>1. The main barrier is still sadly other people's fear and prejudice. As much as we'd like to think we live in an accepting open minded world; we often still don't. Only 2 years ago I faced a teacher who didn't want my disabled son to be friends with the other children in the class because she thought it was inappropriate and would make the other children babyish. Prejudice is alive and kicking and needs to be challenged. We need to put strategies in place to make disabled people more visible and their contribution more valued.</p> <p>Many profoundly disabled people need a carer or interpreter to help them make sense of the world and to keep them safe. My son has Downs Syndrome. He needs a carer with him at all times. He can not be left alone as he would think nothing of turning on the gas, wandering off and would have no idea what to do in an emergency.</p> <p>He needs someone with him at any social event so that he can understand what is going on, what he's expected to do and to help mediate the spoken environment (he is also deaf). Sadly, people do not queue up to help to look after him, although we do have very close friends and family. With help, he can participate, but before even thinking about that, my main interest is simply keeping him alive and healthy; a failure of either makes everything else a bit of a waste of time.</p> <p>The cost of transport. At the moment this is brilliantly met by the motability scheme. Without it, my son would be unable to participate in very little; as it is now, he can. This is one of the few disabled services that works; motability - please don't touch it!!!!</p> <p>Extra equipment. Often need more expensive equipment, robust footwear and clothes. IT equipment is also useful to keep him entertained and quiet in social situations so the rest of the family can get out.</p> <p>2. Motability. Otherwise, scrap the rest of the system and start again.</p> <p>3. Off the top of my head, these are my extra costs this month – total, much to my surprise = £1071</p> <p>£120 Petrol - for journeys I would otherwise not otherwise have had to make  £199.04 Car - my son receives higher level mobility so this is the value of his motability component - if I had to provide a car myself (which would be essential) it would be considerably higher.  £20 Electricity - estimate I have had to keep the house warmer than I would if he wasn't disabled as he has damaged lungs.  £30 Washing - I need to do an extra load every day  £80 Childminding in the evenings –This is so I can go out one evening a week to socialise – important so that I can maintain social contacts and stop me being imprisoned and isolated in my own home.  £40 Clothes – averaged over the year. He's partially incontinent and gets through clothes quickly.  £200 Speech therapy - The local authority pay for his educational needs through his Statement, but that is not adequate to meet his social needs which I pay for with his DLA (£50 per week for weekly sessions)</p>

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		<p>£120 cleaner – sounds excessive but a) I don't have time to clean because I am looking after my son and b) he makes a lot of mess.</p> <p>£10 earplugs for swimming</p> <p>£120 technology. Hard to quantify but a laptop and an element of my iphone are essential to occupy him (means we can take him to restaurants as he's got something to do) and as he gets older, to help him communicate and take part in social activities</p> <p>£32 for a specialist after school club so he can mix with other disabled children (this is subsidised, but £8 is what we pay)</p> <p>£40 shoes – he wears orthopaedic shoes but I need to pay for special trainers so he can join in with sports.</p> <p>£40 – equipment. This year I have bought some industrial headphones (he's phobic about noise) and some specialist software to help him communicate.</p> <p>£20 – playscheme, this is a council charge for one day at a specialist playscheme with support</p> <p>Total - £1071 – wow, I didn't realise it was that expensive and that's not including the cost of time I have to take off work (I am self employed so if I don't work, I don't get paid). You could obviously cut some of this, as most people have to do, but then you move from "independent, full and active live" to "just staying alive".</p> <p>Note that very little is actually spent on care. I do get help with his care, but that is funded through respite (average 5 hours a week) and through the council playschemes in the holidays (average across the year about £20 a week). The current value of the care I receive is roughly an additional £300 a month.</p> <p>4. Who is going to be high rate and who is going to low rate? If for example the test was whether a person could walk 50m and butter a piece of toast, my son would be able to do it, but unsupervised he would in all probability starve to death. I fear that there's a very real risk that he will be categorised as being in the lower rates despite his level of need. Two rates will work if the boundary is in the right place.</p> <p>I would suggest the following categories:-</p> <p>Top level care – All people who we as society can not reasonably expect to live independently. – "protected citizens"</p> <p>Lower level care – those who we can expect to live independently but who have disabilities that make their lives difficult.</p> <p>Top level mobility – All people who can not get out without a car (this should include people with severe mental impairments such as autism as well as physical impairments).</p> <p>Lower level mobility – All people who have a bit of trouble getting around, who might need to occasionally take taxis etc.</p> <p>Please remove any reference to night care which has no bearing what so ever on how disabled people are. I know far too many people who are profoundly disabled (ie can't interact with the world at all) who are on middle rate care because they happen to sleep at night; which is mad.</p> <p>Note that the category "not expected to live independently" should not be taken to mean "not allowed to live independently" or "not allowed to work". If a recipient manages to get themselves to a situation where they are just about living independently they shouldn't lose their entitlement. If they manage to get a job – great, but it would almost certainly be low paid, highly supervised and unusual. It is profoundly beneficial for people with a high level of disability to be</p>

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		<p>out and about in society so this should be encouraged. They shouldn't lose any of their benefits on taking up work. Note that I am talking here about the higher level of entitlement.</p> <p>5. I never knew there were automatic entitlements. Far from being removed, I think they should be extended!</p> <p>I've always felt that DLA should apply the 80/20 rule. If the normal statistical distribution applies, 80% of the applicants should be straight forward with a straight forward (if profound) medical diagnosis. There should be a minimum level of entitlement for a range of conditions that people could apply for without the need for a medical assessment and by providing minimal information. This would certainly apply for the people with the higher level of need who presumably have more profound conditions needing detailed assessment. These are also the people for whom medical interviews are likely to be stressful, traumatic, and unproductive and a waste of time.</p> <p>For example there are approximately 60,000 people with Downs Syndrome in the UK. Life for people with Downs Syndrome has improved enormously over the last 20 years, but it's unlikely to improve to the point where they can live without a lot of help. The vast majority (&gt;95%) are likely to be awarded at least the high rate of care and low rate mobility. Why go to all the trouble and expense of forcing them through a detailed assessment when all you need is their national insurance number and evidence that they have Downs Syndrome? It would easily save millions of pounds a year on just this one condition; money that could be diverted into paying for services for these people. There must be many other conditions which could be similarly categorised.</p> <p>If anyone wanted to apply for higher rate mobility, or even a lower rate of care, they could, but would need to undergo a full medical assessment.</p> <p>That would leave 20% with complex non specific diagnosis which could be assessed through an individual medical assessment.</p> <p>6. First of all you need to find them. The DLA net has been spread so wide that this is going to be tricky. I would start by working very closely with the charities that support the most needy people (Mencap, Cerebra, Headway, The national autistic society, the downs syndrome association, MIND etc) to work out ways to target the people they represent. These are likely to be the most needy people, needing the highest level of support. Incidentally, I think it's essential to get these organisations on side and feeling that the people they represent are going to be protected. I can assure you that at the moment they don't and there's a widespread sense that "the greedy Tories are just out to fleece the disabled so they can give money to the bankers" – not what I think I hasten to add. This view has got to be addressed urgently.</p> <p>At the very basic level, we need to prioritise the need for disabled people to be fed, clothed, warm and healthy. Too many already struggle with this basic need.</p> <p>We then need to prioritise relationships by getting them out and socialising – relationships improve quality of live and ability to actually lead a worthwhile life. To do this they need to be able to get out of the home so we need to identify the people trapped in their homes and understand why they are trapped there.</p> <p>We need to get them out into the workplace by providing incentives to businesses to take disabled people on.</p> <p>7. This goes right back to the initial assessment. Part of the initial assessment should be to decide if a condition is life long and persistent or whether it is</p>

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		<p>temporary and/or likely to fluctuate. Those with fluctuation conditions should be required to submit evidence from their GP or Doctor and undertake regular re-assessments.</p> <p>8. We need to be very careful here. IF the person has actually managed to get the aids and adaptations and they help mitigate their disability (eg wheelchairs, hearing aids, glasses, prosthetic limbs) then of course they should be taken into account. BUT in the real world, these adaptations are a nightmare to get hold of. If a person can demonstrate that they have made reasonable attempts, and failed then they should not be taken into account.</p> <p>I also think DLA should be a two way arrangement and if people's disability is caused by their lifestyle (ie over eating, alcoholism, smoking) or refusal to accept reasonable adaptations then accepting help to change their lifestyle or getting adaptations should be a condition of accepting DLA – within a time limit.</p> <p>9. Obviously you need to publicise what the new benefit is for and what the boundaries are for successfully claiming it.</p> <p>The form is a nightmare. I don't care how you do it, but can you please get it down to less than 4 pages? You only need my name and address once. You only need to know about my son's condition and how it affects him once.</p> <p>With my simplified 2 level system you only need two questions.</p> <p>1 - Can this person reasonably be expected to live independently and if not provide evidence. 2 – Does this person have a disability which leads to extra costs and if so, provide evidence of those costs.</p> <p>If there are only going to be two levels, you don't need to gather detail.</p> <p>What else do you need to know?</p> <p>10. I thought this was about care needs and extra costs of having a disability? Where does "assessment of ability" come into it? If it does need to be included I would suggest a letter from a GP or Doctor or a medical diagnosis</p> <p>Note that not all disabled people consider themselves "ill" but the role of Doctors should be expanded to cover any condition that affects a person's ability to lead a full life, not just traditional illness.</p> <p>11. Most of the disabled people I know would be incapable of participating in a meaningful face to face dicussion. I think this is an outdated view of disability. For the sake of sensibly answering the question I will read it as "face to face assessment". There are definitely people for whom a face to face assessment would be traumatic and other for whom quite frankly, their disability would be so profound that it would be a total waste of everyone's time and money.</p> <p>So, let's have another question on the form:- "Is there any reason why a face to face assessment of this person would be inappropriate" – if so provide evidence (again a doctor's letter). I am thinking her particularly of people with autism for whom these sort of encounters are rarely successful on any level.</p> <p>12. If a condition is life long and is not going to improve then reviews should be set at 5yrs ,1yrs 6 and thereafter every 20 years. I never want to get another letter indicating that my son might have been cured of Downs Syndrome or waste another 2 days filling in a form identical to the one I did the year before; a form which some poor person is then paid to pointlessly assess.</p> <p>Yes, there should definitely be different types of reviews depending on</p>

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		<p>conditions. Some conditions may even need reviews every month (or whatever works out economical in view of my answer to question 13). For example, someone who has suffered an injury which is going to get better should be reviewed perhaps every month. Someone with a life long condition which is never going to get better should never have to be reviewed; unless of course there is some miraculous medical advance.</p> <p>13. Do you seriously expect people to write and say “I’m better now, take the money away”?!!! That’s simply not how people operate. Believe me, the within a few months of receiving the money, it will be absorbed into their general living expenses and there is ample evidence of human behaviour to demonstrate that they will delude themselves into honestly believing they still need it and are entitled to it. You need to take a far more realistic view of what drives people to report or keep quiet about changes. Many people in receipt of DLA then get very significant increases in other benefits. By admitting to changes that may result in them losing DLA you are asking them to lose all the other benefits that are linked. People will go a very long way to delude themselves that they are still entitled. Punishment won’t work as a deterrent – if someone believes they are entitled, they will equally think that the punishment system is for “other people”, not them.</p> <p>A priority should be to make the system for reporting changes work. It’s so bad that people are unlikely to use it even if they wanted to. I challenge you to pretend you want to make a change, and go away now and try to do it. See you again tomorrow. I’ve only tried to use this for carers allowance, but I assume the system’s similar.</p> <p>This is my recent experience of trying to notify carers allowance of a change. Two months ago I got a job that took me over the earning levels for carers allowance so being a responsible citizen (there aren’t many of us) I started trying to get my carers allowance stopped. I phoned (20 minutes to get through) and was asked to do it online. I did it online (another 30 mins once I had got an account, password etc). 2 weeks later I received a very aggressive letter saying that they understood that there had been a change in my circumstances (presumably from the detailed online form I had submitted) and demanding that I needed to fill in an identical paper one, oh, and a separate detailed form for each of my sources of income (but only including one form). I phoned again and was told it was all a bit complicated to stop but they would try – I am still receiving the allowance. And you wonder why people don’t report changes?!</p> <p>Realistically the only way you are going to get people to report changes, is through reviews. It’s critical that reviews are set to be frequent enough to adjust payments if necessary for those few conditions that are subject to change. At every “likely to improve condition” review, the recipient should be clearly told what the payments are for and that they are a temporary payment. The majority of disabled people have conditions that don’t change.</p> <p>I have always thought that it would be psychologically sensible that recipients of DLA should have a bank account separate from their household account for payments to be made into. This would allow recipients to keep a much closer track of what the money is being used for rather than allow it to be absorbed into general household expenses. This would be tricky to enforce but it would be a start for it to be included as advice.</p> <p>14. People simply need to know if they can apply (so yes, it would be useful to do through the benefit’s claiming process as many disabled people are dependent on benefits), where they can apply and how the payment will help them.</p> <p>15. I would work closely with the charities representing these people to</p>

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		<p>encourage them to apply. The charities know the people and are best placed to get advisors out to people.</p> <p>16. If this is a way of streamlining the currently haphazard NHS service, and encouraging the development of a market in aids and adaptations, then this should certainly be an option.</p> <p>17. The assessors should be specifically trained in dealing with disabled children.</p> <p>Para 40 of the report is a bit concerning. It questions whether the assessment should take account of "care needs being provided by other public institutions like schools". I don't know anyone who actually uses any significant amount of their DLA to pay for care needs – they use it to meet extra costs. The award is simply far too low to pay for any meaningful care. Costs of care are in reality met by respite or direct payments. As such, having a child in school doesn't in reality make any difference to the costs of having a disabled child. DLA is already withdrawn if a child is in a residential school placement.</p> <p>18. DLA is the passport to everything, from disabled children's clubs to priority access at theme parks to the SEN statutory assessment process, which is probably one reason why there is now such a high uptake. Every service I use asks what rate DLA my son gets. It's a critical benchmark and it works very well.</p> <p>19. How do you stop it?! Other benefits and services need evidence that someone is disabled so if you don't use the PIP, what do you use?</p> <p>High level PIP should certainly be used to passport other services; if we are using my criteria that these are people who could not be reasonably expected to live independently. We have to undergo enough assessments as it is, so if this could be used as a passport more than the DLA is, then that would be very helpful.</p> <p>People on the lower level are going to have all sorts of varieties of other needs so passporting probably wouldn't be useful or appropriate.</p> <p>20. In my opinion you could use the assessment for PIP to assess a person's need for extra expenses (old DLA), care (old respite), living allowance (old benefit), help and support needed to get into employment and any other day to day living entitlements.</p> <p>You categorically couldn't use it to assess statements of special educational needs (although a report could usefully contribute to the evidence). These are complex assessments which need input from a number of education experts.</p> <p>I would ask who ever produced the motability computer system (which works!) to sell you an adapted version; expanded and used to record all sorts of details about a disabled person; not just about their car! Like with motability any forms could be produced with repetitive data (like addresses etc) automatically generated which saves lots of time. All the data would then be there and available to any government assessors – it should be a condition of receiving these benefits (provided for by the tax payer) that the recipient should allow their data to be available to other authorised parties – ie. Please ride a coach and horses through misapplication of the data protection act.</p> <p>Everything should be coded on the unique identifier – the recipient's national insurance number.</p> <p>21. Can't think of any.</p>

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		22. It should remain a commitment that society should meet the extra costs faced by disabled people. No one chooses to be disabled and disability affects all social classes. The only thing about DLA that I would retain is that it should be a non means tested benefit and the motability scheme.
EM98	15-Dec-10	<p>As a wheelchair user who is in full time employment as a civil servant who employs their own support workers I receive the following payments every 4 weeks  DLA £485  ILF £1235.72  Will I continue to receive the same amount under PIP.  Your consultation states that "In Personal Independence Payment, we intend to move away from a system that awards automatic entitlement for certain conditions; instead we propose to treat each application individually. This will deliver a more personalised service that ensures resources are targeted where they are most needed."  Exactly what conditions do you classify as "automatic entitlement"</p>
EM99	15-Dec-10	<p>My feedback on DLA is due to my current role as social worker for severely learning disabled people being discharged out of long-stay hospital settings. We discharged the last 3 people just over 2 weeks ago (1 Dec 2010). The experience we have had is that most of the people we work with have been in-patients for decades and that it has been very difficult to get benefits (re)instated, including DLA. In some cases it has taken 9 months or longer. This is particularly relevant with HR DLA Mobility as it is a passport benefit for lease/ hire vehicles on the Motability scheme. This means that people with severe challenging behaviour either have to hire their own vehicle at great expense, limiting their opportunities to get out, or have no transport at all. In addition most of the DLA decisions have come back at lower rates than expected and are being challenged.  The length of time that the process takes, the size of the forms and the repetition of the questions all make for additional delays. This is for people who in some cases have been in-patients for 50 years! (NB there are obvious reasons why people have been in settings for such a long time..)  To request health professionals to be present in person at meetings will be very difficult. In my experience most have statutory responsibilities and unless this will be a legal requirement I cannot see health professionals making time. This will mean that DLA applications/ reviews may become very slow.  I have made my comments in my capacity as a registered social care professional.</p>
EM100	15-Dec-10	<p>You are not guaranteeing the quality of life for my son who is profoundly and multiply disabled. He is at the moment living in a home and one of his greatest pleasures is being taken out in one of the home's vans which is funded through the residents mobility payments - if these are to stop for people in homes then the pleasure of going out into the community becomes impossible.</p> <p>I understand that reform is needed but you are also hitting the very people you said you wouldn't.</p> <p>please re-think this policy</p>