

Disability Living Allowance reform consultation – email responses 701 to 800

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EM701	17/02/2011	<p>1. There isn't enough paper in the world to fully answer this question!</p> <p>*From a personal perspective, I have faced physical barriers – poor building design, noisy environments, bad lighting all prevent me doing things on a regular basis. For example I avoid eating in restaurants because often noise levels prevent me from hearing and understanding speech – even sitting across a small table from my partner, whose speech I am very familiar with, I struggle to converse with him in restaurants.</p> <p>*I face attitudinal barriers as someone with hidden impairments. I don't look like I need a seat on public transport, I don't look like I need people to consider my communication support needs.</p> <p>*Things from within the body can also act as barriers. It is very hard to engage with society when one lives with chronic pain or fatigue. These things are hard to mitigate for. There is no adjustment that can be made in my workplace for days when my brain simply won't unfog, and looking at a screen makes me feel dizzy and sick.</p> <p>*I would add that a 9 week consultation period, that occurred with Christmas and New Year in the middle of it is particularly unfair, particularly given the people that most need to engage with the consultation are those that may need extra time and support to analyse and respond to such an important and complex matter.</p> <p>*2. Yes.</p> <p>*Three rates of DLA Care component recognises differing degrees of need with more subtlety than two rates would.</p> <p>*3. I can't speak for all disabled people. We have massively variant needs, and each of us finds our own ways to work around difficulties, and implement different coping strategies.</p> <p>*I can't quantify exactly what costs are impairment related, and what costs I would incur if I wasn't disabled.</p> <p>*I have tried to work out a few costs though, as illustration.</p> <p>*I use crutches to extend the distance I can walk. This is a fantastic tool that enables me to enjoy life outside my home. However, I still have to buy replacement ferrules every few months (shock absorbing ferrules that stop my wrists and shoulders becoming damaged cost about £25 per pair). I estimate this cost at £50 a year. These are not provided by the NHS, this is paid for out of my DLA.</p> <p>*I wear padded gloves to further protect the nerves and bones in my hands, the padding becomes worn and flattened through use and loses its efficacy. Cost £12 a year.</p> <p>*A small cost that I think is an interesting one is if I decide to get</p>

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		<p>a cup of coffee whilst I'm out, I have to sit down to drink that coffee. I can't walk and carry coffee at the same time as both my hands are using my crutches. I need to sit at a table or it's reasonably likely I'll drop or knock the coffee over. This means I need to drink in, which costs me more than taking away - around 40p extra, which if I'm having coffee out three times a week, every week, equals £62.40 a year.</p> <p>*Stopping off in a café also means I can rest. Sometimes this is a necessity rather than a nicety. Sitting in a calm corner means I can recover if I am in a state of sensory overload.</p> <p>*I wear trousers out very quickly, and a result of my Dyspraxia is that I struggle to repair clothes neatly enough for them still to be presentable. This means I end up buying new trousers a few times a year. I estimate I spend £40 more per year than I would were I not Dyspraxic.</p> <p>*I have bought a good quality can opener I find it easy to use. £12.00</p> <p>*I wear sturdy, supportive, lightweight walking shoes. I get through a pair at least every year. £60 per year.</p> <p>*I use a graphics tablet rather than a mouse. £100</p> <p>*I eat good quality, fresh food to stay healthy. I have limited energy levels, and become extremely tired very easily if I do not eat well.</p> <p>*I can't work full time. My job pays me enough to live on, however being limited to three days work a week means my impairment is costing me in the region of £6000 a year in lost earnings! DLA means I can afford to work part time, and still have my basic needs met.</p> <p>*4. I do not believe two levels will be nuanced enough to accurately meet different people's level of need. I am seriously concerned that people that *just* miss the criteria for higher rate support will not be supported adequately through lower rate support. Currently, middle rate care DLA means this is not such a problem.</p> <p>*5. Yes, I believe there are some conditions that without doubt increase people's cost of living so financial support should be automatically provided to those people.</p> <p>*I would include conditions such as Motor Neurone Disease, Multiple Sclerosis, Muscular Dystrophy in this list.</p> <p>*6. Essential activities are surely those that sustain life – feeding, toileting, sleeping, bathing, exercising. People should have the choice over how those needs are met, and how best they can be supported.</p> <p>*What one person considers a full and active life may be considered idle by another person, and too much to cope with by a third person!</p> <p>*7. Simply accept that many conditions fluctuate. The human body is a wonderful complex thing, it isn't a machine and doesn't behave identically constantly. And often, when the appropriate support is put in place, people's conditions are</p>

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		<p>much improved – which is the point of the support!</p> <p>*The best thing you could do would be to listen to the people that are being assessed.</p> <p>*8. No, assessment shouldn't take aids and adaptations into account because those aids and adaptations aren't always available.</p> <p>*For example, I know a man who has his flat set up with rails around his toilet, perching stool in his kitchen, front room arranged so everything is in easy reach, cupboards well organised and everything positioned low down, telephone that he can hear well. In his flat, he isn't disabled by his environment, and he needs no obvious support.</p> <p>*As soon as he goes outdoors he encounters physical barriers, and needs to ask for help, for example, taking things off supermarket shelves, sitting at bus stops to rest. If he goes to his voluntary job he has to ask for help preparing his lunch because he can't open the microwave door where he works. He can't lift their kettle safely. He can't always find a mug somewhere he can reach it.</p> <p>*Also, aids and adaptations continue to need maintenance, and continue to cause additional cost – Wheelchair users will still need to spend extra money on things like gloves, inner tubes, tyres, see my example with crutches given above, people that use assistive technology like speech synthesizers will need batteries, software upgrades.</p> <p>*Systems fail, aids break. They need to be bought again, or repaired. In the interim while the aid or adaptation is unavailable the person may incur much higher costs than expected – to pay for shopping to be delivered, or to buy take-aways, or get taxis where normally someone could get the bus.</p> <p>*9. Your response:</p> <p>*10. Currently a range of people can be, and are asked to provide information.</p> <p>*Many disabled people that have lived with their conditions for a long time are not "ill" and are not under the care of a consultant or specialist. In this type of situation I would suggest the individual is listened to, and documentary evidence is provided simply to confirm that the individual has the condition / conditions named.</p> <p>*People that live with long term health problems are more likely to have a professional relationship with a GP, and possibly consultants or specialists. In this case, it would be appropriate to ask for information from one of these sources.</p> <p>*11. - The discussion must take place somewhere where the person being assessed is comfortable, and where their access requirements are absolutely met without question.</p> <p>*- Someone applying for support is not on trial, and they are not guilty of anything.</p> <p>*- People must be free to be accompanied in any meetings.</p> <p>*12. People with long term conditions shouldn't be subject to</p>

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		<p>frequent review. Someone with Dyspraxia is never going to stop being Dyspraxic. Someone with Cerebral Palsy is never going to stop having Cerebral Palsy. To repeatedly reassess causes unnecessary stress, and will incur costs that are not necessary. *I could see a five-yearly basic renewal for people with long-term conditions being reasonable.</p> <p>*With short term conditions that may improve, two yearly review may be reasonable. But if it becomes clear after, for example, three reviews that the individual's needs haven't changed, they should be considered to have a long-term condition.</p> <p>*13. Your response:14. Your response:15. Your response:16. Your response:17. Your response:18. Your response:</p> <p>*19. Your response:20. Your response:21. Your response:</p> <p>*22. My additional comments are below, taken from a letter sent to Ms Miller. Sections in italics are from an earlier response her office sent to me.</p> <p>"As I have said, we are currently in the process of developing the detail of the new assessment with the help of a group of independant specialists. While I therefore cannot give details at this time of how the assessment will affect [REDACTED], I can assure you that it will not only take into account physical impairments but also mental, intellectual and cognitive ones."</p> <p>*I am glad to hear that mental, intellectual and cognitive impairment will be considered alongside physical impairment. I sincerely hope you also account for the reasonably common situation where someone has multiple relatively minor impairments that collectively work to make an individual moderately (or severely) impaired.</p> <p>*For example, a friend of mine has High Functioning Autism alongside Hypermobility Syndrome. Alone, each condition could be manageable (he is not severely Autistic, and his HMS is bad, but appropriate aids would give him some relief), but combined he suffers extreme fatigue which greatly reduces his cognitive ability meaning he goes into cognitive overload / Autistic meltdown on a regular basis. This further exhausts him, and makes his co-ordination worse meaning he experiences more joint dislocations than he would otherwise. (His wrists dislocate multiple times a day, shoulders daily, knees multiple times a week, hips similarly!).</p> <p>*Because he has to take high doses of anti-inflammatories and opiate-based painkillers to manage the pain from the multiple and frequent dislocations he experiences he is further impaired by the sedating side-effects of the painkillers.</p> <p>*I would be very interested to know who is in your group of independant specialists, and what qualifies them to be called specialists. Are you consulting with disabled people outside of this consultation?</p> <p>"I was pleased to read that Disability Living Allowance enables [REDACTED] to work. Currently the employment rate of Disability Living Allowance recipients is very low, I hope that out reform of</p>

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		<p>Disability Living Allowance, alongside other current benefit reforms such as the Universal Credit and new Work Programme will enable other disabled people to work and enjoy all the advantages that an active working life can bring."</p> <p>*The employment rate of DLA recipients being low is not the fault of the benefit! Being disabled make finding suitable, regular employment challenging, and instigating punitive measures to "encourage" people into work will only increase stress for those who are least able to deal with the pressure.</p> <p>*The document quoted in the DLA consultation document (Disability Living Allowance and work: Exploratory research and evidence review, 2010, DWP Research Report No. 648" (RR No.648).) later states "the main factor affecting the employment rates of disabled people is their disability or health condition" and "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"</p> <p>*Surely it isn't a huge leap of logic to surmise that the types of impairment that result in needing the levels of care or mobility assistance are those impairments that make it very difficult to find suitable work?</p> <p>*Many conditions cause fatigue either directly, or as a side-effect of medication. Whilst someone may be capable of coherent thought and carrying out complex tasks when they are not fatigued, this may only account for half the week, and it can be impossible to predict which days are going to be good, and which bad. How is an employer to make reasonable adjustments for people with this kind of issue?</p> <p>*I know that disabled people can work - I work in an office with a higher than usual proportion of disabled people. But I also know that there's a big difference between someone's theoretical ability to work, and their ability to find a suitable job where all necessary adjustments can be made.</p> <p>*"I appreciate that there are many reasons why the number of people claiming Disability Living Allowance is increasing, but we need to get expenditure on a sustainable footing.</p> <p>*Over the last decade spending on Disability Living Allowance has risen dramatically. In just eight years the numbers claiming Disability Living Allowance has risen from around 2.5 million to nearly 3.2 million - an increase of 30 per cent."</p> <p>*Sadly, human beings on an individual level don't conform to economic demand. If there are 3.2 million people that need the type of assistance DLA provides, there are 3.2 million people that need support. There won't suddenly be fewer disabled people around just because there are fewer in receipt of a benefit, but there will suddenly be fewer disabled people enabled to live their lives. There will be more disabled people living below the poverty line, suffering poorer health because they're having to choose between paying for decent food or</p>

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		<p>heating, suffering with exacerbated conditions because they can't access the support they need, because they're having to choose between some help around the house or paying for specialist physiotherapy.</p> <p>*"The inherited fiscal legacy has forced the Government to make some tough decisions about how we target resources - the Budget deficit is costing this country £43 billion a year in interest payments alone. The Government has tried to make fair choices and to protect those who are most in need."</p> <p>*I suppose subsidising car drivers by delaying a rise in fuel duty, not closing loopholes in the tax system that allow companies to legally avoid paying billions in tax, continuing giving Winter Fuel Payments to all people over 65 regardless of their income or need were all just too tough compared to making cuts that will seriously affect the lives of disabled people, who are already the most financially and socially disadvantaged group in the country.</p> <p>*I am proud to live in a country where I can (and do) pay taxes to support people that are out of work, sick and disabled, on low incomes, or out of work. I would far rather pay and risk a tiny, tiny proportion of fraudulent DLA claims going unnoticed than see the kind of changes that are being proposed by your government, and will see people that can least afford to lose out living in genuine hardship, and suffer increased ill health and decreased independence as a result.</p>
EM702	17/02/2011	<p>Hi, I am unable to answer all the questions on your web site and many disabled people will not be able to put their opinion forward because of this. I can only say that I support the MS Societies response to the changes to DLA. I have Primary Progressive MS and feel physically sick that someone I don't know will make the decision about my benefit. I should hope that any change in DLA is welcomed by the health professionals that support people with MS. My GP and consultant know that I cannot work and need help - why should some office administrator decide on my life changing decisions. Your Faithfully</p>
EM703	17/02/2011	<p>Dear Sir / Madam Please find attached the response to the DLA consultation. Please note that all my responses are in relation to Aspergers. This is the most vulnerable section of British society, it is even discriminated from autism. There is some real work that you have to do here. Kind Regards</p> <p>██████████</p> <p>*1. Your response: I was diagnosed with dyslexia 4 years ago and Aspergers 2.5 years ago so my comments are all in relation to these disabilities.</p> <p>*I am extremely upset at the IT problems you have had and the fact that you will not respond to my email. I spent hours answering this question. I typed it online and do not have a copy but I wanted to make sure that you have this information. If you have not received this can you please let me know.</p>

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		<p>*The first part of the answer concerns the government's inability to educate the UK on autism and aspergers. The discrimination that an adult with aspergers suffers as a result of the negligent NHS and local services is also a barrier. I have provided a depth of evidence to support this on the online form.</p> <p>*In addition to this, there is a poor standard of recruitment in the UK which leads to discrimination and the competency recruitment framework discriminates against the dyslexic, visual thinker. I don't think that there is a brain cell in the government to understand the implications of this. It is great for a word thinker to write competency statements in their applications and in interview to respond to competency questions, but for a visual thinker (this could be dyslexia, autism ADHA etc.) it is much more difficult, as this community find it difficult to organise thoughts in words in a succinct way. It is very stressful and often deters people from making the application. I do not apply for jobs which request these statements because I know I cannot do it well and it causes so much distress. I have spoken to other dyslexic people who find the same problem. It doesn't mean that we cannot do the job, it means that we are different and will do the job in a different way to a word person, perhaps, even better than they do it.</p> <p>*We are being discriminated because the government of this country do not recognise diversity. They think that if everyone makes an application and sits an interview in the same way, that makes it equal, but in fact that discriminates because we are not all equal. You have to do things differently to meet different people's needs. Is it appropriate to have an interview with a panel of 4 people with an autistic/aspergers person? No, it isn't, but we have to suffer this. It is the government, the public sector who do this discrimination, it doesn't happen so much in the private sector.</p> <p>*2. Your response:</p> <p>*3. I feel that I am a good extreme which gives you an idea of the difficulties. I have worked for most of my life, the very nature of my disability is that I am on my own and have no help and support. Here in [REDACTED] both the NHS trust and the Social Services have refused me support, both as a direct result of the fact that they discriminate on the autistic spectrum. They provide support for those with an IQ of 70 and below but nothing for above 70. So I have been left to work out what support I need. After a year of complaints I have been given counselling. I have been unemployed for 2.5 years and for the first year and a half I did not get DLA, when I asked the job Centre I was told it was for those with IQ 70 and below. My housing benefit did not reach the rent and I had to use the Job seekers Allowance. This meant that I was becoming desperate. I did not know what to do or where to go for help. At a point of suicide I went to Citizens Advice who said I should be on DLA and they helped fill in the form. When you are so stressed filling</p>

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		<p>in a for becomes so distressful but also as a dyslexic filling in forms is very difficult. For me the DLA provides the shortfall in my rent. Without it I would be on the streets. It is not hard to understand how people are on the streets. I need to stay in the same house to stay with the same doctor. My GP did not know anything about aspergers but I have now educated him and I don't want to start again with someone new. Also the very nature of the condition is about communication with people and dread of change. No one can see my problems and as an intelligent person I feel ashamed that I cannot do basic stuff so I won't go round telling people I can't do something.</p> <p>*4. I don't feel that the wording of this section includes the Autistic /Aspergers person. To look at me and to hear me talk sometimes you would think there is nothing wrong, but the moment I get stressed I become like a rabbit in headlights, as someone said to me. I freeze and cannot work out simple basic things to do. Because I do not have anyone to turn to for help I need the higher award so that I can buy in help when it is needed e.g. to clean my flat. Sometimes it gets on top of me that I cannot see where to start. I find cooking hard and sometimes I realise I haven't had a proper meal in a week. I have just picked at snacks, so I go out and have a proper meal.</p> <p>*5. I think that things that you will have for life should be automatic. In my case my circumstances are that I am alone and the financial benefits mean that I can live independently if I can buy in things I need as and when. It would be wrong to say based on my needs because no-one has yet identified mine yet. I have but no-one else has. I have no trust in anyone's capability in [REDACTED] and no-one cares.</p> <p>*6. I find this difficult to express in words. Who determines what is essential for everyday life? Some people have a physical struggle in life and some have a mental struggle. What is more important to the individual in life is a priority to them.</p> <p>*7. Your response:</p> <p>*8. Your response:</p> <p>*9. First of all it needs to be recognised that there is a wealth of anecdotal evidence out there that people only get the benefits if they ask. I personally have heard it said at the job centre that they don't tell people what is available to them but if they ask they will tell them and a give it to them. This is a very, very discriminatory practice by the government because you are discriminating against those who do not know about it or where to go to ask for it.*Secondly, the jobcentre staff – disabilities officer – are not educated in present government bills. They did not keep up to date with the Autism Bill. In my own case, I was diagnosed with Aspergers in November 2008 I told the Jobcentre of this in January 2009. No-one told me I could apply. I was desperate because I could not manage my housing benefit to pay the rent. In November of 2009 a friend in London went to a social worker friend and told them of my situation.</p>

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		<p>They said that I should be getting DLA. I asked to see the disabilities officer who told me that it was for those on the autistic spectrum with an IQ of less than 70. By March 2010 I was so suicidal, my last straw was to go to the citizens advice bureau, They said I should be on the DLA and promptly filled in the form with me. When you have the door slammed in your face from all directions by the public sector you have no energy left to fight. My life was put at risk because of the negligence in providing support to fill in that form. I believe that the doctor and the jobcentre should have told me about it and guided me to the CAB for support in filling in the form. At the jobcentre the moment the aspergers went into the computer system the disabilities office should have picked it up, arranged an appointment and helped me complete the form. Two failure exist here. 1) the disabilities officer was not educated in aspergers. He discriminated between a person on the autistic spectrum with an IQ of over 70 and an IQ of below 70. Pure and simple discrimination. 2) the disabilities officer sat there with his head in the sand waiting for people to come to him but if you do not know that he exists or what he does how can you go to him. I believe that these people need to be proactive and take the initiative to meet people. The very nature of my condition is that it is difficult and stressful to meet new people. People like this disability officer should not be making a decision as to whether I am eligible. In my case it was a postcode lottery. Because [REDACTED] have no education in the field of Asperger so he said no to me, but for example in Liverpool they have had a Autism/Aspergers team set up for years, so the area is educated and they will be advised that aspergers is elegable.</p> <p>*I think that there should be someone in each area who is responsible for helping people to complete the claims form. I think that doctors, jobcentres etc should be tasked with guiding the individual to this person so that everyone has a fair and equal chance of making the application. There are two issues here. 1) There is ample television evidence which highlights that people have difficulty in completing the form and those who get help get the benefits which they do not think they would get, mainly because they do not understand clearly what the questions are asking. 2) 1 in 8 people have dyslexia of some kind and those with ADHA or autism are also visual thinkers so the there are a large number of people applying who find great difficulty in completing forms. This is a disability in itself and is not clearly recognised by the government of this country. It doesn't matter what level of intelligence a person has a visual thinker will have problems in understanding what the question is asking and how to express the response in words.</p> <p>*10. Whilst I acknowledge the need for supporting evidence it is important to get the right people. In [REDACTED] there is no NHS worker, no social worker nor local services worker who has any</p>

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		<p>knowledge of aspergers. It would be criminal to get an assessment from an NHS consultant psychiatrist in [REDACTED] because they are uneducated and would say that they do not believe a person has aspergers. I know of several people who have a diagnosis from outside and then are prevented from support because these people are uneducated. GP are also uneducated so any doctor will not do you have to get a specialist an it is not about a 5 minute meeting it is about understanding an aspergers living conditions and how they survive.</p> <p>*11. For an autistic person to have a face to face it needs to be with a person who is educated in aspergers/autism because they need to understand the underlying issues and if they do not act in a calm manner when an autistic person is getting distressed they will cause further distress and anger. Their attitude will then be negative against the person.</p> <p>*12. Each individual needs to be looked at as an individual. A thorough professional assessment should be done in the beginning and reviewed upon changes in that person's life. A person will have autism for life but things will be different if they are working compared to when they are unemployed or if a carer dies and then they are left alone. They will still need the benefits but would use them for different things, e.g.if working they may need to spend more on travel (taxi)to ensure that they get to work.</p> <p>*13. You need to be a more friendly, engaging organisation that shows that you are there to meet your customers needs. You need to instil confidence in your own capability to do your job professionally and it certainly does not come across. I feel we are treated like widgets on a conveyer belt. You just send letters which generate computer statements which people do not understand and these statements bear no resemblance to the person so they are afraid to rock the boat. You need to communicate in person so that person understands. It is also important to recognise that an autistic person might not see a change in the same way that you might see it and that they are afraid to make contact with people to tell them. E.g. If a carer dies and they are on their own they may not tell anyone and miss out on a further payment because they don't see it as a change in their personal ability.</p> <p>*14.</p> <p>*15. My answer applies to the above two questions. You cannot deal with the benefits system in isolation. The public sector works in little silos. They do not communicate with each other and so the service the public receive is so fragmented. I believe that the GP surgery has a key role here. They are in the community and they know their people. They are the key people who have the documents to state a person's disability and they should be providing a service to connect patients with the right local service and social service support. It is such a</p>

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		<p>hostile environment no as I have had a hospital slam the door in my face and say we don't deal with aspergers, social services also slammed the door and don't deal with aspergers. The PCT also did the same until they were pressured by my MP. I think that funding should go to the GP practices to provide a service for all those with disabilities. They should know their patients needs and an administrative service could be set up to identify services in the area which could be accessed by patients. These services would then have to work hard to gain a place on the GPs preferred services list. This would improve quality of service because if they were not good enough the doctors should not be recommending them. An example of this is that as an aspergers person living alone I am not very good at cooking meals. I want to but cannot connect buying and having all ingredients to make. Sometimes I can go a week without having had a proper meal. I feel that I could use my DLA to find a person who will help me set up a rota for meals and just keep a check on things. I asked my GP about a dietician, but he said they don't do that sort of thing. I feel that my GP should have the information as to where he could recommend I go. At the moment I don't know who to trust or where to go. This isn't about the doctor having this information but that the practice has it and he can dip in to recommend. A person like me just gets the door slammed in the face.</p> <p>*16. You talk of aids and adaptations but for me as an aspergers person who is unemployed and living alone is that I us the DLA to make up the shortfall of my housing benefit. And can pay for utilities. The housing benefit do not see disabilities. There is a shortfall in my housing benefit and I was allowed an additional discretionary award. I was working when I moved here and I expect to work again and moving would be so distressing to me as an aspergers at such a vulnerable time when I have no job. They reduced my allowance and stopped the discretionary allowance and said that I could use the DLA to pay the shortfall. I went to my MP because I felt that I was being hit on all sides from the government of this country. They wouldn't provide healthcare, nor social services and they use a competency framework which discriminates me from getting through an interview. I have to fight each of these areas separately but there should be someone to fight them all on my behalf, so that I am not placed in such a distressful state. I went to my MP who contacted the Housing Benefit and they have now reinstated the discretionary award which I have to apply for every 3 months. My shortfall is now around £70per month which comes out of my DLA</p> <p>*17. I am not sure as I do not have them and it would be wrong for me to give an opinion.</p> <p>*18. A person like me does not know what is available as I have worked for most of my life. The DLA allowed me a carer allowance because I am alone. I would not have known about</p>

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		<p>this if the CAB had not mentioned it when I showed them the approval letter for DLA.</p> <p>*19. I think that people would fall through the net because it is common knowledge that DWP would not tell you about it and if you didn't know how could you apply. I am rejected by social services so my only means of benefits are through the DLA.</p> <p>*20. I think that all assessments should be synchronised so that all services saw the same assessment and it would only need to be done by one service That must be a cost saving by the government.</p> <p>*21. I think that you also need to look at the implications of dyslexia in completing the forms because this category of people would be so distressed to complete the form that they just would not do it. This is discrimination and does not provide equality for all in the application process I would never have been able to complete the form, even though it was the difference between life and death, not just because of dyslexia but because I had been rejected everywhere that my health had deteriorated and I would not have been able to think coherently.</p> <p>*22. I feel that you need to show a human side and not just use computer generated statements in your communication. I feel that you need to see people as individual and not just have a standard statements. There needs to be more education for the unseen disabilities e.g. dyslexia, ADHA, autism/aspergers and stop the discrimination. If you have made mistakes because of the lack of education and performance of people at the DWP, then you should accept this and make back payment. I am now awaiting a tribunal because I have requested back payment from March 12 2010 to January 23 2009 when I informed DWP that I had aspergers. You shouldn't be wasting public money on this tribunal when it is clear that you made the mistake. But what is more important is that you put my life at risk and I would be dead now if it had not been for the CAB. I feel that in the very least I deserve the back payment in compensation.</p>
EM704	17/02/2011	<p>1. Too numerous to list! The DDA and the new access rules have brought some improvements but nowhere near enough.</p> <p>*A major problem is institutional discrimination from official bodies such as the NHS and Local Authority departments. This often leaves disabled people with no choice but to finance things that they should be entitled to and that able bodied people would be entitled to.</p> <p>*The abuse by authority of the Mental Capacity act is removing the rights of many disabled people to have their own voices heard and their right to choose family members as allies in the numerous disputes they encounter with officialdom. This is further isolating disabled people and their families – again resulting in higher financial costs.</p> <p>*2. Your response:</p> <p>*3. No individual can answer this question fully as each</p>

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		<p>person's needs will differ.</p> <p>*The list is probably endless but would include such things as, higher heating costs, higher fuel costs, higher laundry costs, higher dietary costs, higher travel costs, higher costs related to equipment (don't believe it all gets supplied – it doesn't!), higher costs related to everyday life overall. Higher costs of clothing as for some people clothes are too easily ruined through their particular disability. Higher costs of needing more of some things than other people would need – oh the list goes on and on and on!</p> <p>*Then there are the silly rules and regs we have heard of like disabled people having to pay a charge for the travel costs of their paid carers getting to them – ridiculous – when does anyone else automatically get travel to work paid! We have also encountered disabled people who are expected to pay for any drinks / food that a paid carer has when taking the disabled person out shopping etc – even more ridiculous – they should pay their own way or bring sarnies!</p> <p>*4. Your response: This would depend on the eligibility criteria for each component. In some cases already it seems that their should be more rates as the most severely disabled people receive no more than people with less needs!</p> <p>*5. Your response: Possibly basing it on individual need would be a fairer concept but this would depend on how fairly the assessment process is designed and administered. For instance if two claimants have Cerebral Palsy, one can walk as his/her condition is mild and one can not walk at all as his / her condition is severe then they would not be expected to be on the same level of benefits, but the person with the milder level of CP should have access to a fair assessment procedure that accurately assesses their level of disability.</p> <p>*6. Your response: That depends on what you mean by 'support' ! IF this is an intention to impose unwanted and intrusive support workers then please bin it immediately! Disabled people should make their own choices about what support they need and how they want to live their lives – they should not be forced to fit the boxes created by paper pushers in offices who have no idea about what people really need and want.</p> <p>* DLA (or it's replacement) should remain a cash payment that enables the disabled person to make their own choices – no return to mini-buses taking people 'on a day out' one every three months!</p> <p>* If disabled people are to be enabled and empowered to live full and active lives then the benefits system needs to reflect that they are entitled to make their own choices about where they go and what they do.</p> <p>* To prioritise support to those least able to lead full and active lives you have to consider the fact that you can not fit people into pre-conceived ideas – you have to fit the ideas to the</p>

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		<p>people and give people choice.</p> <p>*Activities for every day life will differ from person to person – again you can not fit people into pre-conceived ideas - the solution must fit the person.</p> <p>*(If you offered my daughter the opportunity to go to a day centre and be patronised she would use most unladylike language in her response!)</p> <p>*7. Your response: The assessment must take account of variable conditions and so should only be carried out by people who are qualified to address these issues and who will not inaccurately complete the paperwork / reports. It is no good getting a GP to assess the mobility or care needs of somebody who is usually seen by a consultant within the speciality that relates to their condition, it is no good getting a locum with no experience of arthritis to assess the needs of somebody with arthritis. You have to get it right!</p> <p>*8. Your response: If somebody uses aids and adaptation then surely they will say so – most of them will also probably tell you that they paid for them themselves! Using possible eligibility for an aid or adaptation will not create a level playing field as we all know that getting the aids and adaptations needed is a lottery. You could not reduce somebody's benefits because they 'might' be able to get an aid that you think 'might' be useful to them – this is another example of trying to fit people into boxes – it doesn't work!</p> <p>*My daughter might benefit from plenty of aids and adaptations that nobody will supply and so we will never know! (Add to that the astronomical cost of these aids etc when bought privately and DLA simply doesn't cover it – unless you turn the heating off permanently, ignore the special dietary needs, etc. etc.)</p> <p>*9. Your response:</p> <p>*10. Your response:</p> <p>*11. Your response: This would all depend on the knowledge, ability and qualifications of the healthcare professional involved – you wouldn't ask an endocrinologist to perform brain surgery so the health care professional needs to have knowledge, qualifications and experience of the disabilities the claimant has. This should not become a fast track to an easy bonus for health staff who want some extra part time work – they have to have knowledge and experience.</p> <p>*Some people might prefer the assessment to take place at home – others might not – maybe there should be a choice on this – after all – people live in THEIR homes not A home! Being forced to accept a stranger into your home can understandably be seen as an intrusion and would be unacceptable. There are also questions of vulnerability – e.g. if the household consists of a female disabled person and a female carer then they may be wary of a strange male person arriving. Additionally if any part of the assessment is likely to be any form of medical examination both genders should be given</p>

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		<p>the option of a same gender assessor.</p> <p>*12. In some conditions there will clearly be no prospect of improvement and people should not be subjected to the stress of reviews when this is the case.</p> <p>*13. Your response: Ease of understanding will make a difference to some people. Possibly supplying a list of possible changes for people to use as a reference might help.</p> <p>*14. Your response: It might prove helpful to some people – so long as they are not misled into believing that things are automatically supplied when they are not.</p> <p>*15. This depends on exactly what form this proposal would take. For instance, it would just cause stress to force people to access advice and support that is either not going to materialise or be of no use to them as an individual.</p> <p>* 16. This vary from person to person – everyone's needs will be different and they should have total choice and control over the aids and adaptations and the prioritisation of need for each item. Many people have experienced huge problems trying to obtain aids and adaptations – this may be a separate issue that needs dealing with – for instance – ‘wheelchair services’ is a recognised swear word for many disabled people!</p> <p>* 17. Oh dear – children are such an emotive issue when it comes to disability – children should be seen as individuals and assessed as such.</p> <p>*18. Your response: No use at all apart from the Blue Badge. Improvements would need to see many things being made a right rather than current systems where people get things if ‘their face fits’!</p> <p>*19. Nothing would ever improve!</p> <p>*20. No sharing of information without the permission of the disabled person!</p> <p>*Possibly ‘service’ would save money if people were able to avoid social services and still get the things they need – the sooner such provision is taken away from SS and diverted to the choices and needs of the individual the better! Giving control to the disabled person would create huge admin and SS cost savings and make more money available directly to disabled people.</p> <p>*21. Your response:</p> <p>*22. Your response: There was a very strange section that seemed to suggest that somebody who is more able to get around in their wheelchair might be assessed as having less need than somebody who is less able to get around in a wheelchair – this is highly suspect! Is it suggesting that if Fred can get around quicker than Joe then Fred would get a lower rate of benefit? If so then this is appalling ! Fred would still have all the other problems of getting around as Joe does – he will still have problems with public transport, he will still not be able to get up the flight of steps/stairs, he will still not be able to get around public buildings that do not leave space inside for</p>

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		<p>wheelchairs to get around, he will still not be able to fit his chair through a door that is too narrow, he will still have the same level of disability that he already had.*I think there are also grave concerns about the future. Despite all the rhetoric about this remaining a cash benefit it appears that there are plenty of plans lurking to remove it and replace it with enforced and unsuitable support from unwanted and intrusive sources. This would remove choice and independence from disabled people and their families – restricting their lives to an unacceptable extent.</p> <p>*Both components of this new benefit must remain as cash payments with no restrictions on how individuals choose to use it to meet their needs. It will never be enough to meet all their needs but they must have the choice to use it to address the needs that are most important to them as individuals.</p>
EM705	17/02/2011	<p>1. : Attitudinal problems of employers and service providers and an unwillingness to remove physical barriers like steps because there is no government funding for service providers. As a consequence disabled people find it difficult to get jobs and are often on low incomes. Disability aids like wheelchairs are expensive to buy and maintain. I can't lift my wheelchair anymore so I have to have a rooftop hoist on my car that cost £4000 for what is essentially a bit of farm machinery and some fibreglass. When I had it repaired it cost me £600, most of which was labour charges of £95 an hour. Services are also expensive. I have worked hard in order to own my own home and I have to pay someone to do things like change a light bulb. Money is a big problem. I have been unable to get a full time job so I have to top up my part-time salary with my DLA in order to keep mobile and therefore working.</p> <p>*2. : The DLA should be about helping people stay independent and active in the community. The equipment I use should NOT be included in the assessment for eligibility. Because I try to keep fit and healthy I use a manual wheelchair. However, many people I know use electric wheelchairs when they could quite easily use a manual chair. Your document seems to suggest that my award will be reduced because I am trying to keep fit. How does that encourage independence?</p> <p>*DLA should continue to be non-means tested and tax free.</p> <p>*3. : Paying people to do things for me that I cannot do myself is expensive. I don't have any family so I have to pay other people to help me. Transport is a big expense. I cannot use public transport even though buses are supposedly more accessible. In reality they are not accessible if you cannot get to a bus stop; or you can't wait around in the cold and wet; or if you live where there are no buses; or if you wait for one and find there is already a wheelchair user in the space or it is full of pushchairs; or if the driver cannot be bothered to park alongside the kerb and lower the ramp. I have to use a car but the cost of adaptations is horrendous not to mention the cost of</p>

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		<p>petrol and insurance.</p> <p>*4. : I don't see a problem with having 2 rates as long as the rates are realistic and the qualifying assessment is fair and based on a person's need, not the aids and equipment that they may or may not use. The disadvantage is how do you determine who should get which rate and who does the determining. "Healthcare professionals" are not necessarily the best people to decide. I have often been at the mercy of so called "healthcare professionals" who don't understand my needs and who won't listen to me.</p> <p>*5. : The list of automatic entitlements is very small and I think there is scope to add more disabilities to this list. For example, those conditions that cannot be 'cured' or improved. I have a spinal injury caused by a road accident and, short of a miracle, there is no way I will ever walk again. To put me through an assessment every year will be costly and futile because my condition won't change unless it deteriorates through old age and/or further injury. I expect those people whose condition worsens will automatically request that their needs are looked at again.</p> <p>*6. : I don't think anyone can lay down which activities are essential as different people will have different aspirations and abilities. For me the most essential are being able to look after my personal needs, enjoy social activities with friends and to be able to work. It is not right to penalise people who try to be independent and who contribute to society. I probably face greater living costs than someone who sits back and does nothing because I have to buy more aids and equipment to keep mobile and buy more services so I can stay living in my own home. I rely on the DLA in order to work, take it away and I won't be able to afford to keep working on a part-time salary. I recently had to spend £500 having my wheelchair repaired, without the DLA I could not have afforded it and without the wheelchair I could not go to work.</p> <p>*7. : A person with a fluctuating condition still has the condition even though they may have a period of stability. They will still have the same needs. No healthcare professional can predict when the condition will be stable or unstable. Therefore, the person should have continuity of payment even through the good periods.</p> <p>*8. : Aids and equipment should NOT feature in the assessment at all. Aids and equipment are not a choice, they are a necessity. But they do not compensate for the loss of a function like the ability to walk and they do not create a level playing field where everyone is equal in their abilities. Disability equipment is also very expensive to buy and maintain.</p> <p>*I choose to use a manual wheelchair to keep fit and healthy. If I used an electric wheelchair I could go places I can't go in my manual wheelchair, I could go longer distances, I could go up hills and I wouldn't have to worry about uneven surfaces or</p>

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		<p>kerbs. But I choose to use a manual wheelchair because I believe this keeps me healthier and fitter but there are people (mainly healthcare professionals) who are advising me to use an electric chair to save my arms and shoulders. However, I can load a manual wheelchair into my car but I would not be able to load an electric one. So if I decided to use an electric chair I would not be able to drive myself, I would not be able to get to work and therefore I would lose the independence I have fought so hard to keep.</p> <p>*You can't compare people's ability according to the equipment they use. The choice of equipment is dependent on many things including how much they can afford to spend and practical issues like whether the wheelchair will fit through the doorways in the house. If you base the DLA on equipment you will be discouraging independence. What is the point of going to work and paying taxes if you are penalised for doing so. DLA should be about independence and choice, not the other way around.</p> <p>*9. Your response:</p> <p>*10. : Disabled people know their situation best. How many times have I been told by so called healthcare professionals to stand up! They just don't know what it is really like to live with a disability. In my case, it is not just about being unable to walk. I get chronic back pain, I get bad leg spasm, I have poor balance which means I cannot sit unsupported...these things affect my day to day life just as much as not being able to walk.</p> <p>*11. : Who are these healthcare professionals and what training will they have had? They can't possibly understand the full range of different disabilities or how the same disability can affect different people in different ways. It will be very expensive to pay a network of professionals covering the whole country. It is likely that they will be tasked with limiting the number of successful applications in order to achieve the 20% (or more) savings.</p> <p>*You can't expect disabled people to travel long distances for assessments especially as transport can be a big issue for some people</p> <p>*12. Your response: 13. Your response: 14. Your response: 15. Your response:</p> <p>*16. : Mostly I save up for things I need or take out a loan for larger equipment. It is not just about buying equipment there are also expensive maintenance costs especially if you have to call out someone out of hours. The little help I get from the state does not pay for the full cost of the wheelchair, I still have to find half the cost and pay all of the maintenance costs for the life of the wheelchair.</p> <p>*17. Your response:</p> <p>*18. : It is important that passporting arrangements continue especially for the blue badge and exemption from road tax and Motability. Up till now I have not used Motability for my car as I</p>

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		<p>object to having change my car every 3 years because of the extra cost that entails. I have to pay to have the car adapted, then pay to have the adaptations removed and pay again to have the new car adapted. I consider that to be very wasteful. It s time we stopped living in a throw away society.</p> <p>*19. : We would have to undergo more 'assessments' and we are already dependent on the opinions of other people or so called professionals when we make a claim. Why should we have to jump through hoops every time we apply for something.</p> <p>*20. Your response: 21. Your response: 22. Your response:</p>
EM706	17/02/2011	<p>I have only just been alerted to this consultation. The only comment I now have time for is as follows:*Make every effort to see that the procedure for application for whatever benefits that eventuate as a result of your deliberations is crystal clear, written in simple language. I suffer from primary progressive aphasia (of unknown cause) and am gradually losing the ability to speak. So far, I haven't lost any other cognitive or linguistic ability but I'm told I can expect other symptoms to follow. I'm an Oxford graduate and married to a (retired) professor of linguistics but we tear our hair and gnash our teeth at the unnecessary complexity, jargon, ambiguity and just plain unintelligible English in a lot of central government and local government publications and forms. Heaven help less fortunately- educated members of the public!</p>
EM707	17/02/2011	<p>1. Difficulty in accessing information, due to physical and cognitive impairments. Access to support services. Availability of support services. Access to adapted living aids and suitable accessible transport. Lack of disability awareness across society as whole, starting at the very top as these proposals demonstrate. Living with a disability is tiring as well as expensive. Access to shops and services. Disability discrimination, which still exists despite legislation.</p> <p>*2. Contrary to the statements in your document, DLA does not encourage people to give up work. I receive DLA and I work. I have the same job as I had prior to the devastating event that left me disabled, but it now costs me more to do my job. Also my options for extra earnings are reduced, as I cannot work more than a certain number of hours per day as I simply become exhausted, and eventually become ill if I try to take on too much. DLA enables many people to work by providing the funds to pay for additional costs, such as having to use taxis in place of public transport, or needing specialist IT equipment or furniture. Without this help many would become unable to work. If people misunderstand this then it is the responsibility of those who are supposed to be promoting and administering the benefit to re-educate them. I also think that there have been deliberate attempts to target recipients of disability benefits as 'Benefit Cheats' when the reality is rather different. Last year stories appeared in the Daily Mail, Sun, and other places claiming that £1 billion benefit payments were made due to</p>

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		<p>fraud. In fact the number of people fraudulently receiving disability benefits is far fewer than the number who are entitled to receive it but don't because they have either been put off claiming by the complicated process, or had their claims rejected because they have not understood the application process and have not provided the information necessary to support their claim, or had their claims wrongly rejected by a civil servant (not a medical professional). The DWP's own statistics show that £220 million was overpaid, due to fraud AND error in the year 2009/10, not the £1 billion claimed by the Daily Mail in screaming headlines. Against that £290 million was underpaid through error. A study by MacMillan Cancer Relief found that more than half of people with cancer who die as a result do not claim their entitled disability benefits. Any changes should not be framed in a way that would make it even harder for vulnerable, disabled and ill people.</p> <p>*3. Travel costs, paying for carers, any 'disability' aids needed in the home or workplace. Higher food costs if the person is not able to prepare meals from scratch. Extra fuel costs – many disabled people feel the cold badly, and need to keep warm. Cost of medicines. Access to shops and services such as hairdressing. When one has no option but to have all one's shopping delivered there are also delivery costs. Paying people to do things you could have done yourself were it not for your impairments.</p> <p>*4. I don't see how having 2 rates rather than 3 will help to "make the benefit easier to understand and administer, while ensuring appropriate levels of support". In fact it removes a level of support. The only motive for removing the lower rate care component appears to be a cost saving for the government.</p> <p>*5. I think there are some which should mean an automatic entitlement, for example someone who has to attend hospital for kidney dialysis 3 times a week, or terminal cancer patients.</p> <p>*6. Well I don't know about politicians but I find breathing, eating, drinking, sleeping and personal hygiene essential, so assistance with all of these must be provided as required. Access to medical care also. Assistance with travel. It is important that people are not socially isolated; simply meeting bodily needs is not enough if someone is left staring at their 4 walls every day. I don't see why I should become a 2nd class citizen because I have become disabled. I should be able to participate in everyday activities that others take for granted, such as going shopping, going to the bank, meeting friends, visiting the library or getting to work or college.</p> <p>*7. The current Work Capability Assessment used by ATOS medical examiners is not fit for purpose, and it appears that the proposed DLA assessment is going to use the same model. The short interviews allow only certain, pre-defined answers and cannot provide sufficient information about how a person's</p>

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		<p>condition and impairments affect them. The pre-defined answers seem to suggest a 'one size fits all' approach, which is completely inappropriate. The person being examined does not know which boxes the examiner is ticking on his computer. The examiner pays more attention to the computer screen than the claimant. Also the claimant is not given a copy of the assessment so does not have the opportunity to correct any misunderstandings. The fact that so many 'failed' medical assessments are appealed, and very often overturned, ought to show you that this is not working. The appeals process must be costing a small fortune.*It is also a very bad idea to pay people such as ATOS on results, giving them targets to reduce the number of people on the benefit register. The examiner should be an impartial professional with the appropriate training and experience. The interview should give sufficient time for a proper assessment to be carried out. The claimant should be given a copy of the assessment and the opportunity to discuss it.</p> <p>*8. No, as most of us have to pay for those aids and adaptations using our DLA. This can only get worse now that funding is being cut to local services and charities. Also, using an aid doesn't suddenly make a disabled person's life a bed of roses. I use a stick to walk, it stops me from falling over and injuring myself, but it doesn't suddenly make walking any less difficult or painful. As I have one useless hand and arm it also means I have to hold the stick in my only functioning hand, so I still can't carry anything.</p> <p>*9. The form should be available in formats that will make it accessible to people with visual or other impairments (such as language difficulties experience by some people following brain trauma). Help should be available with the form-filling process. Many applicants will be trying to cope with serious illnesses, so the process should be as stress-free as possible. Information about the benefit should be clear and concise and written in plain language. It should also be available in formats that will make it accessible to people with visual or other impairments.</p> <p>*10. A person's regular carer, regular doctor or consultant or regular therapists such as speech or occupational therapists. It should be someone who is familiar with the claimant's history.</p> <p>*11. What will the definition of a 'healthcare professional' be? A nurse, a senior consultant, a physiotherapist? I already have discussions with doctors, consultants, nurses, therapists etc. etc. about my health, and I don't see any point in having yet another discussion with an unknown 'healthcare professional' who may not, in fact almost certainly will not, have any specialist knowledge of my condition, and certainly will not be familiar with my medical history. I am quite happy for my doctors to provide information about me, and I feel this would be far more useful.</p> <p>*12. The frequency of review should be based on a realistic</p>

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		<p>assessment of the likelihood of changes in the patient's condition that may affect their ability, both improvement and deterioration. I believe that this has to consider the opinions of the claimants regular doctors or consultants, who are best placed to know this. The claimant should be given information about their reviews and the basis for the decision. They should be given plenty of advance notice to avoid creating anxiety and so they can make any necessary arrangements. The individual's needs should be taken into account, as they may not be fit</p> <p>*enough to travel. Assessments should not take place anywhere where there may be accessibility issues.</p> <p>*13. How will it be easier for people to understand? This has not been defined. Many people have cognitive deficits and this needs to be taken into account. Changes to a long-term condition may be slow and barely noticeable at first. There should be a clear definition as to what constitutes a change in circumstances so that people will have a clearer idea of what to report, and when to report it. The proposals make the assumption that some people will improve and become ineligible for the benefit. It doesn't seem to have occurred to the authors that many people will deteriorate as life takes it's toll on already reduced capabilities, and will need more support, not less.</p> <p>*14. Information about the benefit should be clear and concise and written in plain language. It should also be available in formats that will make it accessible to people with visual or other impairments. Information should be given on the purpose of the benefit and eligibility. What it is – who can get it – how to apply – how it will be paid – what changes need to be notified.</p> <p>*The form should be available in formats that will make it accessible to people with visual or other impairments (such as language difficulties experience by some people following brain trauma). Help should be available with the form-filling process. Many applicants will be trying to cope with serious illnesses, so the process should be as stress-free as possible.</p> <p>*15. I think this is potentially very, very dangerous. Who will give this advice and support, and what qualifications would they have? What if this advice contradicted advice given by an individual's medical team? I don't believe a person should be forced to take a course of action against their will</p> <p>*16. I buy mine; I can't speak for anyone else. There certainly should be an option to use the payment to meet a one-off cost. The individual should be able to decide for himself or herself how their payment is spent, as they are the ones who are having to live with their disabilities and they know what they need to help them.</p> <p>*17. Your response:</p> <p>*18. A DLA award can be used as evidence to access things such as a Blue Badge and accessible parking.</p>

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		<p>*19.It removes the need for yet more applications, assessments, evidence, etc, so must be less stressful and more cost effective.</p> <p>*20.As I don't receive any other disability benefits or have access to any services other than the Blue Badge scheme and a bus pass I can't really comment. I would imagine a single Assessment could be accepted as evidence for other benefits and services, but surely the only information that needs to be shared would be the fact that the individual was eligible for benefit? I'd be worried about data protection if detailed information was widely shared. An individual should have the right to decide who can have access to their information.</p> <p>*21.People from ethnic minorities should not be disproportionately disadvantaged by any changes, so it is important that information, help and advice be accessible to these people. The same must apply to people with visual impairments, cognitive deficits and mental health issues.</p> <p>*22. I, and most other people, do not believe that these proposals will "enable people to remove the barriers they face to leading full and independent lives." I think it will cause stress, misery and hardship to many of the most vulnerable in our society, and will push many already desperate people over the edge. I also think it will make life harder for people with lower levels of need, as they do not qualify for help elsewhere and DLA is the only available option. If this is removed they may develop higher levels of need as they struggle to manage without help. Alternative sources of support are fast disappearing as Social Services budgets are slashed further and further. Funding to other alternatives is being cut and many local charities are having to close facilities and withdraw assistance. The whole thing is little more than a cost-cutting exercise.</p>
EM708	17/02/2011	<p>1. : Discrimination, illness/impairment, lack of money. For example, I'll never be able to attempt a triathlon due to lack of funds. A non-disabled person who just wanted to give it a try (rather than something to take really seriously) would be able to pick up a pair of running shoes and a cheap bike for about £100 each. For me to attempt the same I'd need around £4000 each for both a racing wheelchair and a handcycle. Cutting my DLA would make me less independent, not more. For instance, if you take my mobility component I will lose my Motability car. Being a wheelchair user I can't carry my shopping home from the supermarket without a car because I don't have any free hands. One answer could be using online delivery services, except without my DLA I wouldn't be able to afford the delivery charges. If you take my DLA I have no idea how I'd shop.</p> <p>*2. : It should remain a cash benefit that people can spend however they need to. It should remain a benefit without ridiculous reassessments for people like me who are never, ever, going to get any better. One source online states that the</p>

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		<p>cost of a DLA to the taxpayer is either £51.37 or £77.33 depending on the type of medical. Working with the higher figure, to reassess all 3.2m claimants would cost £24,7456,000. That's pretty wasteful when you think of all the people like me whose condition will not improve. Especially when you take into account that people with conditions which may improve are on limited term awards so get assessed every 3 or 5 years already.</p> <p>*3. Your response: Everything is more expensive when you're disabled. I live in the centre of London but I can't travel on the tube because it's inaccessible. Taxis and driving are much more costly. I have to spend extra on food because I need to buy takeaways and ready meals when I'm in too much pain to cook. Baths use more hot water than showers but a soak in a hot bath is vital pain relief. I have to spend a fortune on medications I don't get on prescription (I'm currently spending at least £10 a week on indigestion remedies while I wait to see a gastroenterologist). I can't just buy any old shoes, they need to have a decent arch support. I can't just buy any old bra because most won't go round the large and funny-shaped rib cage that's a characteristic of my impairment. I can't just go for a free jog in the open air for fitness I have to pay to go swimming because it's one of the few fitness activities accessible to me. I had to pay a fortune for an iPhone because of its inbuilt accessibility features which other phones don't have. I had to buy a dishwasher because I can't wash up. I have limited choice in the glasses frames that'll fit on my funny-shaped skull meaning I can't just pick up the cheapest pair in Specsavers. I could go on...</p> <p>*4. : Easier to administer? Surely you should be employing people who understand the benefits they're responsible for administering. It's not that complicated.</p> <p>*Having only 2 rates for the care component would almost certainly mean people on the low rate would get shafted. (Is that where you're planning on saving your 20%?)</p> <p>*5. : Of course everything should be assessed for the individual. My mum and I both have/had (she's dead now) osteogenesis imperfecta but we were affected differently so received different rates of DLA. Person A with cancer will almost certainly have different needs to Person B who will again have different needs to Person C. Person 1 with heart disease might be quite sprightly while Person 2 is virtually bedridden.</p> <p>*6. : Surely limiting support to being only for "most essential activities" is at odds with your claim that you want to help people "live full and active lives"?</p> <p>*7. : By listening to the disabled person doing the talking. If they say "one day I can walk 300 metres but then next day I can't get out of bed," don't just tick the box on your computer screen that says "can easily walk 300 metres."</p> <p>*8. : No. Because if you cut my mobility component using the</p>

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		<p>justification “Lisa can mobilise because she's got a car” then you're robbing me of my car because I won't be able to afford it anymore!</p> <p>*Same goes for wheelchairs. A lot of people that need wheelchairs don't get them from NHS wheelchair services due to ludicrous eligibility criteria. So a lot of people have to buy them out of their DLA. If you assessed someone as having no trouble mobilising with their wheelchair thus ineligible for PIP then you're condemning them to not being able to replace their wheelchair when the current one reaches the end of its useful life.</p> <p>*9. : I'm afraid I've not filled in a DLA form since I was 16 so I can't really remember what the form was like/don't know what the current form is like. Pre-application information: I think it's already quite clear what the eligibility criteria are and what it's for. Though the idea that it's an out-of-work benefit could be quashed by the government ceasing sending out press releases to that effect... (“We want to cut DLA eligibility to promote work.”)</p> <p>*10. : The disabled person and their medical practitioners. Certainly not an Atos doctor who only met them for 20 minutes so has no idea what their life is actually like.</p> <p>*11. : The most obvious difficulty is that the Atos medical professionals you plan to use are not appropriately qualified. Like when you send a gynaecologist to assess a man on his level of deafness. Or when you send a nurse with no training in mental health condition to assess a schizophrenic. Or that all the medical staff you use get bonuses for lying and saying that someone doesn't have X condition in order to turf them off their benefits.</p> <p>*Inappropriate circumstances? I think all circumstances in which you send an Atos doctor to do a 20 minute assessment and trust them over a specialist who's been treating that disabled person for 20 years. But I believe the answer you're leading me towards is “in circumstances where an assessment may endanger the health of the claimant,” e.g. Someone with mental health problems who's likely to become suicidal over being assessed.</p> <p>*12. : I realise logic and common sense are difficult concepts to explain but they're what should be used to determine the frequency of reviews. For example: Osteogenesis Imperfecta never gets better. Ever. It's a condition that stays with you from conception to the grave. Calling me up for review in the hope you'll find me cured and can stop my benefits is a waste of money because you won't ever find me having improved.</p> <p>*13. : I know people who've reported that their condition had worsened and as a response they've had their benefits stopped entirely by an Atos doctor lying and saying that someone virtually bedridden has “no difficulty walking”. *If you want people to report changes in circumstances you have to treat</p>

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		<p>them fairly. That's the only way you'll encourage more people to come forward.</p> <p>*14. : Because people applying for benefits are so massively diverse with such massively diverse needs you can't possibly provide advice to all of them as part of the PIP process. Best to signpost to sources of advice, e.g. CAB (if there are any left after funding cuts), Independent Living Centres, etc.</p> <p>*15. : You're planning on pointing people to bank loans to fund a car rather than giving them mobility component? Isn't that highly unethical?</p> <p>*16. : Aids and adaptations are funded from a variety of sources: DLA, Personal Budgets, AtW, DSA, DFGs, etc. A true one-off cost is unlikely to ever occur. For example, you could give me a one-off PIP to buy a computer (because I can't write by hand) but 3 years down the line I'd need another one. And yet another one in a further 3 years. You could give me a one-off PIP to buy a wheelchair, but it needs maintaining and will need replacing once it's useful life is over.</p> <p>*17. : As long as you're fair and intelligent about the process (e.g. bearing in mind that children are likely to have different vocabulary when asked questions) then the process needn't be that different.</p> <p>*18. : DLA is vital in accessing other services. I don't think passporting needs improving from the current situation but it must absolutely not be jeopardised in the handover.</p> <p>*19. : I think the current quality of life disabled people experience would go down the toilet.</p> <p>*20. : I think different benefits need to keep their own separate assessment procedures because they're looking for different things. My DLA assessment is looking at my care needs and my mobility needs. My DSA assessment is looking at what I need in order to study. My IB/ESA assessment is looking at my ability to work. There is no overlap.</p> <p>*21. Your response:</p> <p>*22. : I think you need to scrap the whole idea. Rebranding DLA as PIP is going to cost money, money that could be spent on supporting disabled people. That you intend to cut the DLA bill by 20% despite the fact that by your own admission only 0.5% of claims are fraudulent says it all that these plans aren't about making benefits easier to understand or fairer, it's about shafting disabled people and decreasing our quality of life.</p>
EM709	17/02/2011	<p>1. - Financial - Accessing the correct information and support - Environmental factors - Lack of suitable social opportunities both out and at home</p> <p>*2. Your response: The passport to other benefits that it provides. This should not be dropped from the Universal Credit – people rely on these additions such as the current 'severe disability premium' and the 'carer's premium'. There should be automatic entitlement for certain groups and I feel that 3 rates of the 'care component' allow more people to access the benefit</p>

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		<p>who have lower level, but still genuine and costly, needs.</p> <p>*3. Transport costs are a big issue that we come across on a regular basis. For various reasons people I work with cannot drive or use public transport. They need to meet the costs of taxis and/or specialist community transport. Without help to meet these costs they would be unable to get out and participate in society. Transport costs are often what put people off accessing groups. Social opportunities are another cost that we find people struggle to meet. There are plenty of groups, activities and specialist centres that people can access but these generally have increasing cost implications. With local authorities tightening up their criteria for funding, people have to use their own money more and more to be able to access these opportunities. The same thing applies to carers – gaining meaningful respite opportunities or suitable custom holidays have a high cost attached.</p> <p>*Other common extra costs include; - Comfortable and discreet continence pads (the ones available on the NHS are often unsuitable) - Chiropody - Some aids and adaptations (including community alarms) - Aids for impairments (e.g. digital hearing aids)</p> <p>*4. It reduces flexibility in whose needs are taken into account. It doesn't seem that with regards to understanding two rates would be any more or less easier to understand than three, though administration wise perhaps it is easier.</p> <p>*5. Dementia should be a condition that leads to automatic entitlement as it is a systemic and terminal condition. Currently it does not lead to automatic entitlement. Any accepted terminal condition should mean automatic entitlement. Visual impairment (registered blind) should also mean an automatic entitlement at some level as the extra costs associated with this are evident.</p> <p>*6. Dignity and choice in all things are essential and being able to access the support to make this possible in all areas of daily living is vital. It could be easy to see things like continence needs, food, sleep etc. as being the most vital, but just as important is access to work, social networks, reduction in isolation, the ability to be meaningfully engaged in society. It will vary greatly from person to person. Carers could be given more support to assist those people who need it to apply and the promotion of the benefit to all groups improved.</p> <p>*7. In cases of variable and fluctuating conditions it should be accepted that the condition exists and the 'worst' day taken account of. A fluctuating condition should not exclude someone from an entitlement to DLA. If it is necessary for the person to see a medical practitioner then they should be able to arrange to see them when their condition is at its most disabling, as this is what they are applying for support with.</p> <p>*8. The assessment should provide advice on accessing aids and adaptations and should take account that although</p>

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		<p>generally they may be felt appropriate for that condition this may not always be the case – for example someone with dementia could have extreme difficulty learning how to use a new aid.</p> <p>*9. The form should be more open ended. Instead of multiple pages and tick boxes with confusing questions about speed, distance etc. There could be a few basic questions to establish general conditions and eligibility and then a space for the person to state generally how this condition affects their daily life, with examples to prompt them. There should be other ways for a person to complete the assessment – e.g. jointly with a care needs assessment from social services, verbally etc.</p> <p>*10. This would surely depend on the nature of the illness/impairment that the person was claiming for. A carer could easily provide good quality evidence, support workers, family, even colleagues...those who know the applicant best. Medical evidence could be relevant also, varying on the condition, but it should be accepted that the expert will generally always be the applicant.</p> <p>*11. This is beneficial if it cuts down on the form filling currently required and it could allow the person to express verbally the limitations of their condition and also think about what they can do, rather than focussing completely on negatives and can't do's as the current form does. In this way, and if carried out well, it could be a positive experience for the applicant.</p> <p>*Difficulties could include this being a daunting experience – applicants might find visits to or from a doctor intimidating and stressful, especially if it is someone they haven't met before. The doctor would not know the ins and outs of the applicant's life and would be looking perhaps too medically at the condition and its effects. It may also mean that if a person has a fluctuating condition they are seen on a 'better' day rather than when they really are struggling and require support.</p> <p>*It may be inappropriate to subject someone with dementia to a healthcare professional they do not know visiting them – this could be distressing, especially if don't have full insight into their condition. The same could apply to people with mental health problems.</p> <p>*12. Cases should be reviewed depending on the nature of someone's impairment/condition. It seems unfair to subject someone to a review when they have a long term but stable condition that is unlikely to change. However, if they have a condition that is likely to deteriorate then the reviews should be set at the generally accepted rate of deterioration where possible. If a person is deteriorating but already receives the highest rate of the benefit then this should obviously negate the need for a review.</p> <p>*13. Your response: Advertising the need to report changes – the benefits to the claimant of doing so and the consequences if not. Public advertising that most people are able to access –</p>

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		<p>e.g. television – would seem the best way.</p> <p>*14. - Employment* - Planning for the future* - Legal, money and housing advice* - Services they can access – local and national* - Condition specific information*It would be very helpful if this were provided as part of the claiming process, as long as it did not repeat advice already given. It would be best if it could be given verbally in a 1-1 session rather than sent out in an information book or similar.</p> <p>*15. It should be an individual's personal choice whether to access advice or support or not, as long as they have capacity to make that decision. The information and chance to access advice and support should be given, but in no way should it be a requirement or stipulation - and benefit should be awarded regardless of whether it was accessed or not.</p> <p>*16. In my experience people accept that Disability Living Allowance is to meet additional costs such as aids and adaptations and use this to fund them. If there are large one off costs that can't be met through income and savings then trust funds are the alternative option. A one-off payment of PIP could help in this way, although this has the implication of then leaving people 'short' in coming weeks/months. If there was a way to access an additional component for a one off cost, or to use a lump payment as a 'loan' repayable out of benefit at an ongoing, affordable rate, then this may work.</p> <p>*17. N/A – I have decided not to answer this as I do not work with or have children and therefore feel unable to answer accurately.</p> <p>*18. It has been an important passport benefit, but it is not widely known amongst claimants I have worked with that it is one. This should be more clearly made known and perhaps a more automatic passport should happen (e.g. information sharing should increase).</p> <p>*19. This is a real fear for people as the passport to other benefits and services makes lives easier and more fulfilling. Without the additional support that is currently offered by the benefits and services (e.g. severe disability premium leading to entitlement to Pension Credit, leading to entitlement to Housing Benefit and the recent Warm Front schemes and Blue Badge scheme as examples) people would have a much lower quality of life and less independence – an outcome opposite to the one wished for. In extreme cases loss of passport to other benefits and therefore loss of income could lead to loss of life.</p> <p>*20. The person would need to give explicit consent, but referrals could be made to appropriate support organisations, including in the voluntary sector, and to a care needs assessment from the local authority if required.</p> <p>*21. Not known.*22. N/A</p>
EM710	17/02/2011	<p>1. Help with independence and understanding of complex disabilities. Being allowed to be independent. The proposed new reforms threaten to take that very independence away.</p>

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		<p>*2. All levels of DLA should be kept and catered for. DLA is not broken and therefore does not need fixing. What the government interprets as disabled just to reduce costs is preposterous.</p> <p>*3. Transport, 24hr Care, Special dietary requirements, Care Assistants, Housing, Cleaning and cooking assistants. Getting about.</p> <p>*4. No it won't. What is needed is a more transparent way of deciding if DLA is applicable. There is abuse potential by decision makers if they have only 2 decision criteria to choose from. A lot of people with disabilities not in the categories will have their claims dismissed.</p> <p>*The disadvantages of this are peoples lives being shattered, Carers allowances being taken away, making it difficult for disabled people to cope without this help. As above, no middle ground if you don't fit the criteria.</p> <p>*5. Ideally both, but if I had to choose. All claims should be based on the individual needs and circumstances.</p> <p>*6. You don't prioritise it, as above question.. It should be delivered on the needs and circumstances of the individual applying.</p> <p>*7. By not having an assessment that's doomed to fail. By using the current system using the claimants Dr's and specialists, rather than a private company with a reputation of failing the ESA and IB system with obvious flaws.</p> <p>*8. Your response:</p> <p>*9. Most of the questions are silly on the form, asking how long does it take for this, what would you do with that, how many hours of the day etc. Nonsense. Perhaps a guide to filling the form in or allowing a trained advisor in the job-centre to assist people with the forms, instead of having to rely on charities who are already swamped with the your failed ESA system.</p> <p>*You ask how you can improve the information and who is likely to qualify.. This must mean you have no intention of assessing people on their individual needs and circumstances.</p> <p>*10. Clearly the best people to provide evidence of their Disability (not Ability) are the people treating them. The GP and specialists, Occupational Therapists and CPN's and not someone from Atos. This is not ESA, it's DLA. The sooner you realise this, the sooner you will realise this change is not going to fail just as ESA has.</p> <p>*11. No benefit whatsoever in a face to face discussion. There are already complaints and issues in this process, where these people are coming into peoples homes and lying, making false reports. The difficulties will be claimants with fluctuation conditions being assessed as ok, If this is allowed. The difficulties will also be privately hired advisor who knows very little of the disabilities making uninformed decisions against health professionals who specialise and are trained in the field of disability. Other problems will be further appeals jamming the</p>

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		<p>Tribunal service and DWP just as ESA is.</p> <p>*It would be inappropriate if people with severe mental health issues are asked to justify themselves. This is a real bear bug and Atos staff have no proper qualification in this field. This could cause real danger for the healthcare professional and the claimant, I know if I was asked an inappropriate question or the HCP said something to contradict me or my specialist team. I would probably see them as a danger to myself and attack them.</p> <p>*12. Again, this should be advised by the specialist dealing with the health of the claimant in mind and not a bureaucratic decision. Also people that made to go through Tribunal should be left alone for the duration of the order of the Tribunal.</p> <p>**Also, if a claimant is requesting a review for further assistance, then they should not be at risk of removal of their reward until their award date is up. This is a well known ploy by the DWP to create a real barrier for people using fear.</p> <p>*13. As above, people are in fear. If you take the fear away. Claimants might feel they can be more open. Perhaps a letter every 6 months asking if anything has changed.</p> <p>*14. Your response:</p> <p>*15. Your response:</p> <p>*16. Your response:</p> <p>*17. None, all claims should be looked at on a personal needs and circumstances surrounding the application.</p> <p>*18. Very important, by making this a 2 tier proposition a lot of people will lose housing, carer and the extra support. Losing these will lead to untold tragedy.</p> <p>*By listening to the people involved.. Perhaps setting up committees that you actually listen to rather than ignore.</p> <p>*19. You would have blood on your hands, there have been threats posted on the internet of people taking their own life if this comes about. People losing their freedom to choose, to live the way they want to live. Vulnerable people forced to share properties with junkies, homeless and others.</p> <p>*20. None, you don't need to change it..</p> <p>*21. Your response:</p> <p>*22. You have committed to reduce this by 20% using the excuse of a "Barrier to Work" and Fraud before any medicals, which says you are going to be ruthless in this reform.. You have lied to the British Public saying DLA would be protected under the cuts and then distorted the real figures and waged a media war on the disabled to allow this reform to take place. This exercise should be dismissed as a matter of urgency. You have dismissed the feedback of your own consultancy and provided no evidence of your participation of consulting charities who know the real impact of what you are doing. This will cost you power and I and millions of others can't wait for the next election.</p>

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EM711	17/02/2011	<p>1. Having MS means my life has been taken away. I was diagnosed 15 years ago. I would not even think about claiming DLA, why? I felt ashamed having to ask for help. So pride is destroyed. But after 10 years I filled in the form, I got both parts awarded. Not being able to work, and not claiming anything else apart from DLA money is a huge factor. I have to pay for many extra things due to being crippled with this god awful disease.</p> <p>*Being shouted at in the street... being called a p*** head, or smack head... not very nice at all. So ignorance is a huge problem.</p> <p>*2. A far as I can see DLA is doing the job it was set out to do.... Helping disabled people get through their daily struggle.</p> <p>*3. Heating ready prepared food. Extra clothing. Washing and drying clothes, extra baths.... All due to bladder having a mind of it's own. Not able to walk anywhere, so my mobility car is my lifeline. Before MS I could walk and run miles. Prescription charges for all my drugs.</p> <p>*And making my home easier to get around with rails, and such. Walk in shower... which I can't use on my own.</p> <p>*4. I can see more people losing their benefits with the changes</p> <p>*5. Any that have no cure would be a start. And those who have DR and specialist reports. ATOS re testing, and re testing certain people surely just costs more money.</p> <p>*6. Individually, I suppose</p> <p>*7. By using the appropriate medical people to assess the claimants. And NOT using ATOS who have been programmed to right rubbish, tick box's that have no bearing on the poor person sat opposite them.</p> <p>*8. I'd have to say NO, at the end of the day the person still has a struggle, and even accidents that would not have happened but for their disability.</p> <p>*9. • How could we make the claim form easier to fill in? BY asking one question once, and not asking the same question 3-4 times.... It makes the form very long, it even made me cry.</p> <p>*10. GP and specialist.</p> <p>*11. Face to face, as long as the person is a specialist in the claimants disability. Home would be best. Not knowing where and what you may be about to face in a strange place is frightening.</p> <p>*12. Different reviews for different conditions.... I have MS, will never get better. So can't see the point of putting me through stress every 12 months... plus there is the cost.</p> <p>*13. People are already able to identify, and report changes in the disability they have suffered for years, Giving the payment a new name just creates more red tape and anguish.</p> <p>*14. People should be encouraged to provide a range of information to support their claim. If the information provided is</p>

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		<p>comprehensive enough for a decision to be made then they may be able to avoid unnecessary assessment interviews</p> <p>*15. Your response:</p> <p>* 16. I currently use my DLA and don't see why it needs to be changed</p> <p>* 17. Your response:</p> <p>*18. DLA has been a godsend to me, helps pay for the things that healthy people do for them selves</p> <p>*19. All I see here are more test, more assessments and more stress.</p> <p>*20.OH intimate and personnel details to be shared by been more people. I would hate that.</p> <p>*21. Your response:</p> <p>*22. DLA is my life line, it gives me a little independence, I can get to the local shop, the DR, the hospital. Visit family. Ect.</p> <p>* I only venture out once or twice a week, but my mobility car gives me a little taste of life, company and even a chance to look at the trees and breath in some fresh air. Otherwise I would spend my life looking at four walls.</p> <p>*Just the though of having my DLA taken away fills my eyes with tears, I would not be disabled but totally crippled without it.</p> <p>* Mr Cameron of all people should know how important DLA is to a family with a disabled person. There again my Husband works 70 hours a week and only brings home £1600 a month, NOT and MPs salary.</p> <p>* I can only plead with the government, not to keep being so cruel to us unfortunate disabled people.... We are not scroungers, we didn't choose to become ill.</p>
EM712	17/02/2011	<p>DLA is a lifeline for so many disabled people and gives them their independence, a reason for being, and the will to carry on living. unless you are disabled, you wouldn't understand. My DLA is everything to me, and although i am under four hospital consultants who monitor my progressive disease regularly, i believe that DLA is still fit for purpose. "If it isn't broke, don't fix it" brings to mind, and it's due to a VERY small minority of people who have abused this vital benefit, that the government has decide to penalise the majority of honest people. Nearly all disabled people have been awarded DLA because of vigorous health checks, with many top health officials, consultants, Gp's and their medical records cross checked and checked again.*DLA is one of the hardest benefits to claim as the forms are so complex, personal, and the applicant must have the medical reports. The abolition of this vital benefit in my opinion will result in an increase in suicides and lack of engagement in society of disabled people. (social exclusion). thank you, [REDACTED].</p>
EM713	17/02/2011	<p>1. : Lack of knowledge about their capabilities. Insufficient funds to provide specially adapted equipment that may be required.</p> <p>*2. : I believe that the current level of provision should continue.</p> <p>*3. : We have used the DLA received for our daughter to fund</p>

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		<p>additional speech and language therapy and to pay for our travel costs from Glasgow to Oxford each month to attend speech and language therapy appointments. In fact, the DLA monthly payment has not covered the costs of this in full. We have also paid our travel costs to attend a clinic for hearing impaired children in Los Angeles. We also incur additional costs each month to attend necessary appointments. One parent now works part-time to ensure that our daughter attends all the necessary appointments and so our families income has reduced as a result.</p> <p>*4. Your response:</p> <p>*5. : Yes, I think there should be a recognition that certain conditions or impairments will significantly limit an individual's quality of life and that person may need a high level of extra care, adaptations or equipment.</p> <p>*6. : I think communication and mobility are essential for everyday life.</p> <p>*7. Your response:</p> <p>*8. Your response: Yes, my daughter has two cochlear implants to allow her to hear and I think aids such as those should be included.</p> <p>*9. Your response: I found the DLA claim form very repetitive and the same information had to be supplied in a number of different sections and I think that could be improved.</p> <p>*10. Your response: Our hospital consultant or cochlear implant centre would all be able to provide an assessment of our daughter's ability.</p> <p>*11. : From my own circumstances, this would bring neither benefits nor difficulties. My daughter does not have a condition that requires assessment. She is deaf and there are no grey areas.</p> <p>*12. : I think that if an individual has an condition at birth that will neither improve nor worsen then there is little need for their case to be reviewed. However, not all cases of hearing loss fall into that category but our daughter's does. She is profoundly deaf and that will not change.</p> <p>*13. Your response:14. Your response:15. Your response:</p> <p>*16. : We have not yet required any significant aids or adaptations. However, our daughter will need a wireless FM system when she starts mainstream school and that may not be provided by our local authority and so we may choose to buy this equipment for her. The cost is approximately £1500 and it would be helpful to obtain an 'advance' on DLA and forgo the normal monthly payments to fund large items of expenditure such as this.</p> <p>*17. Your response:</p> <p>*18. Your response:19. Your response:20. Your response:21. Your response:</p> <p>*22. : I would be very disappointed and angry if our daughter's entitlement to DLA, or its replacement, changes as a result of</p>

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		these proposals. The simple truth is that we are financially worse off as a family as a result of her disability. One parent can only work part-time and we have spent a large amount of money to obtain access to specialist speech and language therapy for her. We would be devastated if the financial support that we receive for her was withdrawn.
EM714	17/02/2011	<p>I am lifelong disabled. Always have been and always will be. Specifically I have cerebral palsy (CP) and use a wheelchair 95% of the time. I'm able to stand and take a couple of steps, enough solely to move between bed, wheelchair, toilet, powerchair etc. I also have clinical depression and anxiety. This was not caused by my physical disability but is made much worse by it. I was diagnosed with this in 2003 and have been on treatment for it almost continually since then. I have many concerns about DLA reform.</p> <p>*As someone who is lifelong disabled I've been in receipt of DLA at the rate of Middle rate care and Higher rate mobility since DLA came into being. There is no cure for my CP which means I'll never improve to a state where lower levels or no DLA is needed by myself. CP being a static condition also means that there is little chance of my condition becoming such I require higher levels of DLA. As such I have an indefinite award. That doesn't mean it's a permanent award, it just means that they recognise my circumstances are such they need not be reviewed regularly.</p> <p>*I am concerned the greater impact of these proposed changes hasn't been assessed correctly. I live in Oxfordshire and in 2007 my support from Social Services was withdrawn as I wasn't considered to have high enough needs. Since then the criteria have become even stricter. My DLA has enabled me to continue living alone. It means that I can pay for a cleaner to come once a fortnight and mop my floors, change my bed and clean the kitchen/bathroom. The rest of the time I live in a very messy house I have no choice. It pays for extra washing because I'm incontinent and also because sometimes my clothes catch on my wheelchair and get dirty quickly (and sometimes for extra clothes because they rip). It pays for new batteries for my powerchair as I have no other form of out the house independent mobility but don't qualify for one of the NHS. For heating as I get cold easily. Slightly more expensive foods that come in packets I can open without help and things which are low effort to prepare. If I was to lose my DLA I would have to go back to social services and they would need to find that help for me, something which would likely cost more than the DLA I receive each week.</p> <p>*My family (parents and younger brother and sister) all work full time. They'd have to find a way to help me out much more than they already do. I'm not being melodramatic when I say they would likely end up having to do all of the support that DLA allows me to arrange for myself. Doing that on top of full time</p>

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		<p>work would be very difficult. My mother runs her own business which would likely suffer if we found ourselves in that situation. Surely that isn't good for the economy?</p> <p>*Then there would be the increased cost to the NHS. My family wouldn't want me to feel guilty or like a burden but it's how I would feel. I'm 29 and I'm independent, but I'm really scared I'll lose that. That's making my mental health problems worse – I had a panic attack yesterday about the possibility. If the situation becomes a reality it's very possible my medications will need to be increased at a higher cost to the NHS. I'd also no longer be able to afford repairs and maintenance on my powerchair so would have to go back to the NHS for reassessment there. Parent and other family carers also have a high level of health problems due to their caring responsibilities, again another possibly increasing and likely high cost to the NHS.</p> <p>*Currently I live in a fully adapted flat which I rent from a housing association. It was designed for a wheelchair user as it was built. Without my benefits and the support they provide I could face having to give up my flat and move back with my parents. I've never lived in the house they currently live in and it's not suitable for my needs. A disabled facilities grant or similar would be needed to adapt it, another cost which DLA helps avoid in my case and I'm sure in many others.</p>
EM715	17/02/2011	<p>Dear [REDACTED] and Colleague in the DWP Please find attached my feedback to the current DLA/PIP consultation document.</p> <p>* Thank you for noting my feedback, and I trust my comments will be included.Regards</p> <p>* PUBLIC CONSULTATION ON DISABILITY LIVING ALLOWANCE REFORM</p> <p>*I have been a recipient of Disability Living allowance since its inception in the early 1990's and have greatly valued and appreciated this welfare benefit. I am now completely blind and rely heavily on my DLA for a number of day to day activities, such as paying for taxis, specialist daily living equipment from the RNIB, paying for domestic help and eating out due to the difficulties of cooking. I am very concerned to read of the proposed alterations to the Disability Living Allowance and the proposals to move to a Personal Independence Payment. I have read through the Government's consultation document and would like to submit the following comments as an individual blind person. Thank you for noting these comments.Regards*To answer the questions in the consultation document in Chapter 2</p> <p>*Question 1 Whilst the DDA Act of 1995 and the subsequent Disability Equalities act of 2010 have gone some way to addressing how people with a disability can participate in society and live full active lives there are still some problems and barriers. Public awareness and acceptance of disability in my experience is a lot more positive than years ago, but full</p>

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		<p>participation and access to local services and facilities can still be very difficult in some areas.</p> <p>*For instance, share streets with traffic and pedestrians in certain parts of the country causes visually impaired people a lot of difficulties and means additional costs of taxis and help from others is often required.</p> <p>*Navigation around increasing use of shopping malls is extremely difficult for many visually impaired, and the lack of audio navigation aids makes shopping very difficult in such situations.</p> <p>*Public exhibitions such as galleries, museums and indoor displays are improving on accessibility, but often sighted help is still required to access them, especially where there is a lack of audio or Braille interpretation.</p> <p>*Many barriers have been broken down with increasing technology and the access through synthetic speech to the internet, but this is very expensive for me as a blind person, i.e., my speech programme costs £600 and a basic 40 cell braille display costs £4000. Specialist speech and Braille laptop computers are also available, but several times the cost of a conventional laptop brought by a sighted person on the high street.</p> <p>*More daily living aids are now available from such suppliers as the RNIB, which again enable me to live a more active life, but again there is a lot of additional costs to this, i.e., a talking voice labeler for packets of garden seeds costs £60 or a Braille dymo gun costs £30 and £1.70 for a roll of the Braille tape.</p> <p>*Question 2 I agree with all the aforementioned elements in the retention of these components from DLA to the PIP.</p> <p>*Question 3 Please see my comments in question 1</p> <p>*Question 4 People with a disability have a huge variation in needs, not only across all disabilities but within one particular type of disability. To this means I think there needs to be more than just 2 rates for each component. to accurately reflect the respective amounts people require.</p> <p>*Question 5 I think the benefit should be based on the individuals need and circumstances.</p> <p>*Question 6 ?</p> <p>*Question 7 I think the best way of taking account of variable and fluctuating conditions could be carried out at an assessment process. In the case of visual impairment I think it is important to find out how light conditions, unfamiliar surroundings and an individuals health affects their sight levels. Confidence is also an important factor and this needs to be included in the assessment process.</p> <p>*Question 8 Yes I feel very strongly that the aids and adaptation should form part of the assessment process.*I think the following should be included under aids and adaptations for a visually impaired person extra Lighting, especially in the kitchen High contrast markings around door frames and key</p>

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		<p>holes Railings and where appropriate tactile way finding markings in ones home Adapted items of equipment such as talking microwaves, computers, freeview boxes, mobile phone and scanners.</p> <p>*Question 9 Welfare benefits application forms are generally very difficult to complete, and often require the help of a trained specialist to successfully complete in order to be awarded a benefit. One suggestion to make it a more positive experience I think is to ask people about their length of disability, and what they are actually able to do instead of what they can not do. Maybe include questions on lifestyle, leisure and social activities they like to do and what difficulties they encounter with undertaking these due to a visual impairment.</p> <p>*Question 10 I think a certificate of visual impairment is sufficient evidence of visual impaired and either an Ophthalmic consultant or a qualified rehabilitation worker for visually impaired people is the person best placed.</p> <p>*question 11 A health care professional MUST have good knowledge of disability, but there are so many different disabilities that it is impossible for one health care person to have knowledge and know about all disabilities. This is where a rehabilitation worker for the visually impaired should come in and I think it is important for this to be done face to face with an individual blind or partially sighted person in both their home on familiar ground but to take into account what it is like for that person outside their familiar surroundings.</p> <p>*Question 12 I do not feel it is necessary for visually impaired people to have regular reviews, as the very nature of sight loss is sadly usually one of further sight loss, especially with the aging process.</p> <p>*Unless an individual visually impaired person notices a further drop in their vision I think it is inappropriate for reviews to be considered, as the level of support the person requires will continue throughout their life and the extra financial cost incurred will continue and remain constant if not increase.</p> <p>*Question 13 Maybe an easy to remember phone number or email address could be used.</p> <p>*Question 14 Information on local services for the visually impaired in their area. Clear clarification on what the benefit can be spent on and how long the award is for.</p> <p>*Question 15 ?</p> <p>*Question 16 Should there be an option to use Personal Independence Payment to meet a one-off cost?</p> <p>*Yes, this I think would be really helpful, and specially in the field of technology.</p>
EM716	17/02/2011	<p>Dear Sirs Please find the attached which is self-explanatory and I ask that it be taken into consideration as part of the Consultation process. Yours faithfully</p> <p>*A Response to the Disability Living Allowance Reform Green Paper 2010 by [REDACTED], an individual.</p>

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		<p>*Introduction</p> <p>*I write this from both a personal and professional perspective. As a family we are no strangers to the long term effects of serious illness. As an individual I have multiple disabilities including Spondylosisthesis, Spondylitis, Spondylosis and Lordosis of the spine. Accident related injuries further caused multiple fractures of my back and a severely damaged left leg and knee. Chronic osteoarthritis invades virtually every facet of my body, Chronic Fatigue Syndrome, Diabetes and 'incurable' cancer namely Non-Hodgkin's Lymphoma amongst others are just some of the daily health conditions I contend with.</p> <p>*My husband has diabetes, spine and other bone/joint related problems predominantly caused due to injuries sustained during his frequent and long term status epilepticus, which is the most serious form of epilepsy an individual may suffer from.</p> <p>*Therefore, over the years we have received invaluable support from the Access to Work Scheme, Disabled Student Allowance, and Adult Social Services, live in Housing Association Supported Housing and totally depend on our respective Disability Living Allowance awards so we may lead the most dignified, full and independent lives possible subject to our health imposed limitations.</p> <p>*From a professional perspective I have been involved with those affected by disability for over 20 years. This has been as a specialist, academic committee adviser, consultant, academic lawyer and as a student. Social Security law and Disability Rights have been at the heart of my research interests at both undergraduate and postgraduate level culminating as the key focus of my Ph.D. thesis.</p> <p>*I, therefore feel that I am well placed to voice my personal opinion in this arena.</p> <p>*Question 1 Disability costs (1) therefore by denying this group the upmost financial assistance you are precluding them from participation in society and being able to lead more independent lives. Legislative innovation per se does not eradicate social attitudes to alleviate the daily difficulties that disabled people face every day, indeed examples of disability hate crimes are an example of this (2).</p> <p>*In addition to which, investment in awareness training for those working within the DWP is essential as ignorance has been apparent particularly with regards cancer claimants (3).</p> <p>*The new PIP needs to ensure that the variables of disability are encapsulated in its development and that the actual substantive framework will be flexible and supportive to mirror these inconsistencies.</p> <p>*Question 2 DLA is excellent as a non-means tested, non-employment-based and non-contributory based benefit and also brings credibility for support through the Access to Work Scheme, Adult Social Services Support and other services as necessary.</p>

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		<p>*I would argue that those with conditions that presently have automatic entitlement should remain but this should be extended to include those undergoing cancer treatments with a waiver on any preset 'qualification periods' for this group. This could be implemented on similar lines to the present Employment Support Allowance rules, whereby certain cancer treatments may preclude a claimant from certain prerequisites in claiming this benefit as per the present definitions in the Employment and Support Allowance Regulations 2008.</p> <p>*In addition to which, those who are classified as terminally ill under the present six-month rule as defined under the Social Security Contributions and Benefits Act, Section 66, Subsection 2 (a) be aligned with the 12 month rule as prescribed by the General Medical Council (4).</p> <p>*The minimum qualification period of three months should remain in order to ensure that those living with chronic conditions such as lymphatic cancer are enveloped and supported especially through treatment periods. The possible extension of this minimum period to 6 months would have a huge impact on this vulnerable group, and I speak here from personal experience.</p> <p>*It is also imperative that the three levels of care remain so that clear distinction can be drawn between such tests as the hypothetical 'cooking test', minimal personal day care, and further support and attention in both the day and night care context. Higher rates of care it is assumed would remain therefore it would be those affected in the lower ranges that could be ultimately precluded from qualifying although the outline in the Green Paper is too sketchy to confirm this.</p> <p>*Question 3 As regards extra costs associated with disability then whilst my list is not definitive the overall higher costs of living include care needs, dietary needs, greater utility bills than the average household due to the amount of time spent at home and my lack of resilience to the cold. My conditions also create additional washing need in both laundry and a personal sense and I cannot sleep for more than a few hours due to pain thus more electricity is used especially at night when others would normally be asleep. Additionally, due to my lack of mobility and medication I gain weight easily and have to buy larger sizes of clothes and therefore these are more expensive plus I need to buy lightweight good-quality footwear. Further to which as my gait is ungainly due to my disabilities even with the support of walking aids my footwear life is much shorter than average.</p> <p>*Other miscellaneous costs may be incurred due to my numerous visits to health professionals and my general low immune system plus my lack of mobility means I cannot utilise such schemes as 'park-and-ride' and therefore must pay for expensive town parking, or hospital parking fees but very often also find I have to pay for taxis where other options are not</p>

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		<p>viable for me due to my disabilities.</p> <p>*Shopping for all items including food has to be done online as I am unable to personally shop elsewhere, thus I have the additional expense of having to gain access to the Internet, and running/owning a computer. Purchasing necessary items albeit clothes, mobility accessories or food are traditionally far more expensive to buy in this manner and they ultimately include delivery charges.</p> <p>*Question 4 My comments are as outlined in Question 2 as I can only foresee difficulties with this suggestion especially if a proposed point's assessment similar to the Work Capability Assessment is applied. The problems of which within the Employment Support Allowance are already legendary (5).</p> <p>*Question 5 Please see my response as part of my commentary in earlier Questions for automatic entitlements. However, for other types of assessments these must be undertaken subjectively as general entitlement is not an objective platitude. Disabled people are individuals who will never neatly fit into appropriate generic tick boxes and as such necessitate their own medical team information to be utilised fully in order that appraisals are specific in nature to meet individual needs.</p> <p>*Question 6 The suggested 'focus on the ability of an individual to carry out a range of key activities necessary for everyday life' with 'activities related to an individual's ability to get around, interact with others, manage personal care and treatment needs, and access food and drink' does not fully reflect the rationale that a health condition can have a profound impact on an individual's independence.</p> <p>*The process is a holistic one underpinned by drawing on evidence from carers and other support services in addition to all patients medical health teams. It has to be a subjective assessment not an objective tick box exercise which fails to recognise all the issues at stake and therefore gives an illusion of possible needs only.</p> <p>*For example, my husband may be able to attend to his personal care needs, or cook a meal but if he has a seizure during any of these activities then he could suffer serious personal harm. Additionally, I may be able to pull on my own socks slowly and painfully with an appropriate aid but would then be subjected to chronic pain, discomfort and fatigue which may take a number of hours to recover from. Hence disability is too personal to attempt to give it generic labels and individuals need assessment and input from those who have a distinct comprehension of real needs for everyday life.</p> <p>*Question 7 DLA awards are made on a fixed or indefinite period (6) and therefore are always open to the DWP to reduce or stop the award (7). In addition to which there are also powers to make 'periodic enquiries' to all claimants on all rates of DLA including those originally awarded 'for life' entitlement apart</p>

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		<p>from some exempt groups.(8) Thus from this premise there is already adequate provision to police awards of this nature and it is sensationalistic to suggest otherwise.</p> <p>*This process however, could be supported by firstly accepting that chronic health conditions rarely improve, or if this is the case then that improvement would not be recognised immediately. Therefore an integral part of any assessment process is the medical information obtained from the claimants own specialist team. It would be naive to expect that a 'health professional' could possibly hold the necessary expertise to deliver a fair and all-encompassing triage of the patient's needs. Hence, as an example I would not expect anyone other than my Oncologist and Clinical Nurse Specialist to be totally au fait with my treatment regimes, the side-effects, and the long-term health implications. This is especially in light of the fact that Lymphoma is such an individual disease.</p> <p>*Question 8 Aids and adaptations do not relieve the person of their disabilities nor grant them a whole range of 'abilities' so to suggest that these should be taken into account undermines an acceptance of any fundamental change to an individual's lifestyle. See also my comments in Question 6.*Whilst it may be accepted that for example under the hypothetical 'cooking test' of DLA some aids and adaptations may be reasonable this by no means accounts for a required degree of dexterity, mobility or supervision to use these safely as is recognised and documented in a plethora of case law (9).</p> <p>*In general terms with regards obtaining both aids and adaptations very much depends on the Adult Social Services budget and the designated area that the claimant lives within. On a personal note I found huge differences recently between North East Derbyshire and Rotherham Metropolitan Borough Council Adult services when moving between areas. To the extent that some of my aids were unavailable in my new area and thus I was left with the difficulty of attempting to purchase some of these personally. However, even with my present DLA award I could not finance some of the much needed equipment, due to the already excessive call on this benefit payment. Therefore, I have no further avenue to explore other than already cash strapped charities who have already supported me on previous occasions in the past. *Therefore, no standardisation of services throws up even further difficulties as to what benchmarks the DWP assessment principles would incorporate into such a proposition? Furthermore many adaptations are already means tested and if the recipient is not on Income Support then a substantial contribution to these may already have to be made. Hence, the second part of this question is founded on an uneven playing field to start with and thus makes the implementation of such a prime breeding ground for unfairness and inequality. *Question 9 The process need not be a negative one but still needs to draw on the</p>

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		<p>medical model of inability to do things or 'to view disability as synonymous with problem' (10) rather than a social model where it may be viewed that disability occurs as a result of disabling environmental factors.*Clearer 'tests' could be paraphrased and therefore be more transparent for the claimant to recognise certain 'needs' and respond accordingly. For example, questions based on whether someone has a propensity rather than a descriptive investigation into a 'care need' activity would be simpler to answer in the negative or affirmative manner.</p> <p>*At present on the basis of personal experience DLA forms can take an experienced welfare benefits adviser at least two hours to complete with the client. This time factor has huge impact especially for those living with chronic conditions and find that pain levels and discomfort do not aid clarity of patience when completing such long winded bureaucratic nightmares.</p> <p>*Apart from evidence from the disabled person themselves, information still needs to be retained with regards their main carer, Occupational Therapist Assessments, G. P details, Specialist details and other relevant medical team members.</p> <p>*Question 10 As per earlier commentary the claim form needs to retain details of the medical team/carers involved with the individual who will have first-hand and specialist knowledge required in order to give a full, frank and professional opinion about their care and/or mobility needs to support an applicant's claim.</p> <p>*Question 11 In view of my earlier observations then I can see no benefit to this proposal. Indeed, only higher administrative costs and unnecessary employment of those who may be 'healthcare professionals' but it is unlikely that they would have the specialist knowledge required, or background to be capable of achieving a full and true picture of the claimant's needs. Therefore, we could so easily see a repetition of those appealing a decision spiralling as in the jurisdiction of recent Employment Support Allowance / Incapacity Benefit appeals which have increased by 56 per cent. Or indeed, they have more than doubled on the same period last year – from 25,700 to 52,000 this year – a new quarterly record (11).</p> <p>*It is inappropriate and insensitive to recommend that a claimant with verifiable chronic health conditions be subjected to a face-to-face meeting with an unknown 'health professional' of any description. This will create great upset and anger for a claimant who may have lived with a debilitating illness for many years, or could have just been diagnosed with cancer and be in the middle of chemotherapy treatment. Thus they will have a compromised immune system and may feel far too ill to even contemplate going through further hoops to prove benefit entitlement. From whatever perspective it is unethical and distasteful as it suggests that health teams already involved are incapable of painting a true picture and secondly it implies that</p>

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		<p>the claimant is spouting untruths.</p> <p>*Question 12 See my responses to Question 7 which incorporate this aspect of fixed terms and review processes. This mandate in conjunction with the appropriate claimant's medical team assessments should satisfy the realms of independence in the reviews procedure and ensure sufficient monitoring of an individual's impairment, needs and condition.</p> <p>*Question 13 Penalties are not an ideal response although this is also in keeping within the present DLA framework where benefit could terminate for failure to comply and respond with DWP requests (12).</p> <p>*To reiterate earlier comments contained herein reliance should be placed upon the clients own appropriate medical teams to advise and assist in this matter. A caveat to this point would be that some health conditions are deemed progressive and lifelong whereas some are viewed as having a more 'short-term' care need and so clear distinctions need to be drawn between these.</p> <p>*Hence, an acceptance of associated peculiarities of conditions, underpinned by trusted monitoring by the claimant's own medical teams and limited time frames for awards should ensure that claimants are receiving an appropriate award with the minimum of distress and maximisation of protecting the public purse.</p> <p>*Questions 14 and 15 Charities play a huge role in supporting all those affected by an individual's health condition. The difficulties lie in being able to access such advice and support locally as well as nationally. Certain charities such as Macmillan, the Lymphoma Association and Epilepsy Action are three key charities that my family have relied heavily upon over the last few years. Funding is always an issue; therefore an integrated approach between the voluntary and statutory sectors would provide an all-encompassing approach to this problem.</p> <p>*Question 16 No further comments than please see my response to Question 8</p> <p>*Question 17 Children should not have their DLA award suspended after 84 days in hospital (13) nor potentially their parents Carers Allowance award either. Nor should a child who first becomes eligible for DLA whilst in hospital have to wait until they go home before they start to receive payments. (14)</p> <p>*Children with lymphatic cancer may for example spend many years undergoing treatment in and out of hospital and such, families need all the financial support that they can possibly receive. To penalise families in such a dire situation is draconian as it imposes further hardship on an already vulnerable group.</p> <p>*Question 18 Entitlement to DLA is the foundation stone for accessing a number of services and entitlements. One of the difficulties experienced is the requirement that the Award letter</p>

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		<p>must be produced continuously to a stream of organisations in order to access additional support. A system reinforced with appropriate Data Protection consent could enable a recipient of DLA to furnish the appropriate body with a simple verification PIN or Identity Number to prove their entitlement and thus simplify and expediate the process as a whole. For example the DVLA utilise a similar system for renewing road fund licences under the Road Tax Exemption scheme.</p> <p>*Question 19 This could have a huge impact as many disabled people access these types of benefits and services which include Council tax benefit, Freedom/bus passes, Carer's allowance and various Disability premiums as part of other benefit entitlement. (15)</p> <p>*Question 20 No further comments than already relevant to this question and contained herein.</p> <p>*Is there anything else you would like to tell us about the proposals in this public consultation?</p> <p>*This is a real opportunity to change things for the better and harness resources already in place to achieve the sensible goals of promoting uptake and appropriate level of benefit payable. DLA is too valuable a resource for those with genuine need to lose. PIP however, must meet the changing needs of the individuals in society who may like me, be living with chronic illness. We are a group who desire understanding, support and abhor long winded bureaucracy and unnecessary medicals.</p> <p>*I, like thousands of others are not workshy but do rely heavily on support through agencies and benefits to provide a means to enable me to contribute to society. There are already several current forthcoming changes in the arena of welfare benefits including for example, replacing Working Tax Credit with a Universal Tax Credit scheme. From a personal point of view my already stretched finances coupled with additional anxiety over these proposed benefit changes place me in a situation that no group in a civilised society should find acceptable. The Equality Act's ethos purports to treat disabled and their carers fairly in all spheres of a citizen's life but we now find ourselves being subjected to a direct attack on the very benefit that many of us consider our elixir of life. Therefore, I sincerely hope that Her Majesty's Government will take all received comments on board.</p> <p>*Footnotes*(1) Counting the Cost. Claudia Wood & Eugene Grant. Demos (2010)*(2) 'The cruel toll of disability hate crime' article. Tom Shakespeare. The Guardian Newspaper 12.03.2010 *(3) Access Denied Report Macmillan Cancer Support (2005)*(4) Treatment and care towards the end of life: General Medical Council (2010)*(5) An Independent Review of the Work Capability Assessment Professor Malcolm Harrington (2010)*(6) Social Security Contributions and Benefits Act, Sections 71 & 65, Subsections (3) and (1)(a) respectively*(7)</p>

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		<p>Welfare Reform & Pensions Act 1999 Section 67 Subsection (1)*(8) House of Commons, Hansard, 10 March 199, col 251*(9) CDLA/1714/2005*(10) Oliver, M. 2009: Understanding Disability, from Theory to Practice 2nd ed : Basingstoke. Palgrave Macmillan. *(11) 'Tribunals Continue to increase output despite pressure' News release Tribunals Service January 2011*(12) The Social Security and Child Support (Decisions and Appeals) Regulations 1999 No.991 Regulation 19 (3) 7 (4) *(13) The Social Security (Disability Living Allowance) Regulations 1991 Regulations 8, 10(2), 12A and 12B (1)(b)*(14) The Social Security (Disability Living Allowance) Regulations 1991 Regulations 10(3) and 12b(2)*(15) On line Members Survey Disability Alliance (February 2011)</p>
EM717	17/02/2011	<p>Please find attached my reply to the consultation questions. For your information I am a disabled person in receipt of DLA, Direct Payments and I am also a carer to another disabled person. I hope that my views are read and considered. Thank you for your interest.</p> <p>*1. There is still a great deal of prejudice among some employers towards employing disabled people. It may be helpful to offer substantial incentives to all employers to employ people with disabilities. This may well be recovered in taxes that would be paid by more people with disabilities having been helped onto the employment ladder. I am disabled and I experience there to be a lack of support and funding for specific training courses that would help me to work from home or to set up my own business. Although I have been offered lots of interesting advice I now need funding to act on it. Similarly I am unable to lead a social life due to lack of sufficient funding to do this. Due to my disability I currently do not have access to joining social groups or the opportunity to find myself a partner. This seems to be very significant lack of social inclusion.</p> <p>*2. Paragraph 35 of the reform proposal states: 'by accessing other forms of support in the health and social care systems. We are therefore considering whether there are ways of doing so as part of the administration of the benefit.'</p> <p>*It makes sense that the care component could be replaced by actual care but it would seem fair for a disabled person to be given a choice in the matter. I have a very rare disease and in my case my care needs are complicated, rapidly variable and hard to administer care for. In addition to this I suffer embarrassment and loss of dignity when my personal care needs are freely discussed with third parties by social workers, which also leads to confusion that then has to be clarified. I would prefer to be given direct financial support that I can use as needed based on the medical evidence that I can produce and to really be able to live independently without having to answer difficult and personal questions asked by people who are not medical professionals and are often unable to understand my complicated condition. I would not like my care</p>

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		<p>allowance to be exchanged for services that I would have little control over.</p> <p>*In addition to this although I fully understand that the DLA is not unemployment benefit I am deeply concerned about any proposal to inflict any greater poverty on those who are unable to work due to disability. If the care allowance is to be reduced or removed in exchange for services then other benefits should be increased to reflect the unavoidable poverty that occurs when a person is lacking the commodity of their health to exchange for wages.</p> <p>*3. The cost of being out of work or only able to work part time is the greatest cost that disabled people face and one that seems to be largely overlooked by the current system. It would seem fair to increase benefits for people who are in this situation due to the fact that they are genuinely unable to do anything to change their situation. Disabled people who are able to work should be given support to do so but the greater share of any funding should go to those who are unable to work.</p> <p>*4. The proposal is currently too vague to answer this. It would be advantageous to merge all the benefits into one that is individually assessed according to needs and abilities. It would seem that only two rates would not accurately reflect the fact that people have considerably more than two levels of difference in their needs. Perhaps a point system would be more appropriate. Otherwise I welcome the system being simplified and I find the amount of paper work generated by the current system a complete waste of resources. The current system is paying for me to have help with completing the paperwork that it generates. This is clearly absurd and I am pleased that it is being addressed but I hope that it will not be at a cost to disabled people in a reduction of their overall benefits.</p> <p>*5. Probably the latter but I do not have a strong opinion on this. The question is a little too vague without actual figures being mentioned.</p> <p>*6. The concept of what is considered essential is an interesting one. Eating, keeping warm, keeping clean and healthy are all considered essential. I would like to have a social life and would be interested to know if this is considered to be essential. Isolation certainly leads to depression and this is an illness which costs society so perhaps it should also be considered essential.</p> <p>*7. By obtaining medical certification that the recipient has a variable and fluctuating condition. As I stated above in these cases it would seem appropriate to let the recipient manage his or her own care as it is needed without the added burden of extra paperwork of having to prove how the money is spent. The medical report from the most senior consultant should cover this and people with a clear diagnosis should be trusted.</p> <p>*8. This would seem reasonable providing that a greater level of</p>

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		<p>financial support is offered to those who have limited capability to work. This is the big issue that there has been very little mention of and I think that the DLA should take this into account.</p> <p>*9. Simplify the form as proposed and place more emphasis on medical reports. If a medical report states that a person has certain restrictions and weaknesses then the precise details of what this person can or cannot do should be easy enough to assume without asking detailed questions about it.</p> <p>*10. The supporting evidence for the assessment should be taken from the most senior medical consultant who has seen the patient. I say this because I have a very rare condition and my GP has demonstrated that he remains confused about what it is and the ways in which affects me despite this being laid out clearly to him by my consultants. I would therefore be very keen to ensure that only an expert in my condition is consulted about it and no one else.</p> <p>*11. I would welcome a face-to-face meeting with a healthcare professional because this is the best way to avoid confusion and to have the opportunity to clearly explain how my disability affects me. However, it would be essential that this professional knows about my condition in advance. Due to the rarity of my condition it is complex and difficult to understand and to explain to another person. I have experienced this type of assessment for my ESA and I found the nature of the questioning and the emphasis of the assessment to be quite insensitive and intimidating, which is unnecessary when dealing with a genuine disability. I would like to be able to relax and give my own testimony before being bombarded with questions that are difficult to answer in the context of my condition.</p> <p>*12. If the condition is incurable and there is no reason to believe that it will improve then the reviews should be infrequent because the information collected will only be the same each time.</p> <p>*Yes, there should be different types of reviews that take into account rare and sensitive conditions. The emotional affects of the patient answering questions about his or her condition should be taken into account. If there is a mental illness such as depression or anxiety disorder associated with the condition then a relaxed and 'gentle' approach should be used. Sensitivity should be observed when asking what the patient may experience as embarrassing questions.</p> <p>*13. The criteria for the Personal Independence Payment should be clearly laid out and the applicant should be asked if he or she fits this criteria. The applicant should also be asked to declare the fact if this ever ceases to be the case. Once this declaration is made and medical evidence to support it is submitted there should little need for further information to be requested.</p> <p>*14. No, I think that it would be unnecessary. At the point of</p>

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		<p>diagnosis a consultant will refer a patient to any sort of help and advice that they need to manage ongoing care and treatment. Further to this there are many advisory agencies that competent adults are able to find for themselves. I think that most people are aware of the sort of help that they require and are able to arrange it for themselves. A person should be able to declare what he or she needs and with the backing of medical evidence be able to claim financial support for it.</p> <p>*15. In my experience people who offer advice and support are often not medically trained and yet they ask embarrassing and personal questions and share information with third parties. As opposed to a 'requirement' I would suggest a freedom of choice regarding this matter. People who are genuinely disabled are normally inclined to seek out the best possible way forward for themselves and this should not be imposed on them. Once a condition has a clear diagnosis then there should be limited 'requirements' placed on the patient to have to discuss it against his or her wishes because this is embarrassing, depressing, humiliating and wholly unnecessary. Some privacy please!</p> <p>*16. I find this too vague to answer. It does not seem to address the issue of a person receiving the level of help that he or she truly needs. For example if one person needs a special type of bed and another does not, then I would suggest that the one who needs the bed is given extra funding for this and not be expected to sacrifice other needs in order to fund it.</p> <p>*17. This does not apply to me. In general I would say that great sensitivity should be observed at all times and that educational needs should be taken into account.</p> <p>*18. In my case the DLA has been useful at getting me access to other services and entitlements. However, I could better use direct payment funding if I was awarded it directly and allowed to use it as I see fit for my needs. I would welcome the opportunity to demonstrate that I could use the funds more efficiently and cost effectively if I were allowed to do so. Under the current system I would be expected to provide receipts for each and every service that I buy, which would defeat the object since I would have to employ a service to administer the extra paperwork that this would involve. This is why I employ an agency to provide my services although this is not cost effective and I could source the services myself at a much more cheaply. I believe that in my case my medical report should be accepted as evidence of my needs and that I should be offered total choice and flexibility in how I implement my support. This would be in keeping with the government concept of the Big Society.</p> <p>*19. There is not enough information in the rest of the consultation to answer this clearly. Does this mean that if the Personal Independence Payment is not adequate to meet the needs of the recipient that no further help would be required? If the Personal Independence Payment is enough to pay for all</p>

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		<p>disability needs and to save a disabled person from falling into poverty then there would not be any need for further benefits. However if it is not enough then there would be clearly be a need for other benefits and services to remain available to the recipient.</p> <p>*20. As I have stated above; I am a disabled person who is unable to work and I am also the carer of another disabled person. If all of this could be combined into just one benefit and one payment it would be very helpful. But I would not like to be left worse off as a result of this change. All general information should be shared but private, personal and potentially embarrassing information should not be shared. For example the Employment Support Allowance forms that I have completed and the assessments that I have attended do not take into account that I am a carer. So although I have stated that I am physically able to do a limited amount of work from my own home I am not able to actually do this due to my caring responsibilities. The current system is 'blind' to this.</p> <p>*21. I do not understand this question.</p> <p>*22. The greatest cost of disability in my experience is the loss of the ability to work *and the unavoidable poverty that this inflicts on an individual. I do not feel that this is proportionally represented in the benefit system and I would like to know if this is being addressed in the reform. I understand that the DLA is not compensation for being out of work due to disability but I am saying that since this is the biggest cost that most disabled people are likely to face that it should take this into account. Being disabled with money is a very different world to being disabled without money.</p> <p>**Perhaps the Personal Independence Payment could be means tested so that there is a fair differentiation between people with disabilities who can work and those who are unable to work. I understand the reluctance to discourage anyone from working if they are able to, but on the other hand it does seem unjust for a person who is unable to work to be obliged to live in poverty through no fault of his or her own. It is only fair to 'make work pay' for those who can work and certainly not fair to conversely penalise those who genuinely cannot. I am deeply concerned about the implications of these reforms in relation to this matter. *Furthermore, I find myself in the unusual situation of being both a disabled person and a carer to another disabled person. The complexity of the current benefit system means that the Employment Support Allowance has no recognition of my status as a carer. Therefore, although I have declared myself as being physically able to do a small amount of work from home, my duties as a carer make this impractical, yet this is not recognised to be the case. I would be interested to know how this would be managed under the new system.</p> <p>*I wish to add that I would like all of the hard work that I put in as a carer to be recognised as a proper job and to be paid</p>

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		<p>accordingly. I would like the carer's allowance to be increased and not to be deducted from any other entitlement. I should really be enjoying both the financial and social status of being a working person with a disability and not being frequently assessed as if I were unemployed. I cannot help thinking that I deserve a little more help and respect than I am being given to have continued with my caring responsibilities despite my own debilitating condition. I hope that one day this will be better taken into account.</p>
EM718	17/02/2011	<p>To whom I may concern , The attachment is my response to some of the question from part five of the DLA consultation.*Yours faithfully</p> <p>*1. The problems that prevent disabled people taking part in society are varied. Without a support team around them e.g. family, health care professionals, mentors, some of the people with disabilities would be isolated. For others it is getting the equipment that would promote independence. How accessible are the services that would benefit those with disabilities? Is there easy access to public buildings for the physically disabled?</p> <p>*Do the service providers have an understanding of disabilities such as Autism where the person can have behavioural and/or sensory issues? This lack of understanding can prevent families from using public services. As a consequence the family do what is necessary i.e. school etc otherwise they stay at home. Isolated because staying in is easier; less hassle.</p> <p>*Is there anything else about Disability Living Allowance (DLA) that should stay the same?</p> <p>*2. There will be extra costs in everything; the cost of equipment that the disabled person will need. There are extra transport costs e.g. to the extra hospital appointments and visits to healthcare professionals. If the disability is autism, this in itself can present problems. Some of those on the autistic spectrum have difficulty coping in social situation. The anxiety of being in social situation where things are beyond their control means that they would struggle to use public transport. For such a family the DLA can help toward alternative travel expenses whether it's running a car or using taxis; this stops the family becoming isolated. Cost in paying for support that would enable the disabled person to access events, paying for respite care. *3. The fear for many is that under the proposed system, those who are on a lower rate who really need the benefit, with the current system will get nothing.</p> <p>*4. Each case is different. Each claim should be based on the circumstances and needs of the individual applying.</p> <p>*5. For the majority, most if the support will come from the family.</p> <p>*Look at each case individually getting the views from the disabled person if they are able to express themselves and those of the individuals involved their care.</p>

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		<p>*6. It would be helpful if the healthcare professional that is making the face to face visit has prior experience /knowledge of the condition that the claimant has.</p> <p>*The disabled person's "bad" days as well as "good" days should be taken into account .This should ensure that they are not denied the benefit because of a few good "days".</p> <p>*7. Yes. The assessment should show just how important the aids and adaptations are to the disabled person.</p> <p>*8. Stop the repetition of questions that seem to ask for the same information but in a different format.</p> <p>*9. Get supporting evidence from the claimant's healthcare professionals and other support staff.</p> <p>*10. The benefits are that the healthcare professional will see the disabled person and get the necessary information from them if they can express themselves and those involved in their care. The person whose condition gives them "good" days and "bad" days, would worry that the face to face visit would be on their "good" day. What the disabled person and those involved in their care want is assurances that the healthcare professional is knowledgeable about the disability that the claimant's has. Also the family may not want a face to face visit, seeing it as invasive and insulting.</p> <p>*Some autistic individuals have to a rigid routine at home; and could get extremely anxious if their routine is disturbed.</p> <p>*11. The nature the claimant's condition, the views if expressed, of the claimant, evidence from the claim form, the healthcare professional and other agencies involved with the disabled person could be used to set the frequency of reviews.</p> <p>*The disability and the needs of the disabled person should determine the frequency of the reviews.</p> <p>*12. Your response:</p> <p>*13. There could be signposting to organisations that would be relevant to the claimant. This information could be given as part of the claiming process.</p> <p>*14. Many claimants do not seek advice and support because they are not aware that such information is available to them. Also some claimants have to come to terms with the fact that they have a disability or disability in the family. Signposting at the point of contact to could be a way forward. There has to sensitivity to the feelings of the claimant. Requirement to access advice and support while being welcomed by some could be seen as a hurdle not worth jumping by others.</p> <p>*15. Funds that can be, are met from the DLA. However parent/carers apply for grants from their local council, or charities. Some parents/carers may do fund raising events to be able to buy what is necessary for the disabled person. Using Personal Independence Payment to meet a one -off cost should be an option.</p> <p>*16. Take into account the emotional and physical changes that children go through and the effect it will have on them and their</p>

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		<p>family.</p> <p>*17. The DLA is very important in allowing disabled people to access other services.</p> <p>*18. The quality of life would be impaired. They would not be able to access the benefit/services/events without the Personal Independence Payment. Not being able to access other benefits could incur financial hardship. The disabled person often needs more equipment and/or services e.g. Blue badge. The Personal Independence Payment and its benefits would allow them or their carer to take a more active part in their care and in society.</p> <p>*19. Not sure</p> <p>*20. Not sure.</p> <p>*21. Your response:</p>
EM719	17/02/2011	<p>1. Your response: The fact that society still allows disabled people (including mentally disabled) to be treated as lesser individuals because they are 'different' and may have special needs (ramps for wheelchairs, separate toilets etc)</p> <p>*2. Your response: All of it. It just needs a good overhaul to pick out all the long-term people who were awarded the benefit in the 70's & 80's when it was so easy to apply and receive and have long since recovered.</p> <p>*3. Your response: Heating, decent diets, care and help to do the activities they would like to and some times, having to pay extra rent for ground floor facilities if they are wheelchair bound, home help if they are unable to maintain cleanliness of their home.</p> <p>*4. Your response: It is OK now, there is no need to change this system.</p> <p>*5. Your response: Terminally ill individuals should receive awards within 7 days of applying by being able to fax a simple 2 page application signed by their GP and then fast tracking. My mother was dead by the time the award was passed. Needs should be taken into account, that is why the current system is good, high, middle and low rates cover everyone.</p> <p>*6. Your response: Activities that give disabled people their dignity back. If they cannot see to their personal needs, or cleaning their home, shopping and cooking so they have a decent diet is priority</p> <p>*7. Your response: Ensure that the medical person assessing the applicants have medical knowledge of disability and mental health problems. It's no use sending someone to a newly qualified doctor for assessment; they only have a small area of knowledge after training. These practitioners desperately need to have extensive knowledge of the area of disability and also they need to ask the right questions. Re-assessment every 2 years should be mandatory unless the condition is one that will not improve (spina bifida, schizophrenia, extensive arthritis, etc)</p> <p>*8. Your response: NO!!! If the aids were not there, that person would not be able to function. People can fall with or without a</p>

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		<p>stick or Zimmer frame.</p> <p>*9. Your response: If professionals (support agencies, CAB, health professionals) were to fill in the forms, they are wonderful at asking the questions in the right way and seeing through people (such as if the person is in pain at the interview but has been in pain for some time, so it is not a great issue for them). They also know how to write the answers clearly and concisely for the benefit agency's information. All the agencies in the local area need to be in a brief leaflet accompanying the form when the person makes their application.</p> <p>*10. Your response: The medical person who sees the person on a regular basis and someone who has daily contact with them, it does not matter who that is.</p> <p>*11. Your response: ANYONE who has face to face interviews with a healthcare professional that they do not know (someone other than their own GP) MUST be given access to an advocate and they MUST be offered this, not left to them to ask for one as they might not know about advocacy services.</p> <p>*12. Your response: Every 2 years, except in conditions where the GP or Consultant has stated that there is no likelihood of improvement in the condition, then every 5 years.</p> <p>*13. Your response: Some people are so mentally ill that they cannot function on a daily basis without extensive input. Your PIP works on conditions that people are able to carry out simple tasks. THINK AGAIN</p> <p>*14. Your response: Access to advocacy services, lists of all available services in their area. Keeping it to yourselves just makes people more dependant on the benefit system. There is a LOT of help out there, you can support disabled people by passing this message on.</p> <p>*15. Your response: Yes – ask the services themselves what they think. Consult people who really know their customers/clients.</p> <p>*16. Your response: It is degrading and distressing that people should not have access to adaptations and appliances freely if this will help them turn their lives around or make them more independent.</p> <p>*17. Your response: Children may 'grow out' of the disability, but the awareness that it could be a permanent disability and the guidance of the child's GP is paramount in these cases. GP, child advocate and carer's influence should over ride any 'outside' ideas of the needs of the child. A children's advocate is a very useful person to liaise with.</p> <p>*18. Your response: DLA helps in many ways. It gives people who are less mobile the chance to improve their lives and sometimes this is under pinning the difference between isolation, neglect and feeling part of society with something to live for.</p> <p>*19. Your response: 20. Your response: 21. Your response:</p> <p>*22. Your response: I've run out of time to fill the above</p>

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		<p>information in. Please do not under-estimate the value of DLA awards. To people living in deprived areas, it may mean the difference between living and coping reasonably well and having the ability to be a little more independent to isolation, poor diet and home life. Each tier of DLA corresponds to the ability of the person awarded, allowing them a little extra each week according to their needs. The only change needed to the system is to review all 'for life' claims to review the need of the person. In the real world, no one is going to contact the benefits agency and tell them they no longer need £18.95 + per week, they will carry on claiming and justifying it by saying they must need it or they would not have been given it in the first place. By the way, I am able bodied and very grateful for that. I have needed help in the past for physical problems, but DLA is for people who really need it and I hope that it will be there should the worst happen and I lose my mobility or need care.</p>
EM720	17/02/2011	<p>Extra costs disabled people face:</p> <ul style="list-style-type: none"> *Disability is such a varied condition that people's extra costs will be for a variety of things. *-Firstly, life with a disability/chronic illness is simply more expensive - most disabled people do not have the energy or ability to shop around for the best deal, perform domestic repairs themselves, run a cheap but unreliable car or go without a car, or any other means of getting by on a tight budget. *-Treatments that can have a profound effect on health and quality of life are often not provided by the NHS and are a lifeline for many people living with chronic conditions, but are rarely cheap. *-Mobility costs can be very expensive, and not necessarily covered by the mobility component of DLA. *-Aids and appliances provided by the NHS/local councils often have prohibitively long waiting lists, or are unsuitable for an individual, and so may need to be funded independently. *To remove an individual's ability to choose how to counter their disability is to risk increasing disability in a way this country can't afford – unless it intends to NOT “protect the most vulnerable in society”. *Activities most essential for everyday life: *Eating healthily, toilet needs, mobility, keeping oneself and ones environment clean and healthy, thinking clearly, keeping pain at a manageable level, communication. *How to best ensure that the new assessment appropriately takes account of variable and fluctuating conditions: *-By accepting evidence from the individual concerned, and healthcare professionals they come into contact with, as well as taking into account expert knowledge about the condition. *-By ensuring that the application form/assessment adequately takes into consideration how the condition is at the individual's worst as well as at their best. *-By ensuring that the full complexity of the condition is taken

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		<p>into account – eg someone may be capable of walking a mile but this may then render them immobile for some time. Or they may be able to go shopping, but this may leave them unable to prepare a meal or have a shower, or vice versa..</p> <p>*-By remembering that buying/installing aids and adaptations isn't any cheaper if you only need them three days a week than if you need them seven days a week.</p> <p>*Should the assessment of a disabled person's ability take into account any aids and adaptations they use? *-If aids and adaptations were taken into account it would be vital to have contingencies in place for repairs and replacements, as well as any extras needed – eg at a new place of work.</p> <p>*-If they were to be taken into account when the person does not already have them, then lengthy waiting lists and possible unsuitability should be taken into account in taking the decision as to whether the person can "easily obtain" them.</p> <p>*What supporting evidence will help provide a clear assessment of ability and who is best placed to provide this? Consultants, GPs, physiotherapists and other healthcare professionals the claimant has had contact with are best placed to provide this.</p> <p>*Face-to-face discussion with a healthcare professional: Invisible symptoms can make an enormous difference to a person's abilities, as can the cumulative effect of day-to-day activities. Neither of these issues are addressed by a visit from a stranger, nor is the fluctuating nature of certain conditions.</p> <p>*Benefit reviews: -A specialist in each condition will have a pretty good idea of a sensible frequency for reviews. Also, recommendations from an applicant's GP/consultant/other healthcare professional could be requested with their input for the initial application.</p> <p>*-It would be superfluous to review conditions that will not improve. For certain conditions where there might or might not be improvements, a simple form asking if the condition has improved, worsened, or stayed the same, sent to an individual's healthcare professional (such as a GP) might be a good and cost-effective initial step.</p> <p>*How can we encourage people to report changes in circumstances? By making sure the whole system is absolutely fair.</p> <p>*How do disabled people currently fund their aids and adaptations? Should there be an option to use Personal Independence Payment to meet a one-off cost? My aids and adaptations have been funded by a combination of local government, NHS and DLA. Funding to meet a one-off cost might work in some circumstances, but there would need to be further provision for repairs and replacements, as well as any extras needed – eg at a new place of work. In other cases, the other extra costs arising from disability would still remain, so it would need to be on top of, not instead of, the benefit.</p> <p>*The implications for disabled people and service providers if it</p>

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		<p>was not possible for Personal Independence Payment to be used as a passport to other benefits and services: Unnecessary amounts of paperwork/red tape, delays, limitations and stress. Repeatedly answering questions about disability reinforces that disability. All potentially contributing to reduced ability to play a useful part in society. *Removing mobility benefit from people in care homes would be inhumane as it would render many prisoners unnecessarily, rendering them unable to play any part in society, let alone a useful one. This could not by any means be said to “ensure that priority is given to those individuals who need to overcome the greatest barriers to living full and active lives”.</p>
EM721	17/02/2011	<p>Dear folk on the DLA Reform team Please find attached my responses, such as they could be in the time available. My best wishes to you To: DLA Reform Team Fax: [REDACTED] (repeated fax attempts were unsuccessful; now trying to email)</p> <p>*In relation to all questions: These answers have been compiled in haste; owing to my medical condition, I needed much more consultation time to review my answers, and to proffer positive alternative suggestions to those in (and implied in) this consultation. I am responding as an individual.</p> <p>*1. This is an important question and I’m glad it is being asked.</p> <p>*However, I would like to mention that rushing in welfare benefit changes (including the transfer of IB claimants to ESA – and that apparently before even acknowledged problems are resolved) which: •(probably unintentionally) seem to have ignored many relevant factors and which •seem likely to affect many disabled people significantly adversely •allow insufficient time for people with significant and relevant disabilities to comment in full, and proffer positive, alternative suggestions •seem inconsistent with some of the stated aims, and principles ,of the changes does not contribute to our leading independent, full and active lives. As I hope the DLA Reform Team already knows, problems and barriers for disabled people as a cohort include: •accessing, and retaining access to, education and employment •accessing, and retaining access to, medium and higher paid work •physical access •limited options over methods of communication •public and private organisational systems which partly or wholly deny access •attitudes to disability and to disabled people •lack of awareness, understanding, and acceptance over, access issues •demeaning, demanding and exhausting welfare processes •welfare benefits call-centre staff not having immediate access to relevant access information relating to their caller •apparently, there being no system so that welfare benefits staff have (and implement) relevant information about the reasonable adaptations to their role needed by the claimants with whom they are dealing •the absence, for each welfare claimant, of the allocation of one, long-term, appropriately-skilled and capable key worker who adapts</p>

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		<p>appropriately around their claimants' disabilities and who will handle all welfare-related issues, on their behalf •apparently (and astoundingly, bearing in mind the purposes of 'welfare' and of reducing long term state financial expenditure), no measurement, and no annual monitoring of measurements, of the impact on the health and well being on claimants of each and every step of claiming welfare benefits (including the work of the performance monitoring section). Similarly, for proposed and actual changes to welfare benefits •welfare (and social care) assessment systems where assessors have utterly insufficient information about the factors they are commissioned to assess. Combined with an apparent low regard given in welfare systems to reports about claimants from specialists in their condition/function •misleading information about DLA, attributed to government spokespeople •press articles which demonise and misrepresent welfare claimants as a group •dire lack of availability of appropriate care services •quality assurance systems for care services •the plethora of professional individuals with whom a disabled person may have to relate*•the absence of availability of a single, long-term, appropriately skilled and capable key worker to manage this plethora of professional relationships - if required and requested by a disabled person*•lack of sufficient personal money to overcome a significant portion of the above difficulties and barriers</p> <p>*Re page 3 para 2: What is the evidence that DLA expenditure is unsustainable? What factors have been are taken into account? Do these factors include all relevant financial and non-financial expenditure (including individual, voluntary, charitable, health, social care, welfare costs – and all including opportunity costs? For instance, do the factors taken into account include the consequences relating to 'disabled people with lesser barriers to leading independent lives' who qualify for DLA but who will not qualify for PIP such as:</p> <ul style="list-style-type: none"> *•losses to the exchequer in income tax, and *•loss of the obvious (and vaunted) benefits to the most individuals, and to the nation, resulting from those of these people as a consequence no longer being able to obtain, or stay in, paid work? <p>*Re page 3 para 2: what is the full evidence that PIP will be 'more efficient'? When all the factors in my preceding paragraph are taken into account, can PIP still be described as 'efficient'? Why was the reduction, and level of reduction in the numbers of people eligible, not explained, justified and open to question, in this consultation?</p> <p>*Where is the evidence base for the appropriateness, and consequences, of changing the qualifying periods relating to disability from 3 months to 6?</p> <p>*Our (shared) concern about disabled people remaining independent and leading full and active lives seems</p>

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		<p>inconsistent with the emphasis in the PIP proposals on increased selectivity of claimants who are to be successful claimants. What is the evidence base that it is cost-effective to the nation overall (see two paragraphs above) to exclude so many disabled people from PIP?</p> <p>*I would like to see DLA and any successor benefit extended to include pensioners because disability occurring after pension age does not mean a person needs the benefit any the less than disabilities first occurring when younger.</p> <p>*I welcome the statement on page 16, para 24: 'We remain committed to the social model of disability.' Some medical conditions and some impairments mean that longer time periods are required for such things as partaking in consultation exercises such as this one. Educational examinations allow candidates extra time to take account of relevant disabilities, so what is the justification for selecting what may be the minimum legal time possible for this part of the consultation – and including a long holiday period during the consultation as well? Page 11 states: 'Disabled people are rightly not prepared to accept being restricted from playing an active part in society'. For me, that includes my not accepting that it is right that this short consultation period means that I have not been able to respond to the extent and in the manner I would wish, to this consultation.</p> <p>*I would like to suggest that the 'commitment to the social model of disability' is put further into practice by adapting the PIP proposals so as to be consistent throughout in addressing the problems identified in the social model of disability (which, these days, include addressing all forms of both social and physical barriers). This would involve a lot of adaptation!</p> <p>*My request is that these PIP proposals are stopped now, and full and in-depth research is carried out on the DLA, with sufficient time for each consultation stage, and with consultation which covers all relevant questions.</p> <p>*There's insufficient consultation time for me to explain most of my views about this question.</p> <p>*2. I welcome the following: •It is a cash payment; recipients do not have to account for how it is spent. •It is non-taxable</p> <p>*•Recipients can be in work or not. •Payment can continue when recipients pass their 65th birthday •There are special rules for terminally ill people •Motability is supported I would like to see the following also continue: •There are indefinite awards</p> <p>*There should be automatic awards for a wide variety of medical conditions. Where there is a wide variation in functional ability associated with a medical condition, the automatic awards could be for a particular, clearly-defined level of that medical condition. There's insufficient consultation time for me to explain most of my views about this question.</p> <p>*I believe that these PIP proposals should be stopped now, and</p>

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		<p>full and in depth research should be carried out on the DLA, with sufficient time for consultation, and with consultation which covers all relevant questions.</p> <p>*3. Well, yes, it's good this consultation is asking about this. However, I concur with the authors of DWP Working Paper 21 2005, that welfare benefits only provide a contribution when it comes to addressing the extra costs. I request that in all welfare matters, including those relating to DLA and PIP, from now on, there is never an implication that welfare benefits provide sufficient money to come anywhere near creating a level playing field between disabled and non-disabled people. I do hope those designing and deciding on these proposals are taking into account the content of DWP working paper 21. (Reading the consultation document has raised a question in my mind as to whether appropriate account has been taken of that working paper.)</p> <p>*There's insufficient consultation time for me to explain most of my views about extra costs.</p> <p>*I believe that these PIP proposals should be stopped now, and full and in depth research should be carried out on the DLA, with sufficient time for consultation, and with consultation which covers all relevant questions.</p> <p>*4. Please don't let's pretend that, or be ambiguous about whether, we're talking about appropriate levels of support in relation to equality of playing fields between disabled and non-disabled, and in relation to needs resulting from disability (ref DWP working paper 21). The absence of a definition of 'appropriate levels' could perhaps be construed as being misleading. Therefore I think this consultation should be specific about what the perceived appropriateness is in relation to. DLA provides a token level of support, nothing more.*'...ensuring...' in question 4 also implies that the PIP proposals are sufficiently fit for purpose to ensure they will succeed in providing appropriate levels of support. This I doubt.</p> <p>*There's insufficient consultation time for me to explain most of my views about this question, and there are more fundamental questions which I feel this survey should be asking.</p> <p>*I believe that these PIP proposals should be stopped now, and full and in depth research should be carried out on the DLA, with sufficient time for consultation, and with consultation which covers all relevant questions.</p> <p>*5. This is a really important question. I believe that many, perhaps most, health conditions or impairments should mean an automatic entitlement to the benefit.</p> <p>*Please do a medical and psychological assessment of the impact of welfare-benefit-medical/functional assessments on people with disabilities, and on people who are ill. What is the evidence base that any harm of Atos assessments to claimants is insignificant?</p>

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		<p>*What is the evidence base justifying the removal (in the PIP proposals) of the new automatic (DLA) right of blind people to receive the higher DLA mobility award?</p> <p>*Please arrange any welfare changes in the future so that any assessment process has a positive effect on people's health and well-being.</p> <p>*Re p4, paragraph 6: It would seem both cost-effective and compassionate to retain, and even expand, the conditions exempt from assessment. People with those conditions are inevitably going to face significant extra costs compared with people without those conditions; the assessments proposed would be a waste of time and money.</p> <p>*Re p4, paragraph 7: generalist 'independent healthcare professionals' cannot generate meaningful reports on complex conditions (and such as having a local champion for such conditions seems a woefully inadequate 'solution' to this situation.) Automatic entitlements could be used to resolve this situation, (especially where the level of the complex condition is already medically defined by function!)</p> <p>*Re p4, paragraph 7: complex medical conditions cannot be assessed 'in depth' over the timescales of a DWP assessment. Complex medical conditions may have taken condition-specialist NHS staff (and sometimes a team of staff) years to assess. There should be a list of such conditions; then time, money and the claimant's health should be saved by deeming a DWP medical assessment inappropriate in such cases.</p> <p>*Re page 11: 'Central to Personal Independence Payment will be a new, fairer, objective assessment ' If this consultation is to inform secondary legislation which in turn will determine the detail of the assessment, then I would like to take this opportunity to confirm and emphasise that it seems to me that DWP data shows that the ESA criteria and assessment process are woefully far from fair and objective, and the ESA assessment criteria and process should not be used as a model for PIP. *People who are already ill and/or disabled should not be required to endure an appeals process because of obvious and correctable failures of the assessment system. I find it alarming, and unconscionable, that the proposals imply that the ESA assessment system is/will be sufficiently robust in this respect. For instance, it would be more reassuring to see an ESA system with a low rate of appeals (combined with research that demonstrated that the appeals system was accessible) before using a similar assessment process for another benefit such as PIP.</p> <p>*There's insufficient consultation time for me to explain most of my views about this question.</p> <p>*I believe that these PIP proposals should be stopped now, and full and in depth research should be carried out on the DLA, with sufficient time for consultation, and with consultation which covers all relevant questions.</p>

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		<p>*6. I understand that this is an important question. However, even more important is the question of what is a justifiable cut off point for DLA/PIP? Without a presentation of the pros and cons of various cut-off levels, my feeling is that a widening of the welfare net, to include more people with disabilities, may well be appropriate. I feel that this survey should have explained, and asked about this, rather than swinging straight in with a question which seems to take as indisputable (without justification, and without explanation of the impact on disabled people) the necessity (and financial sagacity) of excluding more disabled people from the welfare system.</p> <p>*I suspect that many people may be inappropriately excluded from the present system, (some intentionally and some unintentionally), and that our country would be better off financially, and as a society, if this were rectified.</p> <p>*I welcome the statement on page 16, para 24: 'We remain committed to the social model of disability.' However, please remember that focusing an assessment on 'the ability of an individual to carry out a range of key activities necessary for everyday life' places that the claimant in the unpleasant and demeaning position of:</p> <ul style="list-style-type: none"> *• (regardless of their stage of acceptance and rehabilitation) having to face the detail of what their disability means in practice *• having to successfully communicate this information to complete strangers, however embarrassing, humiliating and difficult *• having to work to gather, and elicit from others, evidence of the things they cannot do - however embarrassing, humiliating and difficult. For a claimant who has up till then presented a brave and positive face to the world, this can be devastating. In addition, this may adversely affect their relationship with some of those 'others'. For instance, with 'others' who themselves find it difficult to accept disability and, for instance, with GPs who see their role as helping their claimant patients medically, attempts at eliciting the needed evidence can threaten, or end, a previously valued relationship <p>*The three bullet points above describe outcomes for the claimant which are not positive, and I would suggest that the social model would view these outcomes as disabling rather than enabling.</p> <p>*My own view is that an assessment usually based upon the medical condition is more compatible with the social model, and is preferable to the present PIP proposals.</p> <p>*There's insufficient consultation time for me to explain most of my views about this question.</p> <p>*I believe that these PIP proposals should be stopped now, and full and in depth research should be carried out on the DLA, with sufficient time for consultation, and with consultation which covers all relevant questions.</p>

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		<p>*7. For a start, please review again all relevant the Joseph Rowntree Foundation research which demonstrates the high level of costs to the individual resulting from variable and fluctuating conditions. There often seems to be an implication that variable and fluctuating conditions are less of a problem than stable ones, and my understanding is that this is not necessarily so. If this concept were incorporated throughout welfare systems, it may help a lot.</p> <p>*For instance, http://www.jrf.org.uk/publications/disabled-peoples-costs-living:</p> <p>*‘transport - costs were highest for those with intermittent needs’</p> <p>*Re p4, paragraph 7: I suspect that generalist ‘independent healthcare professional(s)’ cannot be equipped to generate accurate and adequate reports on complex conditions, including many variable and fluctuating conditions (even if those professionals are mentored by a ‘champion’). What is the evidence base (including finance and health/wellbeing criteria) that justifies assessment of complex conditions by generalist ‘independent healthcare professionals’?</p> <p>*There’s insufficient consultation time for me to explain most of my views about this question.</p> <p>*I believe that these PIP proposals should be stopped now, and full and in depth research should be carried out on the DLA, with sufficient time for consultation, and with consultation which covers all relevant questions.</p> <p>*8. It seems to me that taking aids and adaptations into account is a waste of assessment time and costs. And taking virtual aids and adaptations would seem to venture into the land of fantasy. Taking aids and adaptations into account would seem to assume/imply that the welfare benefit comes anywhere near compensating for the lower incomes and additional costs experienced by disabled people when compared with ‘non-disabled people’. Most disabled people who have found ways to make the best of their abilities via aids and adaptations will still face significant extra costs, so withholding benefits on this basis seems cruel and likely to have negative psychological impacts desired neither by the government nor disabled people.</p> <p>*There’s insufficient consultation time for me to explain most of my views about this question.</p> <p>*I believe that these PIP proposals should be stopped now, and full and in depth research should be carried out on the DLA, with sufficient time for consultation, and with consultation which covers all relevant questions.</p> <p>*9. Thank you for asking this question!</p> <p>*All aspects of the claim process should effectively elicit the information relevant to a person’s entitlement. Regarding welfare benefits in general, DWP Atos claimant interview schedules, DWP GP claimant report forms, DWP claimant claim forms all seem to omit questions, and wording, most likely</p>

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		<p>to elicit information relevant to the claim. I find this unconscionable. Such a system characteristic could directly result in claimants inappropriately being refused benefit on the basis of no, or insufficient evidence.</p> <p>*Apart from benefits which are automatically tied to medical conditions, each assessment for benefit inevitably pushes claimants into the position of focusing upon, and explaining in considerable depth what they cannot do. This can be very difficult, and also extremely distressing and demeaning. In my experience, every welfare application, assessment, and every step of the appeal process, requires such intense and negative thinking for a prolonged period. So it is important for welfare systems to assess as infrequently as is feasible. Tying benefits automatically to medical conditions would have a huge beneficial effect in respect to this.</p> <p>*There's insufficient consultation time for me to explain most of my views about this question.</p> <p>*I believe that these PIP proposals should be stopped now, and full and in depth research should be carried out on the DLA, with sufficient time for consultation, and with consultation which covers all relevant questions.</p> <p>*10. There is also a need for safeguards that decision makers, 'independent health care professionals' and tribunals, in practice, give appropriate weight to supporting evidence.</p> <p>*Re p18 para 30: I believe 'independent healthcare professional' may be a misnomer. I have the impression that 'independent healthcare professional' means a DWP (or DWP-agent) healthcare professional, which is not the same as an independent one.</p> <p>*I welcome the recognition that the face-to-face assessment is unlikely to be appropriate, or effective, for complex presentations, and hope that this recognition is adequately reflected in claim procedures. I also hope that the guidance on 'what is a complex presentation' achieves the rather difficult combination of including all appropriate complex situations, whilst also being crystal clear to both administrators and claimants.</p> <p>*There's insufficient consultation time for me to explain most of my views about this question.</p> <p>*I believe that these PIP proposals should be stopped now, and full and in depth research should be carried out on the DLA, with sufficient time for consultation, and with consultation which covers all relevant questions.</p> <p>*11. Difficulties with face-to-face discussions (including those with healthcare professionals and tribunals) could include the absence of, or inadequate, appropriate arrangements for:</p> <ul style="list-style-type: none"> *• people with cognitive, and/or communication, difficulties *• complex conditions which the healthcare professional does not understand, especially those where the healthcare professional is unaware that they do not understand. For

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		<p>instance, a generalist medical practitioner should not attempt a one-interview face-to-face functional assessment on a claimant with CFS/ME; owing to the nature of CSF/ME, this would be a waste of public time and resources (as evidenced by CFS/ME appeal rate successes in relation to other benefits).</p> <p>*(Question 11 second bullet point:) Yes, most definitely: circumstances where face-to-face meetings would seem to be inappropriate include where:</p> <ul style="list-style-type: none"> *•a claimant cannot communicate accurately and completely face-to-face, especially where they have another, more effective, means of communicating *•a claimant's medical condition, or health or well-being, will be harmed by the meeting <p>*There's insufficient consultation time for me to explain most of my views about this question.</p> <p>*I believe that these PIP proposals should be stopped now, and full and in depth research should be carried out on the DLA, with sufficient time for consultation, and with consultation which covers all relevant questions.</p> <p>*12. Criteria on frequency should include any adverse impact of:</p> <ul style="list-style-type: none"> *•the review itself on a person's health and wellbeing, and *•the frequency of reviews on a person's health and wellbeing. <p>This should also take into account that a person may also be undergoing health assessments and social care assessments, which may have a cumulative effect on their health and well being</p> <p>*There should be an option for no further reviews to be required unless requested by the claimant. There should also be an option for very infrequent reviews (say, a decade or two between reviews).</p> <p>*It seems that the PIP proposals have decided to increase the assessment for disabled people without consultation on, for instance, passporting from DLA to PIP. I believe that there should be passporting from DLA to any successor, in such a way that the claimant's position is no worse.</p> <p>*Also, if all people were guaranteed a reasonable income, assessment would be drastically reduced, and the lives of disabled people could thereby be greatly improved.</p> <p>*There's insufficient consultation time for me to explain most of my views about this question.</p> <p>*I believe that these PIP proposals should be stopped now, and full and in depth research should be carried out on the DLA, with sufficient time for consultation, and with consultation which covers all relevant questions.</p> <p>*13. There's insufficient consultation time for me to explain most of my views about this question.</p> <p>*I believe that these PIP proposals should be stopped now, and full and in depth research should be carried out on the DLA, with sufficient time for consultation, and with consultation which</p>

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		<p>covers all relevant questions.</p> <p>*14. All aspects of all benefit claims process should very clearly request the specific information relevant to a person's entitlement. Regarding welfare benefits in general, Atos interview schedules, GP report forms, claimant claim forms omit vital questions, and wording, most likely to prompt and elicit information relevant to the claim. I find this unconscionable. It could result in a claimant inappropriately being refused benefit on the basis of no, or insufficient evidence.</p> <p>*It seems to me likely that, in practice, very many PIP claimants will need (and yet may not access) truly-independent-of-the-DWP, top quality advice and information (probably advice and information directly derived from welfare legal expert[s]) when applying for PIP.</p> <p>*Please also see my answer to question 15.</p> <p>*There's insufficient consultation time for me to explain most of my views about this question.</p> <p>*I believe that these PIP proposals should be stopped now, and full and in depth research should be carried out on the DLA, with sufficient time for consultation, and with consultation which covers all relevant questions.</p> <p>*15. Well, the advice and support would have to be both trained, and capable, enough to provide this help, or it will be a waste of time and money. At the moment such sources of advice and support are quite rare, and this year will become significantly even more rare due to national and local economic cuts.</p> <p>*So before thinking of imposing a requirement to get advice and support, a far more important priority is the provision of sufficient advice and support, of an appropriate quality, available in and at appropriate formats/venues/times etc for all claimants, should they choose to access it. Priority should be afforded to facilitating existing such advice sources to continue.</p> <p>*And what is needed are sufficient, competent, quality, legally-informed sources of advice and support which are independent of the DWP.</p> <p>*There's insufficient consultation time for me to explain most of my views about this question.</p> <p>*I believe that these PIP proposals should be stopped now, and full and in depth research should be carried out on the DLA, with sufficient time for consultation, and with consultation which covers all relevant questions.</p> <p>*16. Please try to imagine how many appropriate aids and equipment that people have to do without - or to wait for, for years.</p> <p>*Please also consider what aids and adaptations disabled person need; this may evoke more vital information than how they fund what they do actual buy.</p> <p>*There's insufficient consultation time for me to explain most of my views about this question.</p>

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		<p>*I believe that these PIP proposals should be stopped now, and full and in depth research should be carried out on the DLA, with sufficient time for consultation, and with consultation which covers all relevant questions.</p> <p>*17. There's insufficient consultation time for me to explain most of my views about this question.</p> <p>*I believe that these PIP proposals should be stopped now, and full and in depth research should be carried out on the DLA, with sufficient time for consultation, and with consultation which covers all relevant questions.</p> <p>*18. Passporting arrangements can be very useful, reducing bureaucracy, and reducing the toll taken on the claimant of claiming. However, in my opinion, all passporting arrangements should be paralleled by alternative routes to other services and entitlements so that people inappropriately excluded (for whatever reason) from a 'passport' benefit should not automatically be excluded from other benefits and entitlements.</p> <p>*If the changeover from DLA to PIP happens despite consultation responses from people with disabilities, what would be extremely useful would be passporting people with DLA awards onto the successor benefit, without an additional assessment, and in such a way that the claimant was no worse off.</p> <p>*Re Paragraph 6: It would seem both cost-effective and compassionate to retain, and even expand, the conditions exempt from assessment. People with those conditions are inevitably going to face significant extra costs compared with people without those conditions; therefore the assessments proposed would be a waste of time and money.</p> <p>*(Please compare the ethos implied by the PIP proposals against the outrage expressed by some MPs at being asked to become more accountable for the expenses they claimed. There seems to be a quite different way of regarding MPs and disabled claimants.)</p> <p>*Where claimants have an indefinite DLA award, they should simply be left unharassed, and should not be subjected to the stress and other problems resulting from uncertainties and additional assessments. However, they should be invited to transfer, and have the option of transferring, to PIP, but should not be forced to change over.</p> <p>*As far as I can see, the evidence base for the appropriateness of the ESA assessment system is weak, and the problems with that system should be resolved before it is used to reduce claimant's benefits via links to the DLA or PIP systems.</p> <p>*There's insufficient consultation time for me to explain most of my views about this question.</p> <p>*I believe that these PIP proposals should be stopped now, and full and in depth research should be carried out on the DLA, with sufficient time for consultation, and with consultation which</p>

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		<p>covers all relevant questions.</p> <p>*19. Implications include: reduced claiming of services and entitlements, greater costs for all parties of multiple claims, increased ill-health, stress and misery etc for claimants as a result of the additional claims processes.</p> <p>*There's insufficient consultation time for me to explain most of my views about this question.</p> <p>*I believe that these PIP proposals should be stopped now, and full and in depth research should be carried out on the DLA, with sufficient time for consultation, and with consultation which covers all relevant questions.</p> <p>*20. As far as I can see (eg number and success of appeals, and the proportions of people with CFS/ME allocated to the support group at the various assessment stages when compared with the medical [which also happen to be functional] definitions of CFS/ME) the evidence base for the appropriateness of the ESA system is extremely weak, and the problems with that system should be resolved before it is used to reduce claimant's benefits via links to the DLA or PIP systems.</p> <p>*I believe it is important to avoid any 'merger' of DLA with social care which would result in loss of the research-proven efficiencies of cash payments. I believe that DLA cash payments are of more effective use than the 'fettered' method of social care provision (even those of direct payments).</p> <p>*There's insufficient consultation time for me to explain most of my views about this question.</p> <p>*I believe that these PIP proposals should be stopped now, and full and in depth research should be carried out on the DLA, with sufficient time for consultation, and with consultation which covers all relevant questions.</p> <p>*21. Page 10 para 20 PIP ... 'identifies those most in need of extra support': I believe this intention behind PIP needs to be supplemented, and informed, by identification of risks to disabled/sick people of different cut-off levels from that support.</p> <p>*Page 28 Table 2: 'some disabled people with lesser barriers to leading independent lives will receive reduced support, but this has been justified by the policy aim to focus support on those with greatest needs'. What is the evidence base, and risk analysis, relating to the effect of loss of DLA on those with 'lesser barriers' which informed the policy aim?</p> <p>*What is the evidence base for considering that it is appropriate for 20% fewer people to claim PIP than DLA? What is the equality impact assessment for this reduction? Is the 20% reduction norm-referenced, or is it based upon criteria-based evidence which shows that 20% of claimants do not need to be claiming DLA?</p> <p>*What is the evidence base that the intended 20% reduction is even going to be cost effective when taking into account all facets of its impact?</p>

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		*In relation to the need to reduce overall public expenditure, perhaps there are more effective ways of doing th
EM722	17/02/2011	<p>1. Your response: In my case, social stigma (severe manic-depression coupled with physical disability and illness) and having conditions which can wildly fluctuate from a day-to-day basis. Mobility issues and the huge costs of transport need to be taken into account.</p> <p>*2. Your response:The money should be given to the person on senior carer. Financial independence is perhaps one of the only things most of us on the highest rate have to keep us going. I find it repugnant that people who are on the highest rate of the care component, and have been "reviewed" should undergo new tests. Limbs don't grow back, people with progressive, chronic illness don't get better.</p> <p>*3. Your response: In my case, supervision and using my money to pay others do things I cannot do , such as shopping, household chores, hospital/clinic visits. Many need 24-hour support for feeding, washing, dressing, etc. Clothing/bedding costs are very high in my case having no bowel control. Many services required and not provided for free and require costs</p> <p>*4. Your response:The existing system has 2 rates and appears to work well. I see no need to change it.</p> <p>*5. Your response:Yes. You cannot cure many debilitating illnesses or disabilities. Many on the highest rate are incapable of managing the simplest of tasks on a day-to-day basis. Some people will never be able to find employment due to the severity of their illness/disability. Vulnerable people must be handled with care, not contempt. Compassion not derision. Or perhaps allow people like myself to lawfully be euthanatised.</p> <p>*6. Your response: For me, who is housebound with multiple chronic conditions, internet access and a computer have helped me find a voice to communicate to the outside world. Many people do not have supportive families or have a partner to help. The isolation and loneliness is crippling in itself. It would be nice to have the ability to access services on a more personal basis. There are many support networks online but people such as myself would appreciate services such as befriending, etc.</p> <p>*7. Your response:Assessors need access to full medical records and consultancy reports. I was shocked when I was reassessed last year by a nurse who did not understand the numerous consultant's notes in my file and I found that I had to explain to that person from ATOS what severe/malignant hypertension was and how it leads to a rapid decline a shortens life in some cases where a person might not see the next year. In my case I have tinnitus, blurred vision, severe head pain (I have had 2 mini-strokes), ataxia, heart arrhythmia and tachycardia with a pulse at rest of 120 BPM, incontinence requiring me to be near a toilet at all times, clumsiness, lack of balance, I rely on support to get me out of a chair, oedema</p>

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		<p>which fluctuates wildly on top of having to manage manic depression with attendant hallucinations and psychosis. The nurse had no medical knowledge beyond psychiatry. Professional doctors MUST be used in reassessments.</p> <p>*8. Your response: Obviously.</p> <p>*9. Your response: I didn't realise I was even entitled to DLA until 9 years ago, and I'm [REDACTED] years of age. So I starved and heavily relied on the NHS, not having family or friends for support. People need to know what they are entitled to for help - not just financially.</p> <p>*Perhaps a severely disabled person should have their form filled in by a clinician. Or do away with forms which a person might not be able to understand or fill in. Send a short form to their G.P./clinician instead.</p> <p>*As for point 2, that's your job.</p> <p>*10. Your response: Medical records and reports.</p> <p>*11. Your response: In my experience, it took me 2 months to be well enough to get a taxi to the place where I was reassessed. It's a 15 min. walk away for a person in good health.</p> <p>*I did consider a home visit but would not have been able to say in advance what my conditions would be like on said day. I wish I had done so, in retrospect. I was left waiting for 2 hours in severe pain surrounded by uncouth alcoholics, drug addicts and people with other severe mental health problems which upset me greatly. My health deteriorated in the build up and got worse much after, even though I passed the test. I was suicidal and have a plan worked out. This was MONTHS after the test.</p> <p>*12. Your response: Depends on the condition. Is it controllable? Does it fluctuate? If so, how? Daily? Weekly? Monthly? Yearly? I do not believe in arbitrary times for reviews. They must be flexible depending on the condition(s) the disabled person has. For instance, over the last few years when physical illness started to debilitate me, I could only manage to leave my rented home a handful of times per year at most. I have telephone consultations with my G.P. most of the time which occur every 4-6 weeks. Visits to hospital and for tests need several days of preparation (no food, for instance, in case of accidents as one example.)</p> <p>*Reviews should specialise on the person's condition, whether mental or physical or as in my case, both.*13. Your response: I am use what you mean having never experienced such difficulties.</p> <p>*14. Your response: Perhaps help from the voluntary sector who deal with people who have similar conditions or who have family members/first hand experience of the needs of people like us.</p> <p>*15. Your response: When your disabled, you know it. G.P.s and carers are best placed to advise people on whether they should claim, I would imagine. What needs to be avoided? Complexity, slowness of the system.</p>

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		<p>*16. Your response: I already use my DLA/Income support for such things. My father has/had a prosthetic hand, I don't think he should be/have been charged for it. Likewise with people who need wheelchairs, guide-dogs, walking aids, etc. These are essentials and should come from the NHS budget.</p> <p>*17. Your response: None. If you are disabled and require care, it should be obvious.</p> <p>*18. Your response: I have no idea. Perhaps the form should set out exactly what may or may not be available?</p> <p>*19. Your response: Reduced quality of life.</p> <p>*20. Your response: I have no idea.</p> <p>*21. Your response: I have no idea.</p> <p>*22. Your response: It has been closed to too many charities/support groups thus does not appear fair or balanced.</p>
EM723	17/02/2011	<p>To whom it may concern. Please find attached my response to the consultation. Kind Regards</p> <p>*Response by Richard Alford, Macmillan Citizens Advice Bureau Welfare Rights Worker</p> <p>*Please accept my apologies, but due to lack of time, I have concentrated on the main issues that affect the clients our service, namely people living with Cancer in East London.</p> <p>*In sum, the proposed changes will deny the vast majority of cancer patients help from Disability Benefits. Currently, many of our clients find it impossible to live on Employment and Support Allowance alone, and pay the extra expenses, such as increased fuel and food bills, and travel costs for treatment.</p> <p>*Often these patients develop acute care needs very rapidly on commencing treatment. They often require extensive care when treated as outpatients or discharged from hospital following periods as an inpatient, with friends and relatives often giving up work to help. For example, a patient receiving intensive treatment for Leukaemia or lymphoma is likely to have very low platelet counts and a compromised immune system, as well as chronic fatigue and nausea. Activities such as cooking a meal or using the bathroom are potentially extremely dangerous as a slip with a knife or a fall in or out of the home could cause fatal complications.</p> <p>*These patients, as well as the sufferers of other critical conditions, desperately need to access further support to help pay for their care needs, or the extra expenses of their treatment. They require the financial security to allow them to continue with their treatment and live healthy safe lives. These proposals seem to ignore patients in these situations. Support is desperately needed to plug this hole in our welfare system. The current White Paper proposals are likely to increase the problems faced by such people. Yours faithfully,</p> <p>*1. 2. 3. 4.</p> <p>*5. Should some health conditions or impairments mean an automatic entitlement to the benefit, or should all claims be based on the needs and circumstances of the individual</p>

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		<p>applying?</p> <p>*All claims should be based on the circumstances, but the benefit needs to be able to respond to people's needs when they are affected by certain conditions. A large problem with the current system is the lack of access for persons with medium term care needs and mobility problems caused by critical illness, particular example being those affected by cancer. The three month qualifying period already prevents cancer patients who are receiving Chemotherapy treatment, who often have severe care needs and would be in severe danger without access to care, from claiming any extra financial help (in addition to the £65.45 per week Employment and Support Allowance or Statutory Sick Pay) when they need it most. The proposed extension of the qualifying period to six months, will essentially prevent any person with a chronic condition, who develops sudden care needs as a result of treatment from claiming Disability Living Allowance. This will result in</p> <p>*(a) longer inpatient stays, leading to a greater burden on the NHS;</p> <p>*(b) an increase in poverty experienced by cancer patients, many of whom are currently unable to cover basic needs such as fuel bills and healthy diets, on an ESA income, which will contribute further to the United Kingdom's appalling cancer mortality rate; and</p> <p>*(c) a lack of access to crucial carer's benefits, such as Carer's Allowance and Income Support (for carers) for family members and relatives forced to give up, or reduce work to care for their loved ones.</p> <p>*The care needs associated with some chemotherapy treatments are not disputed. At the most basic level, the side effects of such treatments such as a compromised immune system or a low blood count can make performing ordinary functions in the home, such as cooking a meal a high risk activity. Weakness and fatigue can make even the most basic functions painful and dangerous.</p> <p>*Persons who are affected by such critical conditions and side effects are being neglected by the government's proposed reforms. If such problems are not going to be catered for in the Personal Independence Payment, another form of financial help, in cases of critical illness and short- to medium-term acute care needs would be essential to increasing survival rates, and providing ill persons with dignity and support.</p> <p>*6. 7. 8.</p> <p>*9. The form is currently extremely long and intimidating. For a person who is ill, filling in a 60 page form is almost impossible without professional help. The form should be streamlined, and the questions asked more open, to allow people to express in their own words the problems they have and the help that they need.</p>

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		<p>*Further, claimants need to be treated with respect and accorded the dignity that they deserve during the claims process. Staff should not commence any customer interaction with an assumption that the claimant is attempting to defraud the system or 'sponging.' Staff need to be more responsive to the needs of their claimants and be more accessible – an opportunity to see customer representatives face-to-face would be welcomed by many clients who struggle on the phone or with correspondence.</p> <p>*The turn-around time on PIP claims needs to be significantly quicker than the current 2-3 month processing time for DLA, which often leaves claimants in severe poverty and isolation while awaiting the result of their claim.</p> <p>*10. The patient should be the primary focus in the assessment. Any independent assessment must be carried out by a specially and thoroughly trained medical professional, preferable a doctor, to prevent a similar debacle to that experienced by claimants of Employment and Support Allowance, where staff training and quality control have been sadly lacking, causing humiliating experiences for claims, and spiralling appeal statistics.</p> <p>*11. A face to face meeting with a sympathetic and well trained healthcare professional could be a great benefit to claiming process. A thorough interview with the claimant will make the system appear more open and should reduce appeal numbers.</p> <p>*In many circumstances an interview at an office would not be appropriate. A particular example of this would be claimants with compromised immune systems due to extensive cancer treatment, or clients with continence problems. One claimant known to my advice service, faced the humiliation of a forty-minute bus journey with a commode, in order to attend an appointment for an ESA work-focussed interview. She was not offered any adjustments to cater for her disabilities. This sort of situation is even less tolerable with DLA/PIP and should be avoided at all costs. Assessment centres must be well enough resourced to respond to the needs of their claimants, and they must be sufficiently numerous to avoid long and difficult journeys to assessments.</p> <p>*12. The review should be waived in circumstances where the claimant's health would be put at risk through attendance, such as compromised immune systems and low blood counts.</p> <p>*In terms of evidence, a detailed interview with the Claimant is important, as well as the evidence submitted by their own general practitioners or consultants who often have an intimate knowledge of the claimant's difficulties.</p> <p>*13. Ultimately, people have to feel comfortable when interacting with the service provider. They must be able to trust the customer service representative that they are speaking to and feel that they are respected by the DWP staff. Further, claimants could be sent a response form, possible with a</p>

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		<p>prepaid envelope to submit responses as well as a list clarifying what would be considered a material change in circumstances.</p> <p>*14. A guide to the level of detail expected on claim forms would be essential to helping people make claims and to the transparency of the system.</p> <p>*15. 16. 17. 18. 19. 20. 21.</p> <p>*22. I am extremely worried that the new proposals will prevent access to disability benefits for people affected by cancer. The lengthening of the qualifying period is penal and unnecessary, and will affect those persons undergoing intensive treatment for between 3 and 9 months, who often have severe care needs, disproportionately.</p> <p>*I would propose that the waiting period be abolished completely where critical illness such as cancer is medically confirmed. Of course, only those in need of care and support should receive help, but waiving the qualifying period would ensure that those in need would receive financial help when they need it most.</p> <p>*If it is considered that such concessions cannot be made within the new PIP regime, the government must look urgently at the support available to those affected by acute critical illness such as cancer, their families and carers, as many are forced to live in danger and poverty by the DLA system, and such problems are likely to be exacerbated by the proposals in this white paper.</p>
EM724	17/02/2011	<p>1. There are many factors. Primarily those are:</p> <p>1. The Coalition's naked prejudice and belief that many disabled people are workshy, could be working if they just tried hard enough, or are fakers. Exaggerated Coalition statements about the number of people making false claims for IB and DLA have relied on flawed statistical analysis and played on the public's existing prejudices. Few people these days feel financially secure, and the Coalition is playing public discontent and fear like a fiddle, via propaganda in the right wing media that demonises vulnerable groups like chronically ill and disabled people, unemployed people and immigrants. There have been reports of verbal and physical abuse of disabled people in which the assailants have invoked these now common negative beliefs, e.g. that if someone is disabled they are necessarily a benefits cheat.</p> <p>2. Very simply: lack of money. Being disabled means that not only are you less likely to be able to get a job, you have extra living expenses. We're less likely to be able to put money by for emergencies. I do not know how many people will cope when their DLA and IB or ESA are taken away from them.</p> <p>3. The lack of understanding by both the DWP and employers that many people's chronic medical conditions fluctuate. I'll give you a personal example. I have severe Crohn's disease and consequent Intestinal Failure. In layman's terms, I have had a lot of my bowel removed, and the small amount that's left is full</p>

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		<p>of scar tissue that causes pain and interferes with my digestion. I can't absorb enough nutrients and calories from my food because my bowel is so badly damaged, so I have a feeding tube in my stomach and connect myself to a machine each night to receive liquid nutrients. I'm also on many different types of medication. These treatments are permanent. My stamina and energy vary a lot from day to day, and on the bad days I use a wheelchair. I never know which will be the days when I have severe and frequent diarrhoea, and which days I'll be able to go out without worrying about where a toilet is.</p> <p>*Having read the plans for changes to DLA and IB, it seems likely that I will lose my DLA and be migrated off IB and onto the Work group of ESA. In order to get a job, I will have to find an employer who is fine with me spending large parts of the working day in the toilet, who doesn't mind me having to rush there at a moment's notice whatever I'm doing, and who can cope with me calling in sick on the many days when I don't have the energy to go out.</p> <p>*Why would anyone employ me when they could have someone healthy? It's true that there are laws against disability discrimination in the workplace, but there are also laws to say that all shops etc. should be wheelchair accessible, and any wheelchair user will tell you that in practice, many places are not. *Furthermore, my education was completely disrupted by my illness. I was expected to go to Oxford or Cambridge - instead, I ended up with five GCSEs, which is the bare minimum requirement for most jobs advertised. With so many university graduates out of work, an employer doesn't even need to discriminate based on my health problems: they can quite reasonably state that there was a more highly qualified candidate, or a whole string of them.</p> <p>*My illness also means that I've never had a regular job: I was on benefits alone up to a couple of years ago, when I joined the Incapacity Benefit Permitted Work scheme as a freelance writer. The only reason I can even do that is that I can work part time and from home, set my own hours and defer work if I am unwell. 4. An infrastructure designed for the able which treats living a full life as a disabled person as an optional extra. Our lives are not optional; access to public places and transport and to business should not be optional. And too often, the very systems which are supposed to safeguard us treat us like fakers, cheats and troublemakers. Culturally speaking, while the UK has made great strides for disabled people's human rights, we are about to take a giant leap backward... and there was already a long way to go.</p> <p>*2. It should remain available regardless of whether a person has a job. The core concept of DLA is that it is meant to cover the EXTRA costs a disabled person has in living, yet Ministers do not seem to be taking this into account.</p> <p>*Also, a terminally ill person should NOT be re-assessed. Once</p>

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		<p>they are on DLA, that should not change for the rest of their life.</p> <p>*3. 1. Transport. Despite it being illegal, many taxi firms charge extra (and advertise this widely) if they pick up someone in a wheelchair. Not all buses and trains are equipped to be accessible, and in any case not every disabled person can manage to use them. People with limited stamina and energy will spend extra money on transport of all kinds rather than walking places. Disabled people often face higher costs to begin with because they have to visit their GP, hospital and other health services more, make more trips to the chemist, etc. This is a particular problem when unexpected health problems arise (and in my experience, they do so frequently). The make of feeding tube I use once developed a fault which the manufacturer insisted for many months did not exist (they eventually acknowledged their culpability following restructuring), and I had to keep going to hospital on a moment's notice to get the tubes replaced. As the problem was not life-threatening I couldn't call an ambulance, but it was nevertheless imperative for me to get the tubes changed each time by the specialist nurse, as I use the tube every night. The total cost of this series of urgent hospital dashes was £88 in taxi fares, over a few months. That is a huge chunk of income for a person on benefits, and I know other people with different conditions have had similarly frequent hospital dashes.</p> <p>2. Food. When people have limited stamina and energy, or limited ability to use their hands or stand without pain/difficulty, they often need to buy processed foods and ready meals, or order takeaways, because they cannot manage to prepare a meal from scratch. These foods are much more expensive than the raw ingredients would be. Disabled people living alone also face the well-known extra cost that comes with that: most foods are packaged in family amounts, and there is more wastage when living alone.</p> <p>3. Utility bills. People isolated in their home have greater need of the phone and internet to maintain social relationships and summon help if needed. People with limited mobility feel the cold more and will have much greater expenses for heating, and people who need to wash clothing/bedlinen/etc. more due to continence issues, being immunosuppressed and extra careful about infections, etc., will have higher water bills.</p> <p>4. Carers. If a family member is caring for a disabled person, this impacts the number of hours they can be in paid work, if they can at all. The entire household's income is affected by the fact that one person in the family has a disability, and it is not possible for everyone to claim Carer's Allowance. Many disabled people do not have relatives who can help them, and have to pay for private carers - particularly since the state is increasingly unable to provide adequate care packages. Carers do things for people that are as fundamental as helping them dress, bathe, use the toilet and eat.</p>

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		<p>*4. What an extraordinarily ignorant question. If there are not already multiple rates per component, then the local DWP office has been sending me some very imaginative letters! I, for example, am on the lower rate of the Care component of DLA. 1st question: not necessarily, and a lot of the problems people have understanding the benefits system we have now reflect the fact that DWP staff are often highly ignorant about how the system works. I've been told vastly contradictory things by members of staff in the same office. 2nd question: there are already multiple rates, and I can tell you from experience that it's easy to have different staff tell you different things about what rate you should be on. I had a DWP staffer tell me I ought to be on higher rate Care, but when I submitted a form challenging the existing decision, it was only reinforced. Proper training of DWP staff, with regular updates, are the single biggest thing that would improve the clarity of the system and enable staff to communicate it to the public in a way that they find understandable.</p> <p>*5. I would say that terminally ill people should be automatically and immediately entitled. An email from their consultant or GP (with a system of verification; perhaps unique ID numbers for the doctors to use in interacting with the DWP) should suffice to organize this, such is the urgency of the situation terminally ill people and their families find themselves in.</p> <p>*I would say that some other conditions or impairments should also mean automatic entitlement, BUT this should not imply that other conditions are automatically *not* entitled. There should never be a point where someone's condition alone disallows them from benefits. I would advocate a blending of the two approaches your question implies, in that claims should generally be based on the specific circumstances of the individual, but there should be recognition that some conditions impairments are so overwhelmingly problematic and expensive to live with that DLA is automatically awarded.</p> <p>*6. Mobility within and outside the home (whether that is a private home or an institution), facilitated by whatever mobility aids or support people are necessary, and by public and private hire transport.</p> <p>*Eating and being able to choose one's food, not having to be dependent on whatever's cheapest regardless of whether it is satisfying, nutritionally complete and enjoyable.</p> <p>*Social contact: people should be able to get out of the house to see people; they should not be restricted by the cost/availability of transport methods suited to their needs. People should be able to afford telephone and internet use - these are particularly important when one is housebound or suffering from mental health problems.</p> <p>*Access to education, training and work without jeopardising benefits entitlement. As I've explained, a lot of people with chronic health problems are incredibly vulnerable, and will be</p>

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		<p>moreso when the Permitted Work scheme ends completely.</p> <p>*7. You need to contact people's doctors - no, not their GPs, as happens now, but the CONSULTANTS they specify on their claim forms. Let me tell you what happened to me:</p> <p>*For years in the course of filling in claim forms, I naively specified my consultant instead of my GP in the 'who would you like to have tell us about your condition?' box. I rarely saw my GP for my conditions, which require complex management in the long-term. My consultants at hospital were the people who knew what was going on and how my health affected my life.</p> <p>*When I made the aforementioned attempt to challenge the decision to award me the lower-rate Care component of DLA, the DWP staff member I spoke to explained to me that his fellow staff never contact consultants, because they assume consultants will not get back to them.</p> <p>*In other words, claimants are misled by your forms into thinking that the most useful and relevant professional perspective on their conditions will be sought and taken into account. This is a huge problem. *What I would suggest in addition is that you hire medically trained people to read and interpret claim forms. At the moment you have people with no medical training or understanding, essentially using the forms as a checklist. No interpretative skill is needed or understood to be needed.</p> <p>*NHS cuts mean that many medical staff are going to lose their jobs. Logically, it would make sense if these people were offered jobs in the benefits system. You can no longer treat the claim form processes as something to be subcontracted at the lowest price; ATOS have proved again and again that they are incapable, but I don't believe the problem can be solved by simply subcontracting another similar organization and not fundamentally changing the way claim forms are viewed.</p> <p>*8. 1st question. No, they should not be taken into account. It's completely ridiculous and unrealistic to suggest that someone's inability to walk is completely balanced out by the fact they use a wheelchair. Using a wheelchair is NOT equal to walking; a vast number of places and transport are not equally accessible, and prejudice means that a vast number of workplaces will not welcome a visibly disabled person. This applies to all aids and adaptations. 2nd question. When you say "might" be eligible for and "can easily obtain", you expose the flaws in the logic of such a proposal. Very often, what one is officially *supposed to* be able to obtain and what one actually *can* obtain are two very different things. This is particularly true given the massive funding cuts that are in effect across the health and social care sector. Do you really think there will be enough wheelchairs and other equipment/services for people who need them NOW, when there weren't even before the recession and associated cuts?</p> <p>*9. I'd love to be able to fill in a claim form online, like I can with</p>

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		<p>my tax return. As with HMRC's system, it should let you save the form whenever you like and go back to it later - this would be great for people who feel intimidated by long forms, or have trouble sitting at a computer/typing for long periods. The other advantage of HMRC's system is that at the end I can choose to save my return as a PDF or plain text file - this would be very handy for benefits claimants too.</p> <p>*Naturally, the website would need to recognize the common voice-activated typing programs, and text-to-speech ones, so that visually impaired people and people whose hands are not functional enough to type could use the system. *An email query system would be really helpful too.</p> <p>*10. Please refer to my earlier answer about contacting the consultants specified by claimants. I would also encourage assessments by physiotherapists and other nominated medical personnel who have experience of the claimant.</p> <p>*11. In my experience this can be a mixed blessing. I used to have a doctor come to the house to assess me for IB, and it was good in that they could help me to understand the questions (a lot of people have trouble understanding that they need to talk about the full spectrum of their condition, the bad days as well as the good ones). I had more confidence in that system because I was talking to a doctor - generally they were, or had been, GPs - and so I could assume a higher level of understanding than I could from a non-medical individual. There was one occasion when a doctor seemed highly skeptical of me, and the main problem I can see is for people with conditions like Chronic Fatigue Syndrome where some doctors don't even believe the condition exists. But seeing a doctor still gives them a higher than otherwise chance of having their needs understood, since the alternative is someone doing a box-ticking exercise at ATOS. *One issue is that doctors who do this work might be a self-selecting group. On the one hand you might get the really compassionate doctors who want to ensure that people in dire need of benefits have their needs recognised, but you might also get the jaded, burnt-out doctors who are exhausted from the demands of general practice and have the attitude that a lot of claimants are malingerers and it is their job to do a witch hunt.</p> <p>*There needs to be some thought about how to find a happy medium - certainly, these doctors' performances should be audited somehow, and NOT in a 'they get marked up or down for the number of people they find should/shouldn't receive benefits' way.</p> <p>*Requiring a face to face meeting is inappropriate where someone is bedbound or housebound. A friend with Chronic Fatigue Syndrome has not been able to claim benefits because the DWP insists that he comes out to see them; they have been very obstructive when he has asked for a doctor to visit him instead.</p>

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		<p>*There are also issues regarding people with some mental health problems: if someone is very distressed and perhaps suicidal, in some specific circumstances I can imagine their being pushed over the edge by the requirement for an intimidating meeting in person. I would be very wary about making benefits receipt contingent upon a face to face. Think about the kinds of people who perform poorly in job interviews, exams and other highly charged situations - not everyone expresses themselves well, and ironically this can be particularly true of some of the people in greatest need of support.</p> <p>*Also, something I've heard from other disabled people I know: when asked to have a face to face meeting, or when attending a tribunal, I've known people who were afraid to look too well-kept (washed or brushed hair/clean and tidy clothing/personal expressions such as hair dyed unusual colours, tattoos or facial piercings) because their experience of the DWP suggested that unless they looked unkempt, it would be assumed that they must be well enough to work.</p> <p>*Finally, as someone who was recently attacked in my street and threatened with being burnt out (this was a disability hate crime) and has a lot of fears about strangers coming into my home, I would find it highly intimidating if I was told that it was mandatory to receive a home visit.</p> <p>*I might choose to arrange one and find ways to cope with it if I absolutely could not get out of the house, but there should never be a situation where someone is told, 'We are coming to your home and if you do not let us in, you will not get benefits'. Again, there are many, many vulnerable people for whom this would be a problem, including rape victims (imagine if you needed benefits and the decision hinged on your allowing an unfamiliar man in your home when doing so reminded you of the rape).</p> <p>*It should also go without saying that every effort should be made to accommodate the claimant with regard to dates and times convenient for them for any face to face meeting. They should be allowed to have someone with them, and they should be allowed to record any such meeting and to have said recording taken into account in any subsequent challenge, tribunal or legal situation.</p> <p>*12. Different types of review sound like a good idea. There is at present a longer gap between IB reviews for people whose conditions are regarded as severe and uncontrollable - this is only sensible, both from the point of view of saving claimants unnecessarily frequent and distressing reviews (how often would you want to talk about your incontinence to a stranger?), and saving the DWP money. It should be common sense (and again, listen to doctors on this) that people with certain conditions and impairments are unlikely to experience change of the kind that means they no longer need their benefits.</p>

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		<p>*Also, terminally ill people should not have reviews: it is painful and demeaning to them and their families at the very time when the system should be supporting them instead of adding to their distress. My friend's father has had terminal cancer for five years. Despite the period of his survival, it is very much a matter of "when", not "if" he is going to die. Yet he recently got a letter from the DWP asking him why he was still claiming benefits. He telephoned the office and apologised to them for still being alive. He should never, ever have had that experience.</p> <p>*13. The reason a lot of people don't keep you informed is that their conditions fluctuate so much - having a good period should not mean I lose my benefits, specially since a bad period will follow and I will then be even more vulnerable. It would be good if you monitored people gradually over time rather than jumping to remove benefits.</p> <p>*Maybe if someone has a fluctuating condition and wants to work, it should be possible for them to be fast-tracked if they stop being able to work, i.e. if they get worse again they can return within weeks to the level of benefits they were previously on.</p> <p>*14. Explanation of how decisions are made. You need to make public the guidelines you give to decision-makers, about different conditions, etc. Transparency should be the watchword.</p> <p>*15. I'm having difficulty understanding the question.</p> <p>*16. Yes, definitely.</p> <p>*17. I don't feel equipped to answer this, but I would suggest taking paediatricians' experience into account - many conditions present differently in children and will have very different effects on them to adults. Talk to specialists so that you understand their specific circumstances.</p> <p>*18. I understand from others' experiences that it's been very effective; perhaps not always perfect, but it would be terrible if the existing passporting arrangement ended.</p> <p>*19. Poverty for disabled people and a bureaucratic nightmare for the DWP. Let's not forget the reasons passporting was introduced, and let's also not forget that passporting saves the DWP an enormous amount of time and money because you don't have to assess the same people several times asking basically the same questions, for multiple services. Getting rid of passporting would be a woeful, inefficient and costly backward step.</p> <p>*20. I don't have enough personal experience to answer this.</p> <p>*21. Unfortunately due to considerations of time and energy I'm not going to be able to answer this.</p> <p>*22. I have never in my life known such widespread fear of poverty and fear of the Government as I have since the proposals became public. The proposals in themselves have done terrible harm to the way disabled people view government</p>

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		and the way the public views disabled people.
EM725	17/02/2011	<p>I am writing to give my response to the proposed changes on DLA. DLA isn't broken - please don't fix it.</p> <p>*1. Your response: physical barriers- lack of ramps, small signs etc. Mental barriers- discrimination. Lack of support, lack of confidence, pain, energy levels. The things they are unable to do because of their disability.</p> <p>*2. The way of submitting evidence, no medicals, different rates</p> <p>*3. Your response: equipment, increased cost of energy due to being at home more, buying processed food, having to have a car or using taxis as unable to use public transport, parking costs, fuel costs, increased costs of accessible holidays etc, paying for carers, cleaners, paying for accompaniment/supervision/support, medication costs, lost income due to sickness absence, lost income due to inability to work, respite..... this is probably different for every disabled person.</p> <p>* 4. Your response: The three rates existed for a reason, to allow for different levels of need, and I feel these are necessary.</p> <p>*5. Your response: certain conditions should carry automatic entitlement, conditions which are stable, unlikely to change- either deteriorate or improve, and where they are already assessed using standardised measures by health service, such as paralysis, sensory impairments etc. Terminal illnesses should have automatic entitlements. Other conditions, such as mental health difficulties, affect different people in different ways, but this assessment of needs can be based on existing medical evidence, not medical assessments.</p> <p>*6. Your response: meaningful daily activity, socialising, being able to leave the house, shop, see friends, function, attend treatment, access support, work towards their goals for life.</p> <p>*7. Your response: ask the individual, and their health care provider- they already know!!</p> <p>*8. Your response: should consider any tasks which are harder for the disabled person to do, even if they can do the task with aids. Such tasks may take longer or take more energy, or not be practical. You can't assess people for aids they don't have or use, that is simply ridiculous.</p> <p>*9. Your response: Not cut support to advice agencies to help with forms. Forms clearer, questions more straightforward, examples given in questions. Have info relevant to particular conditions to send out with forms. Have the forms read and assessed by people with medical knowledge. Not have a form cover the same assessment as a medical- this is patronising, and offensive as it communicates an assumption that the claimant is lying or unable to assess their own health</p>

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		<p>accurately.</p> <p>*10. Your response: medical evidence from the person's own health care team, and evidence from that person. Evidence from carers.</p> <p>*11. Your response: this is incredibly stressful for the person, and is a waste of time and money. The info already exists, in health records, and in the knowledge and expertise of the person, and their health care team. If ATOS conduct the assessments, they will be worthless. Having someone visit at home is extremely stressful and humiliating. It's not necessary.</p> <p>*If such appointments are deemed necessary, these should be for the more complex conditions, stable health conditions or disabilities do not need this level of assessment.</p> <p>*12. Your response: Timescales should be based on medical evidence from the person's own health care team, based on the likely progression of their condition. Stable conditions should not need regular review. Something like stable sensory impairment should not need to be repeatedly assessed. The person should be able to request a review is scheduled should their functioning deteriorate. A form based on a copy of the last report, with spaces for amendments/additions, should suffice for all but the most complex/changeable conditions.</p> <p>*13. Your response: make this easy!! Allow multiple methods of communication- email, text, etc. Allow people to nominate someone to communicate on their behalf- not everyone is always able to do this. Make it less intimidating. make staff better trained (sounding like they care would be a good start) and make it so that you can call and say what you need to, without being passed to 5 different people.</p> <p>*14. Your response: YES they need benefits advice workers- people live with their disability full time and may not be aware of the things they don't do or do differently due to their disability. These staff are vital and know what questions to ask. This should be offered to everyone applying, in a way that suits them- face to face, at home, over the phone, by email etc. These staff need to be independent to the claims process- so they are not motivated to discourage claims.</p> <p>*15. Your response: I don't feel it is appropriate to "require" people to access help they don't want. This is patronising and demeaning. Disabled people are able to make their own choices, however unwise these may be, unless this is assessed as not so (see Mental Capacity Act 2005)</p> <p>*16. Your response: absolutely, the option to meet a large expenditure with future payments should be offered, although advice would need to be provided to ensure full consideration of the impact of reduced future income is considered. It would be great to see benefits able to provide maintenance/repair/insurance contracts which are non profit for these vital aids.</p>

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		<p>*17. Your response: The normal level of care required by healthy able bodied children. Arrested/delayed development and what would be considered age appropriate for a child. The emotional impact and stress on parents. Impact on siblings and other family members. Not all costs are financial in nature but services can be provided to ameliorate these, such as respite and befrienders.</p> <p>*18. Your response: DLA is crucial as a gateway benefit, to other services and benefits. Enhanced levels of income related benefits, disabled travel concessions, carer free schemes, social tariffs on energy bills. *19. Your response: this would be huge, it would require many, many more assessments to be conducted and massively increase bureaucracy, costing a huge amount of money. It would also be extremely stressful for claimants, who already find it difficult to claim. It can be demeaning and demoralising to constantly be having to prove oneself, and many may end up not accessing support they would be entitled to.</p> <p>*20. Your response: Info from DLA from health professionals could be used to assess for income related benefits such as ESA, ruling out the need for repeated assessments. There should be a national card scheme to enable those with hidden disabilities to more readily access support. A blue badge should be automatically issued if there are assessed mobility needs.</p> <p>*21.</p> <p>*22. Your response: Just a few things....</p> <p>*DLA is a vital benefit for disabled people to meet the extra costs incurred as a result of having a disability. It is NOT an out of work benefit. It enables many disabled people to access employment or volunteering, and be part of society. I am alarmed by how many politicians refer to DLA as an out of work benefit, and are clearly ill informed. If they are not ill informed, then they are misleading the media in a disingenuous attempt to demonise benefits claimants.</p> <p>*Secondly, the rate of benefit fraud for DLA is tiny, around 0.5%. This is because it is already ridiculously difficult to claim- there is no need to make it harder! Given that fraud is so low, the government's plans to decrease spending on this sort of benefit by 20% is unrealistic, cruel, and victimises the most vulnerable in our society. Given the rate of fraud, one can only conclude that the government intend to withhold benefits from genuine claimants, who genuinely have needs due to disability. Again, victimising the most vulnerable and already most marginalised group in our society.</p> <p>*Thirdly, I massively object to the intention to have ATOS healthcare administer medicals for this new proposed benefit. ATOS have more than adequately demonstrated their complete incompetence, their utter contempt for benefits claimants, and their commitment to profits above all else with the medicals for IB/ESA. These medicals are delivered by poorly trained staff,</p>

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		<p>are not even GPs, never mind specialists in all the health conditions they come across. They use a computer program to assess, selecting and matching phrases on screen with a claimant's answers. Often claimants aren't asked about particular areas of functioning, and miraculously, these areas are assessed in the final reports. It is clear ATOS get financial incentives for finding people fit to work, and this is no way to assess health. The rate of appeals, and subsequent backlog, is enormous. The appeals system costs the taxpayer a fortune, with many claimants having their benefits reinstated (around 70%). ATOS cost the taxpayer a fortune. What's more, the medicals are extremely stressful and humiliating, with claimants being treated appallingly. The CAB and other advice services have independently assessed ATOS's "contributions", this is not just personal opinion, rhetoric or anecdote.</p> <p>*DLA is currently assessed by evidence from a claimant's own health care team. The people who know their health condition the best. The people who understand the impact on their functioning the best. The people who know the individual. THE SPECIALISTS!!! Why pay poorly trained ATOS staff when the knowledge and expertise already exists within the NHS? I would argue that the person best placed to assess the impact of someone's disability or chronic health condition is their health practitioner. So I believe it is unwise and a waste of funds to see ATOS employed to do this.</p> <p>*Finally, I would like to talk about how crucial DLA is, in enabling people to function, to live a life, and to maintain some sense of dignity and independence. I have a somewhat interesting perspective on this.</p> <p>*I am registered blind. I receive DLA, which I use to help me meet increased costs, such as buying processed foods as I find it very hard to tell when things are done and to cook without injuring myself. It contributes towards the costs of taxis, as I cannot use public transport for unfamiliar journeys, when it is dark, when it is too brightly sunny, or when the constant eye strain causes migraines and my vision deteriorates entirely. It allows me to have carers accompany me to places and social events, as I would be unable to safely navigate these. It contributes towards delivery costs, so I can shop online, as I find it difficult to find things in a store or supermarket.</p> <p>*I am also a carer for someone with long term mental health problems, including severe depression, anxiety and PTSD. Her DLA contributes towards the cost of extra energy bills, as she rarely leaves the house. It enables her to use taxis when her anxiety becomes too much, or she needs to travel at busy times. It pays for ready meals, for when the depression means her concentration is impaired, and cooking would be both impossible and dangerous. It enables her to order things online when her anxiety is severe. It allows her to get taxis home after therapy, and at other times of high distress. It enables her to go</p>

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		<p>out at night, accompanied by a carer, which would be impossible if she had to use public transport, due to anxiety and confusion.</p> <p>*Finally, I am a CBT therapist. I work with people with common mental health problems. Every day, I see examples of how DLA can enable people to continue to function, to contribute to society, to work, attend education or training, or volunteer. To have some measure of independence. Unfortunately, I also see daily the huge negative impact that rejection/withdrawal of benefits has on people's lives and ability to function. I have watched as people's health deteriorates, due to the stress of not knowing if they will be able to keep a roof over their heads or get to work. Particularly, I see the huge detrimental impact of ATOS "medical" assessments on people's lives. DLA IS NOT BROKEN. DON'T FIX IT. TRY TAX AVOIDANCE. THAT'S WHERE THE REAL MONEY IS, Regards,</p>
EM726	17/02/2011	<p>I am 25years old. I have recently graduated and have been in fulltime work since November. I have Ehlers-Danlos syndrome and use a wheelchair. Please find attached my thoughts on the DLA reform. Regards</p> <p>*Response to proposed DLA reform*Whilst difficulties face by many people who suffer temporary incapacity, for example a period of reduced mobility due to a sports injury, differ vastly from the everyday and sometimes lifelong struggles of those with chronic illness or disability, the proposed six month qualification period concerns me. A high proportion of individuals with acquired disability become disabled suddenly, for example through traumatic injury resulting in paralysis or through stroke. Such individuals incur vast equipment and care costs from the outset of their disability, whilst adjusting to the emotional impact of their situation.</p> <p>*Regarding automatic entitlements, it is important that all cases are considered with respect to individual need. However it is vital that terminal illness remains a special case. It is also imperative that the process for review is not overcomplicated.</p> <p>*It was my understanding the DLA was intended to provide financial support for both human and non-human sources of assistance. Disability related aids and adaptations whilst notoriously expensive, can change lives. I place high value on my independence, saving up my mobility allowance enable the purchase of a lightweight wheelchair. The NHS does a fantastic job (and has saved my life multiple times) however it does not have the financial resources to provide very lightweight wheelchairs to all those that would benefit from one. I have no doubt that this is also the case for top of the range hearing aids and other equipment that enables thousands of individuals to function. My lightweight chair makes the difference between being able to propel myself and need someone to push me, to being able to work full time as opposed to part time. My chair was funded entirely through my DLA, as are replacement tyres</p>

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		<p>and the gloves that enable me to self-propel without cutting my hands. DLA enabled me to pay for the costly adaptations which enable me to drive – the use of a car is vital for many disabled people to work, attend hospital appointment, access training and do voluntary work.</p> <p>*I agree that the system has become too complex – the current application form is very time consuming and lacks clarity – adding to the burden of people with disabilities and their carers.</p> <p>*I agree that those that can work should be supported to do so. However the government appears to be telling people (many of whom desperately want to work) that they should be employed whilst simultaneously drastically cutting funding for schemes (such as Access to Work) that have previously supported people to achieve sustainable and meaningful employment.</p> <p>*Barriers to leading independent, full and active lives include fatigue, pain, additional time taken to achieve very basic activities – even with assistance, high costs of aids and adaptations.</p> <p>*The main extra costs that disabled people face include: equipment, employing personal assistants/carers, additional transport costs, heating and electricity bills (extra laundry etc), special dietary requirements.</p> <p>*Reducing to two rates per component will lead to the benefit forcing people into an even smaller number of possible boxes – this can not possibly take greater account of the diversity of disability.</p> <p>*The activities I believe to be most essential to everyday life are:• Staying safe• Eating and drinking• Personal hygiene• Social contact• Getting about• Working</p> <p>*I believe that taking to account a disabled person's ability to use aids and adaptations would result in penalising people for the hard work they have put into learning to use equipment or adaptive technology. This will discourage independence and foster a far greater dependency on the state.</p> <p>*Proposals to take successful use of aids and adaptations into account concerns me greatly. It is my understanding that disability benefits are designed to support individuals with the financial burden incurred through the employment of personal assistants the purchase of aids and adaptations, which enable some of the most basic tasks to be undertaken.</p> <p>*The claim form could be made easier to fill in by reducing the length of the form and pointing to sources of support at the application stage.</p> <p>*Each individual should be appointed a co-ordinator, responsible for collecting supporting evidence.</p> <p>*Ensuring that processes are straightforward and clear would encourage people to report changes in circumstances.</p> <p>*In terms of funding aids and adaptations, few costs are truly one-off, for example powered wheelchairs require an annual service, batteries need replacing etc.</p>

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		<p>*When assessing children it is vital to take into account that children by definition are constantly growing and progressing through developmental stages, thus any aids or adaptations will need replacing more regularly.</p> <p>*With regard to passporting arrangements the link between the mobility component and the blue badge scheme is very useful as it is one less form to fill in. Closer links with occupational therapy and social services would be useful.</p>
EM727	17/02/2011	<p>1. Difficulty using public transport. Isolation, Stigma that they are just benefit scroungers, esp with hidden disability. Difficulty paying essential bills when their income drops due to illness. Problems looking after their personal care without help.</p> <p>*2. Your response:</p> <p>*3. Will detail the problems that people affected by cancer face:</p> <p>*Travel costs, for example people affected by cancer and unable to access hospital transport and public transport due to highly compromised risk of infection, nausea and sickness face paying large taxi fares to get to their numerous hospital appointments. They also incur extra travel costs in a bid to stay active in the community because of the health issues detailed above. Higher fuel bills due to being at home, and from feeling very cold, weak, tired and weight loss.</p> <p>*4. Will having two rates ...? This benefit has been constantly changed and messed around with. It is still incomprehensible to many people affected by illness. Obviously impossible to say without knowing the criteria for both.</p> <p>*• What, if any, ...? Your response:</p> <p>*5. health conditions or impairments that should have an automatic entitlement to the benefit: Motor Neurone Disease. People undergoing lengthy and extremely debilitating treatments for some cancers – i.e. leukaemia treatment often takes intensive treatment for over a year with immune systems completely destroyed to enable to possible stem cell or bone marrow transplant.</p> <p>*6. Your response: Getting out and about without needing to rely heavily on the goodwill of others. Keeping your dignity and respect at home; washing and toileting needs.</p> <p>*Being able to cook and eat fresh food. Being able to communicate in a meaningful way with others.</p> <p>*7. Your response: The best way to ensure that the new assessment appropriately takes account of variable and fluctuating conditions would be to talk to occupational therapists, to actively ask the question about good and bad days. To take into account the cumulative effect that a fluctuating condition can have on a person's ability to take part in society and to lead a meaningful life, esp to work. Not many employers would welcome a person off sick on a regular basis because their condition disables them off and on.</p> <p>*8. Your response: If you decide that a person can manage in a wheelchair, will you take into account the ease of pushing that</p>

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		<p>chair without help? The ease of using public transport? Getting in and out of many local shops? You need to take into account the issue that is a person can get in and out of a bath using a grab rail, can they do so safely? What if they fell?</p> <p>*9. Your response: Honestly – I have seen many manifestations of the DLA form. It is hard to know how it could be easier to fill in. You need to make it explicit that people need to expand on the tickboxes, or you need to accept and award on tickboxes alone. Publicise it. Train frontline staff, esp in jobcentres as to its criteria. I have seen many claimants come to our service after DWP frontline staff on hearing a person has cancer has said, “you should claim DLA”. We then are left to manage expectation and fully explain the criteria.</p> <p>*10. Your response: Independent, impartial, non-performance led occupational therapists. GP reports. Medical reports by the doctor and the consultant or clinical nurse specialist who knows the condition best and the problems with mobility and personal care that the condition can give rise to.</p> <p>*11. An important part of the new process is likely to be a face-to-face discussion with a healthcare professional.</p> <p>*• What benefits or difficulties might this bring?</p> <p>*Given the ESA medical assessments undertaken by Atos, I can only state that using this method is an extremely bad idea. We successfully challenge on a regular basis incomplete and incorrect assessments. The appeal rate for ESA challenging the EMP assessment should tell you that this method is not working. *Any private company working to targets or performance based criteria will never be able to make an unbiased assessment. I strongly feel there is conflict of interests by using your appointed medical assessors.</p> <p>*• Are there any circumstances in which it may be inappropriate to require a face-to-face meeting with a healthcare professional – either in an individual’s own home or another location?</p> <p>*Your response: Special rules. People detailing that they need to avoid public places due to phobia or extremely high risk of infection.</p> <p>*12. How should the reviews be carried out? For example:</p> <p>*• What evidence and/or criteria should be used to set the frequency of reviews?</p> <p>*• Should there be different types of review depending on the needs of the individual and their impairment/condition?</p> <p>*Your response: For progressive conditions a face to face review should not be necessary.</p> <p>*13. The system for Personal Independence Payment will be easier for individuals to understand, so we expect people to be able to identify and report changes in their needs. However, we know that some people do not currently keep the Department informed. How can we encourage people to report changes in circumstances?</p>

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		<p>*Your response: DWP letters are historically baffling in their layout. The type and font used in the DLA award letters does not clearly enough set out that people need to report changes. it is usually buried in a mass of type on the 2nd or 3rd page.</p> <p>*You state in your consultation that two thirds of DLA awards are for an indefinite period and you imply that because of this many awards are not checked for years. I would challenge your assertion as for quite a few years now “indefinite” has meant three years only. In my experience most awards are “reviewed” after one year. This is reasonable. 3 years for special rules claims is reasonable.</p> <p>*For progressive and degenerative disease it is not appropriate to reassess yearly. Sanctions are not the answer. You need to clearly state that an award will last only as long as needs are present.</p> <p>*There are barriers to contacting the DWP and the DCS – cost or telephone calls to BDCs, inability to get through, language and disability being just a few.</p> <p>*14. What types of advice and information are people applying for Personal Independence Payment likely to need and would it be helpful to provide this as part of the benefit claiming process?</p> <p>*Your response: We see so many claimants who just feel completely overwhelmed by the dla claim form and feel completely unable to complete the form without assistance.</p> <p>*The layout is unclear. You ask people to tick the relevant boxes and then ask if there is anything else they may want to add. I have yet to see a successful application from a claim form where the claimant has just ticked the boxes. You need to be explicit that they need to provide additional information to support the ticked boxes.</p> <p>*We are welfare rights professional and it takes us two hours to fully complete a DLA form, and this is with us knowing the criteria. You need to set out very clearly what information you want.</p> <p>*15. Could some form of requirement to access? Your response: The DWP routinely tell people to go to their local advice agency to get advice and help completing benefit forms. We are in effect doing your job for you, for free.</p> <p>*If you make it a requirement to access support and advice the DWP needs to fund it. Many advice agencies have a waiting list of three months to complete a DLA form due to being under resourced.</p> <p>*It would be helpful to have dedicated form fillers in Jobcentres to anyone that needs to apply. They need to be impartial.</p> <p>*16. How do disabled people currently fund their aids and adaptations? Should there be an option ...? Your response: Disabled people often try to access aids and adaptations via their local authority adult services. Often due to cost they cannot give what is required. Many people buy their own aids</p>

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		<p>from their benefit income. Option to use as a one off cost: If the state has made a pledge to look after its vulnerable then people should not be having to pay for their own wheelchairs, for example.</p> <p>*17. What are the key differences ..? Your response:</p> <p>*18. How important or useful ...? Your response: DLA has been of use regarding blue badges and motorbility cars and the severe disability premiums for people on means tested benefits. To facilitate passporing the DLA should automatically inform benefit agencies of the award. There would need to be a benefit question on the DLA form.</p> <p>*19. What would be the implications ...? Your response: Loss of independence re blue badges, taxi card and motorbility cars, leading to many people becoming isolated and housebound, unable to get to the shops, buy their own food, shop for their own clothes, get to work and be able park nearby, get to vital hospital appointments.</p> <p>*We have to apply for grants for people to be able to attend chemotherapy and radiotherapy appointments due to being unable to drive to appointments (congestion charge and parking costs), or unable to take public transport due to severe weakness, nausea, fatigue and extremely high risks of infection. This is because they have been unable to passport to the blue badge because of not getting the highest rate of DLA mobility. Many people affected by cancer have extremely long and debilitating months of treatment. Their ability to mobilise is variable, normally completely debilitated for the first week or two of Chemotherapy, becoming better in week three, then the cycle begins again. They are spending hundreds of pounds just to attend appointments. When not at hospital they stay home, practically housebound as they cannot get out and about.</p> <p>*We see many people in fuel arrears due to the drop of income due to their illness and the amount of time they are at home. A normal winter fuel bill would be around 40% of a JSA weekly income. This is unacceptable for people with disabilities to have to prioritise food over warmth and light. The severe disability premium goes a long way to alleviating this.</p> <p>*20. What different assessments ...? Your response: You already use ESA medial assessments to make your decisions in some circumstances. The criteria is completely different and given the quality of many Atos assessments I feel this is an unacceptable route to take.</p> <p>*Esa is a work replacement benefit, DLA is surely to enable people to live independent and meaningful lives taking into account the problems that they routinely face.</p> <p>*21. What impact could? Your response: People who do not have English as a first language often have a bad success rate of claiming DLA even when their needs would clearly suggest some entitlement. This is because they find it harder to access the JCP, and many have literacy problems.</p>

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		<p>*22. Is there anything else you would like to tell us about the proposals in this public consultation?</p> <p>*Your response: "The benefit can act as a barrier to work"</p> <p>*You need to make it clearer that people can work and receive DLA, examples would help. "If you are in receipt of DLA with the highest rate of mobility because you have difficulty getting around, you can use your motorability car or your blue badge to help you get to work"</p> <p>*Maybe introduce the concept of what help you receive (or would benefit from) in the workplace. I: e regular breaks, someone signing for you.</p> <p>*Special Rules.</p> <p>*A claimant does not have to be receiving palliative care only to qualify under the special rules. Many people affected by cancer will be treated curatively right up until they die, with further curative treatment planned. A DS1500 report by a qualified, highly knowledgeable consultant who has decided to treat curatively even though the prognosis is extremely poor should be preferred over a Atos medical opinion stating as treatment is curative then the special rules must then not apply.</p> <p>*We strive to educate consultants precisely as to the defined criteria of the special rules. If asking for a medical report from a consultant or treating doctor, you could consider asking if special rules apply, and set out your criteria clearly.</p> <p>*You could also consider making it very clear that this potentially "harmful information" will not be divulged to the claimant. Many doctors strive to keep the patient positive, and will not give harmful information that may adversely affect their patient.</p> <p>*The individual must have a long-term disability (6 month backward test)*This will affect many claimants affected by cancer who are completely debilitated for up to a year by the effects of their treatment, They will incur huge additional costs at the time they most need assistance.</p> <p>*Payment will stop if the individual is in hospital or a care home</p> <p>*This is completely unreasonable. The costs that many people face do not disappear because they are in and out of hospital. Conversely they face increased costs due to travelling to and from hospital, having to rely on friends and family to maintain their homes.</p> <p>*My clients affected by cancer spend many days here and there in hospital. Sometimes being admitted without warning due to low blood levels, infection etc. They are usually inpatients for a few days or a week at a time, but the implications of having to report these frequent unplanned stays in hospital each time, especially at a time when they are so unwell, would lead to stays not being reported.</p> <p>*Care needs and mobility problems so not cease because a person is an inpatient. Many patients have daily visits from family members who incur costs travelling to the hospital to</p>

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		visit, who help the patients get up and about, who help bring them clothes, and items from home, who continue to care whilst the person is an inpatient.
EM728	17/02/2011	<p>1. : Cognitive & memory problems: Some people with disabilities such as hydrocephalus, severe dyslexia, brain tumour, or some form of epilepsy find it hard to remember things and can get confused. This causes particular problems in new situations and they will need support in the form of a carer or helper to access and orientate before they feel confident to be independent in that particular situation.</p> <p>*Finding your way can be particularly difficult in partially sighted or confused. Steps cause problems for people with mobility problems. Travelling can be difficult if you can't see to read maps or signs or tube or train stations are not announced. Bus journeys can be difficult if you can't see or recognise when to get off. If looking uncertain or look lost you are very vulnerable, and without a helper or taxi or mini cab, you may avoid travel or new experiences</p> <p>*Disabled people often lack 'friends' – they may not be working, they may not make eye contact with people, they may not hear what is said. They would be accessing events and situations alone often looking 'different'.</p> <p>* 2. : Not means tested is important. So too is the knowledge that providing your disability is permanent, it will not be taken away. The acceptance of medical evidence is important. The simplicity of it is a huge advantage.</p> <p>*People with disability will always have to by a few extra things for personnel use. They may earn less because they are unable to earn a large amount of money because they are limited to what they can do or the hours they are able to work. As there are cut backs now everybody is going to struggle for work and money, But as some people are limited to what they can do or the hours they can work they are most likely to lose their jobs first,</p> <p>*DLA is therefore extra important now so that the disabled can upgrade equipment, repair glasses etc, get out to, say, computer classes; otherwise the disabled will sink to the bottom of the pile, reversing much of the good work that has happened in recent years</p> <p>*3. : 1) mobility: taxis and cabs for non routine journeys. 2) Extra equipment for home and mobility use. eg. adaptive software, white canes, hearing aids, wheelchairs and glasses that can be purchased independently – NHS is essential, but to operate on a par with non disabled sometimes you need something more appropriate to an individual need. 3) Insurance is also more expensive 4) repair and renewal of equipment eg glasses, - disability can cause breakages and many of these might not be seen as obvious eg. Walking into a door or obstacle if you are visually impaired and breaking a tooth, someone with epilepsy damaging something as they fall etc. 5)</p>

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		<p>other 'hidden' items might be physiotherapy, essential to get back to work or be active, but not available on NHS eg epilepsy and shoulders dislocating etc. 6) help with cleaning, shopping, forms, set up of equipment, cooking etc – often has to be paid for – and is essential for many disabled people</p> <p>*4. : This seems very complicated. Difficult to even understand as a question. Anything that is more complicated will be detrimental. The current simplicity of the current DLA is one of its advantages.</p> <p>*5. : I think some health conditions and impairments should mean an automatic entitlement to the benefit as people.</p> <p>*6. : Cooking, cleaning (or paying for a cleaner) shopping and keeping fit, access to leisure facilities. To prioritise support to those people least able to live full and active lives should have what they have now higher rate or lower rate of care.</p> <p>*7. : this is where the current DLA is good. Some months you may not need to spend the whole of the allowance, but it is saved by the individual towards the unpredictable and often greater needs that require immediate financial input. EG epilepsy – no fits for 3 months, then 1 or more causing confusion and damage, needed carer and helper, transport, physiotherapy, glasses repairs . . . in this state the disabled person would not be in a position to 'apply' or request additional help. It is needed there and then. Especially if someone needs to get back to work. People with bad sickness records are the first to go – whatever the legislation.</p> <p>*8. : aids and adaptations often expensive and are essential for independence, the ability to work etc. Eg a video magnifier for a partially sighted person in the home to read letters, labels, handwriting many books and other printed matter is likely to be between £2-3000 and is not standard. Daylight task lamps, talking scales, mirowaves, large print keyboards, adaptive software such as Dragon, lunar or jaws are beyond most peoples means, and should be included.</p> <p>*Also, there are the more personal items eg. Nhs glasses may allow you to 'see' to some extent, but to have ones that don't make you look strange, that are lightweight so you don't get headaches, and look 'normal' so you can fit are important – the same with hearing aids. Also, some NHS wheelchairs need to be 'pushed'. The purchase of a more easily self propelled one, or one that manages curbs, immediately makes someone less dependent and more useful to society.</p> <p>*Someone with aids and adaptations will need them renewed and repaired, and they may benefit from more. someone without them may well need them too – each situation is different – one size does not fit all.</p> <p>*9. : Access to all forms in all formats at all post offices, including audio explanations. Also on email. Help with filling out the form to be available at post offices. The radio – ie BBC in touch programmes etc should go through it question by</p>

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		<p>question to explain the implications – otherwise many disabled will be penalised or miss out because they cannot understand or misunderstand the questions.</p> <p>*10. Your response: doctors and consultants and other specific disability professionals. In some cases charities may have information sheets or can write on behalf of an individual about the effects of a particular disability. School heads may be able to help with additional information in the case of school leavers about to embark on adult life and independent living.</p> <p>*Full names of disability and how each one can affect them even if the individual does not want to declare how the disability affects them as they want to live a normal life.</p> <p>*11. Your response: Who is this health care professional? One person would not know the effects of the symptoms of, say, hydrocephalus, or lack of nerve endings, or what someone can or cannot see or hear, or how some injury prevents movement.</p> <p>*Many disabled people have several components to their disability eg epilepsy + cognitive brain damage, + balance problems + lack of strength on one side + visual impairment.</p> <p>*How much time is the health care professional going to take – will they spend a day or week with the client – if it is a half hour form filling exercise the client and perhaps doctor would be able to do it without the meeting.</p> <p>*My worry would be the desire of many people to ‘please’ or say what they think the interviewer wants to hear, or forget or not mention some of the problems in a stressful and perhaps perceived intimidating situation. It would be essential that the disabled person had an advocate with them – a sort of trade union rep.</p> <p>*12. : reviews should be as infrequent as possible. Many disabled people already have many health related appointments - most disabilities are lifelong.</p> <p>*13. : an annual or biannual letter, email or telephone call asking if your circumstances have changed. Doctors surgeries send out periodic letters asking for confirmation you are still in their catchment area – it could be similar</p> <p>*14. : it should be separate from the benefit claiming process. Benefit claims are means tested. Disability is a separate issue.</p> <p>*15. : don’t know</p> <p>*16. : currently the DLA can be used in some instances. Perhaps the suppliers of some equipment could claim direct from the fund eg like Access to Work can fund some training</p> <p>*17. : don’t know</p> <p>*18. : very important. It makes leisure facilities, eg swimming baths possible, can help with disabled train reductions, concessions to courses, theatres and cinemas etc. Everything in fact that makes the disabled person, usually on lower than average income, participate and be an active member of society</p> <p>*19. : it would mean these other benefits would not be</p>

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		<p>available to the disabled eg help with some dentistry etc – all the things that make people normal, mobile, fit . . .</p> <p>*20. : I would have thought the current DLA was reasonably simple to administer. The tendency of government departments to overcomplicate matters is becoming more and more difficult for most citizens to apprehend. The current format or ‘are you in receipt of the DLA’ seems a simple passport</p> <p>*21. : most of the monitoring forms i fill in for employers list ethnicity, gender religion etc. I have seen very few with disability on the list.</p> <p>*22. Your response:</p>
EM729	17/02/2011	<p>1. :Access to information on financial assistance and grants to help with access and care. If individual plans are developed with individuals most people would choose to work and live independently but this can only happen if a support structure is in place.</p> <p>*2. :I believe that there should be a separate care and mobility component and therefore this should stay the same. Assessment process works in its present form, however lengthy the paperwork. If an award is made for a child, then surely there is no need to keep revising it if medical opinion is that is will never change?</p> <p>*3. : Children - special boots and shoes - very expensive and difficult to source. Travel to and from hospital and specialist appointments. Extra bedding. Adapted bathrooms and kitchen. Larger car than average to accommodate specialist equipment. Wipes, bibs and clothing and associated washing costs. Heating - need to keep constant background heat. Travel to special clubs activities which are usually not local. Holiday's need extra space and environment so low cost activities like camping are not accessible. Adaptation to garden.</p> <p>*4. : Difficult to access if individual does not have a recognisable diagnosis. Nightmare to administer. Administrators would have to experts on medical issues to access whether someone is referred for a medical or not. If an individual does not get one of the components then does this mean that the carer will not be able to claim carers allowance, even though they care 24/7?</p> <p>*5. : Individual needs and circumstances - everyone is an individual, there are always common themes but no two people present in the same way.</p> <p>*6. : Extra money for those who are not mobile without external aids. It affects choice and options drastically. House maintenance and cleaning, shopping,driving a car, recreational activities like social clubs and cinema, library, gardening</p> <p>*7. : Annual review from local GP who could review individual and confirm any changes. This could be as easy as a signature on a form.</p> <p>*8. : No - if someone cannot move around without a wheelchair</p>

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		<p>- then they cannot move. A wheelchair might mean that they can move around but it is not a permanent appendage. Assessment should be made with aids and adaptation. Assessment purely on the individual.</p> <p>*9. :Form filling should be based on as little criteria as possible. Either someone can walk unaided or they cannot. Either someone can be left alone or they cannot. Either someone can be responsible for their own safety or they cannot. Either you are disabled or you are not. Simple criteria = easy to understand whether you qualify or not.</p> <p>*10. : Local GP - GP assessment.</p> <p>*11. :That person might not be aware of their disability and how it affects them, or what support they get from others so that they can lead as normal a life as possible. Home visit would give healthcare professional a better understanding of homelife. Children under 18 should not be assessed.</p> <p>*12. : Permanent disabilities should not need reviewing. If that person gets maximum benefits then they should always be entitled to the benenefit. Everyone reviewed by GP on annual basis if disability not assessed as permanent.</p> <p>*13. : GP assessment.</p> <p>*14. : There should be a pro-active approach to people getting benefits - referral by GP or healthcare professionals.</p> <p>*15. : Everyone should be given the option of advice and support. It should be up to the individual whether they take up this offer.</p> <p>*16. : My experience is that the immediate family fund aids and adaptations or they go without. One off costs should be funded by separate fund.</p> <p>*17. : My daughter was 13 years old before a cause was found for her disabilities. It has been almost impossible to fill out forms as a result as no-one could appreciate her disabilities and how it affected her life. An annual review at a GP would have helped and they could confirm that nothing had changed. Children if they cannot walk at the time of applying unaided should get full mobility allowance up to age of 18. Children if they are assessed as needing 24/7 care at time of applying should get it up to age of 18. Why keep reviewing?</p> <p>*18. : Crucial - for blue badge, crucial on holidays/leisure actiivites. Central recognised benefit that 'proves' you are disabled. Crucial for carers allowance. However, it would be better to have a badge/passport saying that you are disabled that you could show - it permanent disability had been assessed and also badge/passport for carer.</p> <p>*19. : Whole system would break down as you would have to prove every time the same things that had already been assessed. One long assessment that last a lifetime would simplify system - annual review from GP should be enough to ensure changes are noted.</p> <p>*20. : No information should be shared, open to abuse. One</p>

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		<p>assessment is the only practical and cost effective option going forward.</p> <p>*21. : All assessment should be carried out by someone of the same cultural/linguistic background.</p> <p>*22. : No consideration has been given to the impact and knock-on effect on families within the current proposals. No help should be means tested. A life-long passport/badge for permanent disabilities would be an efficient and cost effective solution. Having a disabled person/child has a devastating effect on families, their collective income and is totally life limiting. Any process that is quick, accessible and long-term giving an element of certainty would be most welcome and allow families to plan for their future with an element of certainty.</p>
EM730	17/02/2011	<p>This governments intention to change the way in which disabled people are supported in society is flawed and wrong.*We cannot understand the logic in seeking to change a benefit where the rate of fraudulent claims is one of the lowest at 0.5%. Even before the medical assessments were introduced, the stated intention was to reduce the number of people claiming by 20%. Not only is this pre-empting the results of the medical assessments, but it also would mean that 19.5 of genuine claimants would lose out. As we all know, apart from Ms Maria Miller, DLA is not an out-of-work benefit, but is there to help with the extra costs associated with being disabled, of which there are many. This is true whether someone is in work or not. In fact, DLA supports people by enabling them to go to work, if they are able.</p> <p>*We are concerned at the many reports of people with profound disabilities who have been passed as being fit and able to work, when this is not the case. Apparently, and rightly so, these people are taking their cases to Appeal. And why is a private healthcare company being paid vast sums of cash to carry out these assessments, when before it was appropriate for one's own doctor and consultant in the NHS to provide evidence of need? GP's are being entrusted with massive budgets in the future, but are not being trusted with supplying information of this nature.</p> <p>*We also understand that the Personal Independence Payment will have tighter eligibility criteria, which means that people currently in receipt of DLA will lose out. If sick and disabled people are forced into work they cannot do or cannot find, how are they supposed to live? Many innocent people will be placed in an impossible and cruel position. It is no exaggeration to say that people are going to die. The proposal to cut the mobility allowance from children and adults in schools and residential homes is unfair and wrong, and we protest very strongly on their behalf. This measure would dramatically and negatively impact on quality of life for these people. There is no comparison with hospital patients. There is no 'overlap'. Going</p>

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		<p>out when one chooses, not having to ask whether the Home minibus is available, or whether there are staff able to drive it at a certain time, there is simply no comparison. The administrative cost of this entire exercise, the amount of money being paid to Atos Healthcare for 'tick-box' medicals, the cost of the appeal tribunals, must be eye-watering. The cost to disabled people in terms of anxiety and despair is immeasurable. Yours sincerely,</p>
EM731	17/02/2011	<p>1. I do consider myself to lead an independent, full and active life despite having multiple sclerosis and needing a wheeled frame to help me walk and a wheelchair for longer distances. However, achieving a high quality of life has taken a great deal of effort on my part and support from others.</p> <p>*Public transport is very difficult to use, either because it is very tiring or because there is simply no suitable access, as on most of the London Underground. Taxis are therefore very important in enabling me to work and get around generally, and I would not be able to afford these without the Access to Work scheme and the DLA (particularly since government cuts to local authority finances led to major reductions in the London Taxicard scheme).</p> <p>*Another major problem for the mobility-impaired person is that the outside world often seems like one huge obstacle course. Stairs with no rails, big, heavy doors in offices and public buildings, nowhere to sit down when queueing... Everything I do has to be carefully planned, often with numerous advance phone calls. To resolve this problem, I would like to see better guidance for landlords on accessibility adaptations for buildings, and much better enforcement of existing legislation. Please, no more 'historic building' excuses for the likes of the London Underground.</p> <p>*In general, I have also received the impression that many disabled people are prevented from leading a full life by poor education. This can be about lacking the ability to find information – i.e. when people don't know about assistance schemes or their right to workplace adaptations. But it's also a broader problem to do with education, linked to social class. I am a middle-class person educated to master's degree level. I know it is my right to be able to work and that I am good at what I do, so it's only fair that I should be able to compete on a level playing field thanks to DLA and Access to Work. This is the kind of confidence I get from my educational and social background, and I would like all other disabled people to feel the same way.</p> <p>*2. The rate of the allowance for people with higher mobility needs should stay at least the same.</p> <p>*3. I can't speak for all disabled people, but taxis are the number one extra cost for me. I also need to pay a cleaner at home.</p> <p>*4. No strong opinion on this.</p> <p>*5. No strong opinion on this.</p>

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		<p>*6. Just getting outside is a big deal for a lot of disabled people. Leaving the house becomes something to dread when you worry about falling or being stranded somewhere exhausted. Even the thought of constantly having to ask for help everywhere you go because of poor access to buildings and transport is offputting.</p> <p>*7. Multiple sclerosis can involve being reasonably OK one week and bed-bound in hospital the next, with an arduous recovery period involving regular physiotherapy (likely to involve taxis to a hospital or clinic). If a person with a history of disabling MS relapses has been turned down for support on the basis that he or she was reasonably well at the time of an assessment, the case should be marked as 'liable to relapse'. Then, if a serious relapse happens and the person needs financial support, a letter from the person's neurologist should be enough to activate the allowance.</p> <p>* 8. What does this mean? That you won't get an allowance if you've already managed to improve your own quality of life through taking the initiative to get yourself a wheelchair?! By all means make sure a disabled person knows about all the help available through different schemes, but please don't use this as an excuse for cutting down their financial support.</p> <p>*9. I found the claim form rather long and tedious, but I think it's important not to simplify it too much; otherwise people may not be able to give a full picture of their situation. Regarding the information about what it's for and who is likely to qualify, you really cannot state the key messages too often. When the government announced last year that it was due to review DLA, every single media report I heard or read was under the misconception that the allowance was for people unable to work. Now I see from your consultation document that a large proportion of the people receiving the allowance even believe this! Your key messages need to appear at the top of every application form, every relevant website page, every leaflet and every press release. I think the new name is a good idea, though, and will help with any future publicity effort.</p> <p>*10. No strong opinion on this.</p> <p>*11. No strong opinion on this.</p> <p>*12. No strong opinion on this.</p> <p>*13. Every single leaflet or application form for the allowance needs to have the number of a hotline you can call and an email address you can write to when you need to report a change in circumstances. This also needs to appear on every relevant website page. Importantly, people going into hospital need to know that they can get in touch when they come home and have their allowance immediately reactivated. What puts people of reporting changes is the fear of losing the allowance or having a delay in reactivation - or even being required to start again with the application process at a time when they are most in need.</p>

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		<p>*14. It would be good to find out from focus groups of disabled people and charities like the MS Society what support schemes have proved most helpful (e.g. Access to Work and London Taxicard until recently) and list these on a leaflet, with a brief description of what each one does, how you qualify and their contact details.</p> <p>*15. Is this allowance based on the fact that someone is disabled, or not? A person is no less disabled because they seem to be lacking in initiative. By all means improve support and information to those who do not 'take action', but it would be grossly inappropriate to punish some disabled people for this by withdrawing or reducing their allowance.</p> <p>*16. My walking frame and wheelchair come from an excellent NHS scheme organised through my local integrated therapy services team. I guess I wouldn't mind contributing something towards the cost from my DLA or any future version of the allowance, but a contribution like this should be capped at a modest fixed amount and be consistent throughout the country.</p> <p>*17. No strong opinion on this.</p> <p>*18. This is very important – please at least keep the same arrangements in place. Being disabled involves endless form-filling which able-bodied people are not subjected to, and passporting can help to bypass the worst of this.</p> <p>*19. There would be even more inequality between disabled and able-bodied people and a strong disincentive to access the full range of support services.</p> <p>*20. No strong opinion on this.</p> <p>*21. No strong opinion on this.</p> <p>*22. I think it would be helpful for the policy-makers to have more face-to-face discussions with disabled people, as not everybody has the time or abilities to give written responses. I would be happy to participate further in this way.</p>
EM732	17/02/2011	<p>I respond as an individual disabled person. Please note that I have not replied on your form, as requested, because I do not have the necessary software. The numbered responses relate to the questions posed and I have provided additional feedback at the end.</p> <p>* 1. The Government's Office for Disability Issues own research and statistics shows categorically that disabled people continue to face problems and barriers in every aspect of their lives: *http://odi.dwp.gov.uk/disability-statistics-and-research/disability-facts-and-figures.php#ls *- i.e. living standards, employment, education, independent living, leisure, social and cultural activities, civic involvement and volunteering, transport, communications, justice system and housing.</p> <p>* 2. DLA should remain non-means tested and payable on the basis of self-assessed need, regardless of family circumstances and employment status. The current procedure is lengthy and intrusive but disability / impairment is complex. The process</p>

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		<p>needs to reflect the complexity and diversity of mobility and care needs.</p> <p>* 3. The extra costs that disabled people face are many and varied. Some examples are:</p> <ul style="list-style-type: none"> * - extra transport costs (examples: in my case, a minimum charge of £12 in taxi fares, every time I leave my flat; £80 taxi fare to friends on Christmas day, versus estimated petrol cost of £2.07; taxis to physiotherapy, osteopathy, chiropody, consultant appointments, etc.) * - extra medical costs (£40 for an osteopathy appointment, more frequently when I am employed, due to extra strain on my body - I am a wheelchair-user) * - increased costs for ready-prepared food (due to limited dexterity and severe tremor in my hands)* - addition hotel costs as family / relatives' homes are not wheelchair-accessible (eg. £350 at Christmas time) * - £45 for individual yoga-tutoring (group classes are not suitable for wheelchair-users) for pain management and maintaining muscle control and balance * - extra holiday costs, as I require fully wheelchair-accessible accomodation (cheap B&Bs are not suitable for wheelchair-users) * - increased electricity costs for extra heating (as someone with a degenerative neurological condition, my circulation is extremely poor and I require monthly chiropody treatment) * - additional telephone costs (eg. instead of socialising which requires travel expenditure; numerous phone-calls to address disability-related matters) * - non-prescription medicine, etc. <p>* However, if the government wants to base its reform of DLA on solid evidence of additional costs incurred by disabled people, I would refer you to the report produced by Scope/Demos:</p> <p>*http://www.scope.org.uk/sites/default/files/Counting_the_Cost.pdf</p> <p>*This report shows clearly that there is no simple relation between level of functional needs and disability costs. Disabled people living without care can also incur significant disability costs.</p> <p>* 4. Without knowing what the rates will be and what the assessment process will be, it is impossible to answer this question.</p> <p>* 5. Assessments and reviews are time-consuming and costly. Diagnosis is not always an accurate indicator of costs. A system which can be flexible would, in the long-run, be more efficient and cost less. For example, why should someone who has become quadraplegic undergo a lengthy assessment, if a GP can confirm this diagnosis? Clearly this person will incur significant disability-related costs.</p> <p>* However, maybe the assessment process would be more</p>

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		<p>detailed for a non-disabled person who suddenly finds themselves diagnosed with something that, in some cases, is not permanent (eg. a back problem)?</p> <p>* What is the role of GPs in the process, given that they will have a greater understanding of their patients' needs than assessors could ever have?</p> <p>*Claimants who have a poor relationship with their GPs should have the option to request an assessment / review with an alternative assessor appointed by the benefits system.</p> <p>* It is a waste of money to review an existing claimant who has a permanent condition (eg. Cerebral palsy) or a degenerative condition (eg., cerebellar ataxia, muscular dystrophy, motor neuron), unless the claimant requests a review if his/her condition has deteriorated and wishes to be assessed for a higher rate of benefit. Many of us live with life-long conditions so there is no point reviewing us to see if we are still eligible for DLA. We will not get better and, in fact, many of us are getting worse!</p> <p>* Why require someone to have a condition that lasts a minimum of 12 months? Someone with a severe back injury may be severely incapacitated and need significant support (& therefore incur extra expenditure) for less than 12 months.</p> <p>*6. All disabled people should be supported to live full and active lives and make their equal contribution to the Big Society. An ability to perform everyday activities is not always an indicator of disability-related costs. I am an employed professional postgraduate and live relatively independently but DLA is vital in enabling me to do this. Without DLA it would be more difficult for me to work. Disabled people should be enabled to engage in all activities that non-disabled people do. To prioritise those activities means the government does not believe disabled people should be able to do the same things that non-disabled people do.</p> <p>* 7. The government should take advice from organisations that represent people with variable and fluctuating conditions on how to ensure that the new assessment meets these people's needs.</p> <p>* 8. If the aim of DLA / PIP is to meet disability costs and promote independence, it should be the recipient's decision what to use this additional money for. Aids and adaptations do not necessarily eliminate disability costs, such as those I have listed in my response to Question 3. All of the disabled people I know have encountered occupational therapists, physiotherapists and social workers at some point during their lives - is it not part of their job to ensure that disabled people get any necessary aids and adaptations? It is worth noting that many aids and adaptations require maintenance and/or replacement, hence additional cost. *It would be wrong to not award someone DLA because the assessor believes that a range of aids and adaptations will eliminate some disability-</p>

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		<p>related costs. This would render DLA assessments highly speculative and therefore inaccurate. I know many disabled people who have been provided with aids that simply do not meet their needs, as well as people who have waited ages for aids to be delivered / replaced / upgraded and for adaptations to be made to their homes. I do not know any disabled person who has refused to make use of aids / adaptations which genuinely increase their ability to do something.</p> <p>* 9. It is essential that the assessment process gives claimants the opportunity to provide all the information they want to. Sometimes claimants may want other professionals to provide additional information to support their claim and the process should welcome this.</p> <p>* 10. Claimants themselves are best placed to provide information about their situation. Claimants should have the option to nominate other people that they would like to provide supporting evidence about their circumstances, such as GP, consultants, social worker, etc. Some claimants may not want to do this, in which case the decision would defer to the assessor.</p> <p>* 11. Face-to-face discussions are costly and should therefore be kept to a minimum. If a claimant has an on-going or degenerative impairment (see question 5) which his/her GP can confirm, why are face-to-face meetings necessary? In cases where a face-to-face meeting is necessary, the claimant should have the option to be visited at home or have the meeting elsewhere. It is also worth noting that one healthcare professional cannot possibly understand all the impairments that disabled people have, nor the impact disability has on our lives. In my own case, I have to explain what my impairment is, and its effects, to every health professional I meet, apart from those who specialise in neurology. Likewise, healthcare professionals will not necessarily understand the disability costs that all disabled people incur.</p> <p>* 12. Common sense should dictate the frequency of reviews (see question 5). Clearly someone with a possibly temporary condition would be subject to a more regular review process than someone with a degenerative condition, although liaison with this person's medical team could be sufficient to merit continuation of the benefit.</p> <p>* 13. Personally I do not know any disabled people who claim DLA unjustifiably and we are shocked by government suggestions that many of us shouldn't be getting this benefit.</p> <p>* 14. Any advice and information that enables disabled people to live independently is welcome but I do not see how this will impact on whether a person is eligible to claim DLA or not.</p> <p>* 15. How can someone be required to access advice and support? I do not know any disabled people who need support but have not tried to get it, whereas I know many disabled people who have tried to get support and not been successful.</p>

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		<p>Disabled people do not see DLA as an alternative to trying to access good healthcare, suitable housing and appropriate support.</p> <p>* 16. Disabled people who cannot get necessary aids and adaptations through the NHS, Social Services or local authorities presumably have to finance them by their own means (where this is possible). Clearly it isn't possible for many people to finance things themselves, or there wouldn't be such high numbers of disabled people living in poverty. It is essential that applying for a Disabled Facilities Grant remains as straightforward and quick as possible. I am told it is not easy and that funding is limited.</p> <p>*17. Parents of disabled children can incur significant additional costs, on things such as therapy and medical-related matters, specialist assessments and equipment, extra travel costs, increased utility costs, extra bedding, specialist toys and clothing. It is therefore vital that disabled children remain entitled to DLA. * I do not wish to make any response to questions 18 - 21.</p> <p>* However, I would like to make the following points:</p> <p>* a) I am a postgraduate, professional person, who happens to have a significant impairment. However, my ability to currently live relatively independently does not limit my expenditure on disability-related things. In fact, it is my ability to use DLA for such things as maintaining my health and helping with additional travel costs that enables me to be a tax-payer. Without DLA my ability to work could actually reduce.</p> <p>* b) I am appalled by the proposal to withdraw the mobility component of DLA from people in residential care. As this issue is part of the overall DLA reform, why doesn't the DLA consultation even ask respondents whether we agree with this particular proposal? If one is not paying attention, one could overlook this particular proposed change, a change which will have a significantly detrimental impact on 80,000 disabled people's lives. I think this is particularly disingenuous of the government. How can Mencap and 26 other charities be wrong, arguing that the mobility component these people currently receive does not overlap other funding?</p> <p>http://www.mencap.org.uk/page.asp?id=20515 These organisations know how much these people depend on DLA to live active and independent lives. Removing this vital means of travel will severely limit their ability to play their part in the Big Society.</p> <p>* For the DLA reform to be effective, the government must understand why it costs extra to live as a disabled person and what DLA enables disabled people to do. I plead with you to read the report that Scope commissioned Demos to write about the costs of disability:</p> <p>http://www.scope.org.uk/sites/default/files/Counting_the_Cost.pdf</p>

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		<p>*This report shows that the functional impact of a person's disability is not an accurate indicator of disability costs.</p> <p>* My view is that the proposed cut in the overall budget needs to be reversed and greater consideration given to the findings in this report before decisions are made which could result in even more disabled people living in poverty and / or unable to lead independent lives. The Scope/Demos report also shows that the proposed changes could result in many disabled people with less complex needs, but very high disability-costs, being left without vital support.</p> <p>* In addition, if the government really wants to reduce the costs of living with a disability, it needs to address some of the barriers disabled people routinely face in society, in areas such as housing, transport and employment. Even disabled people in receipt of DLA are still living in poverty due to the full scale of the costs disabled people face.</p> <p>* Lastly, I would like to say that I am appalled by the fact that, for this consultation on DLA reform, the government sought exemption from its requirement to allow at least 12 weeks for the process. Not only has the consultation period (6/12/10 - 18/02/11) spanned the Christmas holidays and New Year, a time when many people take time off work, but it has also given disabled people and the organisations that represent us less time to consider the implications of the proposals and formulate our responses than is usually allowed for such a consultation. Indeed, in my view it would have been appropriate to extend the usual consultation period, as a "reasonable adjustment", in acknowledgement of the massive implications of the DLA reform. The government's own Code of Practice says that consideration can be given to "longer timescales where feasible and sensible". Instead we have had only 71 days, compared to the 84 days usually allowed. Does the government genuinely believe this is a fair way to treat its disabled citizens?</p> <p>**ADDENDUM** I look forward to hearing how you will ensure that my concerns are heard and acted on. I would also like to know what you intend to do to make sure that the government seriously re-considers a set of proposals which could result in even more disabled people living in poverty. I write as a postgraduate, professional person.</p> <p>*For your information I am also writing to Richard Ottaway MP, Iain Duncan Smith MP and Baroness Jane Campbell of Surbiton about this matter. Yours sincerely [REDACTED]**</p>
EM733	17/02/2011	<p>1. Cognitive & memory problems: Some people with disabilities such as hydrocephalus, severe dyslexia, brain tumour, or some form of epilepsy find it hard to remember things and can get confused. This causes particular problems in new situations and they will need support in the form of a carer or helper to access and orientate before they feel confident to be independent in that particular situation.</p> <p>*Finding your way can be particularly difficult in partially sighted</p>

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		<p>or confused. Steps cause problems for people with mobility problems. Travelling can be difficult if you can't see to read maps or signs or tube or train stations are not announced. Bus journeys can be difficult if you can't see or recognise when to get off. If looking uncertain or look lost you are very vulnerable, and without a helper or taxi or mini cab, you may avoid travel or new experiences</p> <p>*Disabled people often lack 'friends' – they may not be working, they may not make eye contact with people, they may not hear what is said. They would be accessing events and situations alone often looking 'different'.</p> <p>*2. Your response: Not means tested is important. So too is the knowledge that providing your disability is permanent, it will not be taken away. The acceptance of medical evidence is important. The simplicity of it is a huge advantage.</p> <p>*People with disability will always have to by a few extra things for personnel use. They may earn less because they are unable to earn a large amount of money because they are limited to what they can do or the hours they are able to work. As there are cut backs now everybody is going to struggle for work and money, But as some people are limited to what they can do or the hours they can work they are most likely to lose their jobs first,</p> <p>*DLA is therefore extra important now so that the disabled can upgrade equipment, repair glasses etc, get out to, say, computer classes; otherwise the disabled will sink to the bottom of the pile, reversing much of the good work that has happened in recent years</p> <p>*3. Your response: 1) mobility: taxis and cabs for non routine journeys. 2) Extra equipment for home and mobility use. eg. adaptive software, white canes, hearing aids, wheelchairs and glasses that can be purchased independently – NHS is essential, but to operate on a par with non disabled sometimes you need something more appropriate to an individual need. 3) Insurance is also more expensive 4) repair and renewal of equipment eg glasses, - disability can cause breakages and many of these might not be seen as obvious eg. Walking into a door or obstacle if you are visually impaired and breaking a tooth, someone with epilepsy damaging something as they fall etc. 5) other 'hidden' items might be physiotherapy, essential to get back to work or be active, but not available on NHS eg epilepsy and shoulders dislocating etc. 6) help with cleaning, shopping, forms, set up of equipment, cooking etc – often has to be paid for – and is essential for many disabled people</p> <p>*4. Your response: This seems very complicated. Difficult to even understand as a question. Anything that is more complicated will be detrimental. The current simplicity of the current DLA is .one of its advantages.</p> <p>*5. Your response: I think some health conditions and impairments should mean an automatic entitlement to the</p>

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		<p>benefit as people.</p> <p>*6. Your response: Cooking, cleaning (or paying for a cleaner) shopping and keeping fit, access to leisure facilities. To prioritise support to those people least able to live full and active lives should have what they have now higher rate or lower rate of care.</p> <p>*7. Your response: this is where the current DLA is good. Some months you may not need to spend the whole of the allowance, but it is saved by the individual towards the unpredictable and often greater needs that require immediate financial input. EG epilepsy – no fits for 3 months, then 1 or more causing confusion and damage, needed carer and helper, transport, physiotherapy, glasses repairs . . . in this state the disabled person would not be in a position to ‘apply’ or request additional help. It is needed there and then. Especially if someone needs to get back to work. People with bad sickness records are the first to go – whatever the legislation.</p> <p>*8. Your response: aids and adaptations often expensive and are essential for independence, the ability to work etc. Eg a video magnifier for a partially sighted person in the home to read letters, labels, handwriting many books and other printed matter is likely to be between £2-3000 and is not standard. Daylight task lamps, talking scales, microwaves, large print keyboards, adaptive software such as Dragon, lunar or jaws are beyond most people's means, and should be included.</p> <p>*Also, there are the more personal items eg. NHS glasses may allow you to ‘see’ to some extent, but to have ones that don’t make you look strange, that are lightweight so you don’t get headaches, and look ‘normal’ so you can fit are important – the same with hearing aids. Also, some NHS wheelchairs need to be ‘pushed’. The purchase of a more easily self propelled one, or one that manages curbs, immediately makes someone less dependent and more useful to society.</p> <p>*Someone with aids and adaptations will need them renewed and repaired, and they may benefit from more. someone without them may well need them too – each situation is different – one size does not fit all.</p> <p>*9. Your response: Access to all forms in all formats at all post offices, including audio explanations. Also on email. Help with filling out the form to be available at post offices. The radio – ie BBC in touch programmes etc should go through it question by question to explain the implications – otherwise many disabled will be penalised or miss out because they cannot understand or misunderstand the questions.</p> <p>*10. Your response: doctors and consultants and other specific disability professionals. In some cases charities may have information sheets or can write on behalf of an individual about the effects of a particular disability. School heads may be able to help with additional information in the case of school leavers about to embark on adult life and independent living.</p>

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		<p>*Full names of disability and how each one can effect them even if the individual does not want to declare how the disability effects them as they want to live a normal life.</p> <p>*11. Your response: Who is this health care professional? One person would not know the effects of the symptoms of, say, hydrocephalus, or lack of nerve endings, or what someone can or cannot see or hear, or how some injury prevents movement.</p> <p>*Many disabled people have several components to their disability eg epilepsy + cognitive brain damage, + balance problems + lack of strength on one side + visual impairment.</p> <p>*How much time is the health care professional going to take – will they spend a day or week with the client – if it is a half hour form filling exercise the client and perhaps doctor would be able to do it without the meeting.</p> <p>*My worry would be the desire of many people to ‘please’ or say what they think the interviewer wants to hear, or forget or not mention some of the problems in a stressful and perhaps perceived intimidating situation. It would be essential that the disabled person had an advocate with them – a sort of trade union rep.</p> <p>*12. Your response: reviews should be as infrequent as possible. Many disabled people already have many health related appointments - most disabilities are lifelong.</p> <p>*13. Your response: an annual or biannual letter, email or telephone call asking if your circumstances have changed. Doctors surgeries send out periodic letters asking for confirmation you are still in their catchment area – it could be similar</p> <p>*14. Your response: it should be separate from the benefit claiming process. Benefit claims are means tested. Disability is a separate issue.</p> <p>*15. Your response: don’t know</p> <p>*16. Your response: currently the DLA can be used in some instances. Perhaps the suppliers of some equipment could claim direct from the fund eg like Access to Work can fund some training</p> <p>*17. Your response: don’t know</p> <p>*18. Your response: very important. It makes leisure facilities, eg swimming baths possible, can help with disabled train reductions, concessions to courses, theatres and cinemas etc. Everything in fact that makes the disabled person, usually on lower than average income, participate and be an active member of society</p> <p>*19. Your response: it would mean these other benefits would not be available to the disabled eg help with some dentistry etc – all the things that make people normal, mobile, fit . . .</p> <p>*20. Your response: I would have thought the current DLA was reasonably simple to administer. The tendency of government departments to overcomplicate matters is becoming more and more difficult for most citizens to apprehend. The current</p>

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		<p>format or 'are you in receipt of the DLA' seems a simple passport</p> <p>*21. Your response: most of the monitoring forms i fill in for employers list ethnicity, gender religion etc. I have seen very few with disability on the list.</p> <p>*22. Your response:</p>
EM734	17/02/2011	<p>1. Extra costs due to disabilities. Physical inaccessibility of services, buildings transport etc. Not being able to do things spontaneously because of the extra planning involved in checking/booking access.</p> <p>*Extra time that having a disability takes up, both in daily living activities and the extra administrative tasks.</p> <p>*2. Your response:</p> <p>*3. Extensive and varied costs, far too many to list comprehensively, but they include-</p> <p>* Cost of personal care, both employing and liability insurance for them, cost of needing accompanying to appointment, shopping, events etc, buying, maintaining, replacing and insuring mobility equipment, around the house aids or personal care equipment, adaptation to housing, extra heating costs, additional transport costs due to lack of accessible transport and not being able to go short distances on foot or bike, extra costs of car parking because of having to use accessible parking and taking longer to do things like get around the shops and not being able to use public transport, extra transport needed for hospital appointments etc, cost of adaptation to car (buying maintaining and replacing), needing a car that is reliable not being able to risk driving an older (cheaper) less reliable car, medical costs and alternative therapies. Additional cost for accessible accommodation, holidays and issuance (including not being able to book last minute deals) specialist clothing, replacing clothing that is worn out quicker, extra laundry costs, shopping in more expensive places because they are nearer/more accessible, home delivery, additional dietary requirements, more expensive food with easier to open packaging or ready meals if preparing food is difficult, extra security because of vulnerability, help with doing jobs that could otherwise be carried out by a non-disabled person e.g. house hold chores, decorating, DIY, gardening, car wash and maintenance, extra cost of activities or hobbies needing specialist equipment or extra support (e.g. when I went scuba diving I had to pay nearly double because I needed an extra instructor because of my disability)</p> <p>*4. Current system is really not that complicated! It allows for more variation due to different disabilities and needs, and is more able to be tailored to each individual. There may be people who where entitled to in middle rate, who then are reduced to the new lower rate and therefore lose out on money.</p> <p>*5. Some should receive at the very least some level of automatic entitlement. It increases administration costs and the</p>

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		<p>stress and burden on disabled people time not to have automatic entitlement. There are a number of disabilities that with mean the person will incur extra costs no matter what their ability is to cope with their disability.</p> <p>*6. Personal care, daily living, and cleanliness could be perceived as the most essential but social interaction also plays a massive role in disabled peoples well being and ability to cope with their disability. It is not just those with a visible disability that are most needy. It would be good to have a facility to fast track some claims, as the costs start straight away, as well as back dating payments.</p> <p>*7. Your response:</p> <p>*8. This is not a clear question. Do you mean that someone who uses an aid to help them cope with their disability would get less money because they have found an alternative coping strategy or more money because of the additional costs incurred of buying, maintain, insuring and replacing the aids that they use?! Just because someone uses an aid does not mean that they are not hit by the numerous extra costs that having a disability entails. If you are suggesting that you might be able to identify and help sores equipment that will make people's lives easier, then that would be positive. But it's possible that just because one aid is helpful to someone does not necessarily mean that it will work for someone else.</p> <p>*9. The questions can often come across as insensitive or limiting (not giving you the appropriate opportunity to give the information that matters)</p> <p>* It is notoriously difficult to find out what benefits and help is available to you. Even a number of professionals working in the disability sector do not know all the information. Linking benefits would help, for example, when applying for one benefit, there could be information on other benefits you might be entitled to. Additional training to those advising people with disabilities. For example, a specialist in places like hospitals/spinal injury centres to help people set up their benefits. A designated person in social services/community living support who is able to help people discover and apply for benefits. Also forms available in different formats, including easy read.</p> <p>*10. It is varied depending on people disability. It might be a person's GP or specialist, however, if the responsibility is placed solely on GPs or health care professionals, this with add an extra burden to the NHS. It needs to be someone who is well trained to understand and be sympathetic to individuals differing needs. It should not be solely base on peoples abilities to cope with their disability or carry out day to day tasks, as that does not mean that they will not incur extra costs.</p> <p>*11. For some people, the difficulty of leaving their home to visit the professional, for others the feeling of invasion of privacy if the professionals have to visit them in their home environment.</p>

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		<p>Therefore the ability for it to be a flexible process to best suit each individual is important.</p> <p>*Being seen by someone who does not already know or understand your case can be very frustrating and un-dignifying. Having to explain specific details about you disability and its effects to someone who is a stranger can be a very stressful, intimidating and embarrassing experience. The feeling of the assessment being impersonal can feel insulting, like you are not a full human being.</p> <p>*12. Having a disability is a massive burden and is time consuming and can be stressful. The additional time drain and stress of having you benefit regularly reviewed is a great cause for concern. Not having awards that are awarded for life time or indefinite not only causes an additional and unnecessary burden to disabled people but also massive additional administrative costs of notification and carrying out the reviews. Especially given that there are a large number of disabilities out there that are “stable” and will certainly not get better, and will be very long periods of time before they are likely to deteriorate further. These really should receive the security of having the benefit awarded indefinitely. For some people a “self regulating” review might be appropriate, where they can request a review if they feel their situation or disability has changed, but otherwise they continue to receive the benefit as if it was indefinite. Or a review form that give you the opportunity to just say nothing has changed.</p> <p>*13. Sometimes this may purely be because of the number of different departments that you have to inform, and the misunderstanding that reporting it to one covers them all. You could link up information, so that when you report a change to one department, you have the option for it to be reported to other relevant departments all in one go.</p> <p>*Also a reassurance that by reporting a change they will not necessarily lose their allowance all together, or have to go through extensive reassessments.</p> <p>*Also making it easier to report a change, could be done by phone, email via a website, could be a multiple choice to chose what change you are reporting and space to fill in extra details.</p> <p>*14. Yes. Information on what other benefits, support or help is available to them. Possibility of linking them up with someone else who has already been through it. Information on their rights, Disability Discrimination Act, who to complain to if you feel you are not being treated properly.</p> <p>*15. No. It would add extra pressure and stress if there were additional requirements it could put people off applying. When you become newly disabled, there is so much to take on board, you can’t do it all in one go. Pressurising people to take on more than they feel capable of in one go is not fair. Also, people might find it insulting, like they are being told that they can’t cope with it.</p>

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		<p>*16. Paid for out of personal expense, charities (including national, local and ones specifically set up for the individual, donations, grants, gifts, compensation awards, other benefits (e.g. access to work) social services, hospitals/NHS, short/long term hirer, buying second hand, cheap or inferior aids.</p> <p>*People should be allowed to spend their PIP money on whatever they want, whatever they think suits them best. They should not be limited on what it can be spent on, because there are so many different bits and pieces of extra expenses that having a disability entails, you could not fairly regulate it and make sure that they are don't out of pocket due to their disability.</p> <p>*17. Burden on parents and rest of family, different social needs, harder ware and tare and growing out of equipment.</p> <p>*18. VERY useful. I have lost count of the number of times I have had to photocopy the first page of my award letter and send it off to different places. Instead of having to send of the piece of paper, having a system for allowing information sharing so you can sign to say to allow them to access the DLA/PIP information (all of/or specific elements of) without having to send them the letter. Some things could even be automatic. It would be good to provide information on things that you might be eligible for, like reduced band council tax, cinema pass for your assistant.</p> <p>*19. It would be awful! It would cause lots more paper work, forms to fill in, administration, stress, time consumption, repetition of giving information, and people not getting all the help they are entitled to because of the extra complication involved. There would be delays in claims because of the extra administration and checks involved.</p> <p>*20. Your response:</p> <p>*21. Meaning that those that don't like to cause a fuss or feel like they are a burden to people (particularly older people) are less likely to get the help and support that they deserve. Also it disadvantages those that find it difficult to understand and fill in forms or organise paper work due to either dyslexia, learning disability or mental health issues.</p> <p>*22. Given that there is a public consultation on this, I think it is bad how little it has been publicised. I only found out because my local social services informed me that were where proposed changed. There must be a very large number of people who it will affect, who won't hear about it in time to have their say, or even until the changes are put into place.</p>
EM735	17/02/2011	<p>1. Your response: Most services are accessible without some for of specialist aids which are very expensive. An example it the software that I am using to complete the form. With magnification software that cost me £850 I would not be able to use a computer. I rely on public transport which is in decline so Taxi's have to cover the routes which are not accessible. I have difficulties seeing my way around the shops to read labels,</p>

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		<p>prices and products. This is made increasingly difficult by the shops frequently changing the layout, therefore require assistance.</p> <p>*Access most services require reading, most of which is in small print. Therefore it is necessary for me to rely on others to read for me or use low vision aids, which again cost money. Even access to a mobile phone requires adaptation as the manufacturers do not consider the use by visually impaired people.</p> <p>*Lighting around the house needs to be increased, this leads to additional cost in utilities bills. All of these points cost more . The biggest barrier is society itself after all it is the majority with there lack of consideration that create the barriers for all types of disability. DLA helps to cover some of the additional costs I incur.</p> <p>*2. Your response: The concepts of DLA is a good one, it is the abuse by the minority that has forced this government move.</p> <p>*3. Your response: As previously mentioned, hugely inflated prices for adaptive technologies to allow access to mainstream equipment. Utilities bills for lighting and heating. Transport costs for general daily life and additional to attend more frequent hospital appointments, Additional equipment to maintain independence and to pay for support and help from others.</p> <p>*4. Your response: I think the two rates for both components maybe be simpler. However it does not take into account the varying scales of support that individuals need in accordance to level of need. It could mean that some people that would have had middle rate care under DLA may be reduced to a lower rate under the PIP.</p> <p>*5. Your response: If somebody has a life long condition that will remain unchanged for life shouldn't need to be re-assessed frequently. Some conditions should be recognized as automatic entitlement, especially those that will not improve over a lifetime. It is of concern that the assessment may not be completed by people that are not specialized in a specific field such as consultant ophthalmologists.</p> <p>*6. Your response: For Visual Impaired it has to be safe management of Daily Leaving Skills, Communication and Mobility. Social inclusion to avoid isolation should also be a priority. Consideration has to be given when allocating benefits to not only the use of physical carers, but funding to help with additional costs for equipment, utility costs and transport. Quality rehabilitation services we help with delivering services and this should see growth over the coming years and not the current trends of cuts. Services should promote the use of PIP to buy equipment etc to increase independence.</p> <p>*7. Your response: It should be based on a Person-Centred approach. The government is keen to allow disabled people to</p>

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		<p>become experts of their own disability and plan to meet their own needs. However I am sure that the assessment will of a pigeon hole nature where individuals will be categorized labeled and placed into certain criteria. It should be holistic and consider how the individual is coping with their disability and making use of resources. If somebody is very independent because they manage the disability well and make good use of their DLA to do so, it should not be assumed that they don't need the new benefit. Consideration has to take into account what specialist equipment they use, do they need extra money for running costs of lighting etc. It should not solely be linked to care provision.</p> <p>*8. Your response: As previously mentioned if a current aid or purchase of a new aid is needed to overcome a barrier created by society and allow an individual to be independent then it should be considered. Equipment is often a short term expense where as a physical care person is a long term expense. As previously mentions additional cost towards lighting should be considered, for someone with a visual impairment this could be a expensive but vital necessity to maintain safety in the home and allow a great deal of independence and quality of life.</p> <p>*9. Your response: Comes down to clear concise information. Consult with potential claimants about what needs to go on the form and its accessibility. Get those that are to use the form to design it. Create a working party to look at this form and include disabled people like me in the the design and campaign process. We have the first hand experience.</p> <p>*10. Your response: professionals that work in the field and the individuals themselves. There needs to be consultation with the individual, medical and social care providers. The individuals views should be paramount, as the government state 'The disabled person is the expert in their own experience.;</p> <p>*11. Your response: Is the health care professional a specialist in my disability. Probably not!!!! I live with it day in and out, and experience the barriers on a day to day basis. How can a health care processional empathize or have experience with my situation. However if the professional is of a specialized background then their understanding may be more empathetic and supportive, understanding my needs, equipment and future aids. The venue of the assessment is also crucial, is the venue accessible to the assesss. Many people find medical professional intimidating and are uneasy to be around.</p> <p>*12. Your response: Reviews should be set on an individual basis. If it is a condition that is short term, or progressive then they would probably need assessing more frequently. For those that have a life long conidtion that is stable or unlikely to change then it should be reviewed less frequently.</p> <p>*13. Your response: Advertising similar to the Tax Credit</p>

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		<p>System. Possible annual letter/form to remind and give opportunity for changes to be declared.</p> <p>*14. Your response: The information needs to be clear concise and states clearly what the benefit is for. Advice on completing the form should also be readily available.</p> <p>*15. Your response: Don't really understand the question.</p> <p>*16. Your response: I use my DLA to partially fund my aids and equipment. PIP she be allowed to pay for equipment but think it better to be made regularly basis. If you need to keep applying ever time a new piece of equipment is need would make the process bureaucratic and put people off. Additional utility costs should also be considered to meet the additional costs of lighting etc.</p> <p>*17. Your response: It needs to be considered how the disability effect the child above a non-disabled child. Equipment and aids should also be considered.</p> <p>*18. Your response: One thing that does concern me is the access to the Disability Element of the Working Tax Credit. Currently you have to be in receipt of the DLA to be entitled for the the additional credit element. Have the government allowed for this or will that entitlement be removed as well.</p> <p>*Online benefits check system may be of an advantage and a government computer system that automatically checks entitlement for others benefits one one is being claimed.</p> <p>*19. Your response: Many benefits and other services would go unclaimed or used.....ultimately saving the government money!!!!</p> <p>*20. Your response: A single computer system for benefits and taxes. Greater communication between benefit departments, health and social care and the person consent.</p> <p>*21. Your response: The proposals may marginalize some ethnic groups as they may feel rigorous assessments and investigations intrusive. However the policy should try and encourage to reach those on the fringes of society to create greater inclusion. I think many of the disability groups will find these proposals very difficult to stomach and fearful of the policies impact.</p> <p>*22. Your response: I think some of the the ideas are good in practice. However have concerns that a lot of disabled people may lose out significantly because they cope independently well because they maximize the benefits they use, especially those that are working. Looking at the bigger picture, more needs to be done to encourage employers to employ disabled people. That is one of the biggest barriers to a disabled life.</p>
EM736	17/02/2011	<p>1. • Poor accessibility to public transport and buildings• The high cost of buying and running a car; high cost of taxi fares• Reduced employment opportunities due to lack of jobs and employers' poor perception of disabled people.</p> <p>*• The high cost of specialised wheelchairs and other aids and adaptations. • Onus on disabled person to show they are being</p>

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		<p>discriminated against e.g. access to buildings.</p> <p>*2. Yes, receiving the DLA means that disabled people can apply for other services without having to 'prove' the extent of their disability each time, e.g. when applying for a blue badge or an exemption to paying the congestion charge in London. Being automatically notified of special government services (such as help for eligible disabled people with the digital TV switchover).</p> <p>*3. • Paying for running a car including petrol, and insurance, MOT, servicing/repairs because of adaptations to a car. • Paying for adaptations to the car either for a disabled person to drive or to be a passenger. • Having to purchase specialist equipment or mobility aids, particularly when Social Care or the NHS are not prepared to take into account the specific needs of the person's disability or the waiting list is too long. • Servicing, repairing and insuring specialist equipment and mobility aids. • Paying for specially designed clothing. • The extra cost of heating – most disabled people will feel the cold more than most. • Having to eat a healthy/special diet for medical reasons or maintaining weight due to lack of mobility. • Maintaining a condition by carrying out recommended exercise such as swimming.</p> <p>*4. Yes it will be simpler having two rates per component. The disadvantages might be to those who are 'borderline' cases in each rate.</p> <p>*5. Claims for health conditions which are being 'treated' should be based on the needs and circumstances of the individual applying and not given automatically and should be based on the 'Qualifying Period'.</p> <p>*Those who are terminally ill should continue to receive automatic fast track entitlement.</p> <p>*The current list in Annexe 1 should be reviewed to include more life-long disabilities such as Muscular Dystrophy and Multiple Sclerosis.</p> <p>*6. The only fair way to prioritise support is for each applicant to have an assessment when they claim, then regular periodic reassessments to make sure the claimant is still eligible or needs more/less benefit.</p> <p>*The activities that are essential to everyday life are: The ability to get yourself out of/into bed each day, washing, dressing, feeding, preparing meals and drinks, ability to get out and about into the wider community, weekly food shopping, ability to administer own medication, get to hospital appointments.</p> <p>*7. Regular reassessment of claims, and liaising with the claimant's doctor/consultant about his/her condition. This should be made clear at the outset of an assessment and should be overridden where a greater disability becomes more pronounced.</p> <p>*8. No, assessments of a person's ability should not take into account any aids and adaptations that they use. For many</p>

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		<p>people the NHS and Social Care will only provide the cheapest options available or refuse to provide what their client needs because of funding issues or a 'one size fits all' approach.</p> <p>*Disabled people often have to buy their own equipment which are always very expensive and for mechanical and electrical equipment, there is the cost of regular servicing and repairs, and sometimes replacement not to mention insurance.</p> <p>*Taking aids and adaptations into account would impede a person's ability to live a full and active life by causing even further restrictions and limiting freedom of choice. The consultation mentions, for example, taking wheelchairs into account. If this is done in a negative way, disabled people might feel forced to use cheap models which are not entirely suitable and for electric wheelchair users, they'd be restricted if they want to upgrade to a better model which would give greater freedom. Aids and adaptations are a necessity not a luxury!</p> <p>*9. Make the forms shorter. Provide a helpline for claimants to contact or signpost to organisations that can help with filling in forms. Send out information by post to existing claimants, disseminate information via recognised charitable bodies. Regularly update all websites that carry information about benefits.</p> <p>*10. Information sharing will be important here. Although the Government plans to use healthcare professionals in assessments, they might not have the detailed understanding of some conditions. In these instances it is important to get the right information by liaising with the claimant's GP and/or consultant.</p> <p>*11. The benefits of face-to-face discussion will be:</p> <ul style="list-style-type: none"> • A more accurate assessment of the claimant • Less likelihood of fraud <p>*Difficulties might be:</p> <ul style="list-style-type: none"> • Arranging time off work to attend the appointment • Difficulty in getting to the appointment • Difficulty in getting a specialist consultant <p>*Circumstances which might be inappropriate to require a face-to-face meeting:</p> <ul style="list-style-type: none"> • If someone is terminally ill. <p>*12.</p> <ul style="list-style-type: none"> • Prognosis - how quickly/slowly a condition deteriorates • Whether any treatments the person is receiving will result in the person being well again after treatment is complete. • There should be different types of review depending on the needs of the individual and their impairment/condition. <p>*13. This can be done by carrying out periodic assessments/reviews of a person's claim – either by face-to-face meetings or by asking claimants to fill in a type of 'self-assessment' form or another sort of 'renewal' claim form. Make it easier to report changes by having a dedicated help-line or via a website.</p> <p>*14. Yes it would be helpful for people applying for the Personal Independence Payment to get advice and information during the claiming process. The kind of information to consider providing is:</p>

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		<p>**• Whether there is a Wheelchair Service in a claimant's area and how to get a referral.</p> <p>*• The type of wheelchair that a Wheelchair Service can provide and what claimants should do if the Wheelchair service cannot provide a wheelchair that is suited to an individual's specific needs (for some reason)</p> <p>*• Whether claimants would qualify for help from their local Social Care service, what kind of equipment/services Social Care will provide, and the referral process.</p> <p>*• Details of car dealers that take part in the Motability Scheme</p> <p>*• Information of where to get a driving assessment and information about car adaptations for disabled drivers or for disabled passengers.</p> <p>*• Information about whether claimants would qualify for a Disabled Facilities Grant or other such grant to enable a disabled person and his/her family extend their home and obtain aids and adaptations. Force local authorities to be transparent about exactly what the qualification criteria is because often this is not made clear, particularly with regard to finance and a person's savings/income</p> <p>*• Provide signposting to condition specific organisations, for example, Muscular Dystrophy, Multiple Sclerosis, cancer charities, etc</p> <p>*• Details about the Access to Work scheme and other information on where disabled people can go to get advice about getting work or training.</p> <p>*• How to get Care/assistant services – local authority/private providers, etc.</p> <p>*15. A 'three strikes and you're out' approach might be a way forward.</p> <p>*If repeated requests for information are ignored by a claimant, one way to ensure that this would work is by issuing some sort of threat of enforcement, for example, you might have to write and say something like 'After repeated requests for information, we still haven't heard from you. Please contact the department by (give a date). Failure to respond will mean your benefit will be cancelled.'</p> <p>*Or another way would be for an assessor/officer from the benefits office to pay a visit to the claimant by appointment. If several appointments are missed, a letter advising the claimant that their benefit may be stopped might be appropriate.</p> <p>*There may be pitfalls to each approach. The benefits office would need to be careful where claimants have a mental health issue and are unsupported by a carer or social services.</p> <p>*16. I have funded my own aids and adaptations by saving my DLA because I prefer not to rely on my local authority or NHS. This is because of poor experiences with them, in particular my local authority as their 'one size fits all' approach wouldn't have helped me maintain my independence if I'd accepted their help. Therefore, I value the freedom of choice that the DLA gives me.</p>

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		<p>*I have used my DLA in the past to buy an electric wheelchair and lease a car through the Motability scheme.</p> <p>*17. Not applicable.</p> <p>*18. This is a very important part of DLA! It means that eligible disabled people are able to get things like a Blue Badge, exemption from paying the congestion charge, free/discounted parking in some areas, access to 'Warm Front' products, help from government regarding the digital switchover and other government schemes, Motability.</p> <p>*19. • For claimants – the stress and inconvenience of having to keep applying for services and having to give evidence, get GP reports/signatures, - some GP's will charge for this service – and have to possibly attend more face-to-face assessments.</p> <p>*• For service providers – having to process/check forms, collate information, have to employ decision makers, have to check evidence, have to set up an appeals process, and excessive costs to service provider. Massive duplication and increased costs to be borne by service providers, a downward spiral.</p> <p>*20. The Access to Work (AtW) process is appalling and needs streamlining. This is what I'm going through at the moment.</p> <p>*Despite a recent AtW assessment to say I need a specific new electric wheelchair for my place of work, I've been told by AtW that I have to get my GP to refer me to the Wheelchair Service. Then if the Wheelchair Service say they can't/wont provide the wheelchair recommended by the ATW assessor, the Wheelchair Service have to write to me stating that they can't/wont help, then I have to send a copy of the letter to AtW so they can reconsider and pay for the wheelchair. This is utterly ridiculous! Surely if there is funding from the NHS for electric wheelchairs, AtW can liaise with the NHS on my behalf? Surely, on having had an assessment by AtW's assessor, the Wheelchair Service should accept the AtW assessor's report therefore eliminating the need for a referral by a GP? Surely, the NHS and AtW can pool their resources to help pay for an electric wheelchair? If the Government is serious about supporting disabled people at work something needs to be done about this.</p> <p>*I agree that the other examples that the Consultation document mentions (chapter 3, page 26, number 8), should also be streamlined. Having to constantly deal with different organisations every time is very frustrating, very annoying, very soul destroying and very time consuming.</p> <p>*21. Reducing benefit, especially if you take into account aids and adaptations in a negative way, could seriously affect a disabled person's freedom of choice over their care and the equipment they need. This could lead to people not taking up DLA because of the fear they will be penalised by the reduction in benefit. This could have a knock on effect of them requiring more assistance than if they had had small and effective aids or</p>

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		<p>adaptations.</p> <p>*Service provision is patchy throughout the country, whether by a Local Authority or other organisations so disabled people rely on the DLA to access services.</p> <p>*It would be worth looking into raising the age of eligibility for the new benefit in line with the changes to the state pensionable age.</p> <p>*22. It would be helpful if various organisations could share information about a disabled person, with their consent, where services overlap so that disabled people don't have to keep approaching multiple agencies to ask for help.</p>
EM737	17/02/2011	<p>As a severely disabled person, I welcome the opportunity to respond to the consultation on Disability Living Allowance reform.</p> <p>*1. Barriers to participation and living a full and active life</p> <p>*Question 1 What are the problems or barriers that prevent disabled people participating in society and leading full and active lives?</p> <p>*I am profoundly deafblind, as well as being a wheelchair user and having epilepsy and other medical needs.</p> <p>*Deafblindness is a unique impairment that affects each individual in different ways and deafblind people face a wide range of barriers in communication, access to information and mobility. The needs of deafblind people are greater than and different to the needs of blind people and of deaf people. My sensory impairments also interact with my other impairments, giving rise to different and greater difficulties, and costs, to people with just one of my impairments.</p> <p>*I communicate using deafblind manual (a specific type of tactile fingerspelling) and braille. This means that I am unable to communicate with the majority of people without the support of a deafblind manual interpreter. This applies even to the simplest of interactions such as asking who is at the door. I am unable to communicate with my family, many of my work colleagues, transport staff, shop staff, neighbours, workmen, many former friends and so on. This results in extreme isolation.</p> <p>*When I do have an interpreter, I am still restricted in my communication because deafblind manual is a slow method of communication (approximately a fifth of the speed of speech) and, therefore, I cannot keep up with group discussions.</p> <p>*I read information using Braille. Very little information is provided in Braille. Increasingly, I am finding organisations providing print or audio, neither of which I can use, and no longer providing Braille. When Braille is provided, it is often too late. For example, my energy supplier does provide bills in Braille but the Braille bill frequently arrives after the payment was due.</p> <p>*I also use specialist technology to help me access information. I use a computer with special software and a Braille display so</p>

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		<p>that I can use email, Internet and other applications. I also have a scanner with optical character recognition software that enables me to scan some printed documents and read them on the computer's Braille display. However, many websites are inaccessible to me and only some print documents will scan. So, whilst this equipment is very important to me, it only partially overcomes the barriers I face with accessing information. The equipment is also very expensive. For example, just the Braille display cost around £3,000 and for equipment for my personal use there was no financial assistance to purchase it, I had to pay for it myself.</p> <p>*I am unable to get out and about by myself because</p> <ul style="list-style-type: none"> • I cannot hear or see traffic so cannot cross roads safely without assistance • I cannot see landmarks and orientation cues and cannot hear environmental sounds to assist with orientation • I cannot communicate with members of the public, transport staff, etc • I cannot see or hear announcements and information at train stations etc • I cannot self-propel my manual wheelchair, which requires two hands, at the same time as using a cane to feel for obstacles and for a safe path, which would require a third hand. • I live in an inaccessible first floor flat with no lift. To get out of my flat I have to drag myself on my bottom down outdoor stairs, whilst someone else carries my wheelchair. • etc. <p>*In order to be able to communicate with others, access information and get out and about I need support from a person with specialist skills, including</p> <ul style="list-style-type: none"> • fluent deafblind manual • the ability to interpret from spoken and written English into deafblind manual • the ability to provide me with the right information about what is happening around me • the ability to guide a wheelchair (note that guiding a wheelchair is different to pushing a wheelchair, it involves steering and using tactile communication to provide me with relevant information whilst I remain in control of propelling the wheelchair) • etc. <p>I work four days per week, with help provided both by the Access to Work scheme and by my employer. Access to Work funded equipment for me to use at work and pay for a support worker and interpreters. This support is very important to me. However, Access to Work do not pay for travel expenses for my support worker, so I have to pay for these. My employer also has to make very significant adjustments, which go beyond what most people would consider reasonable adjustments. I am fortunate to have found a job with a supportive employer but because of the extent and progression of my impairments I am at risk of losing my job.</p> <p>*I receive a small amount of social care support, in the form of Direct Payments to pay for a communicator-guide to help me with things such as shopping and paperwork. However, this is woefully inadequate. For example, social services will not pay for me to have support to travel to and from hospital</p>

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		<p>appointments, to visit family or friends, to get involved in my local community or to get exercise. This lack of support severely restricts my quality of life. DLA is important in enabling me to pay for a little extra support, which at least gives me a tiny bit better quality of life.</p> <p>*The attitudes of other people also form a very significant barrier to my participation in society. This discrimination, such as people refusing to speak to me on the telephone through an interpreter, refusing to make reasonable adjustments such as providing an interpreter or information in an accessible format, speaking to my support worker or interpreter rather than to me, and so on. It also includes verbal abuse and hate crime. For example, recently when travelling by train with a support worker, a passenger spent about half an hour loudly proclaiming to the rest of the carriage that I was stupid and a lazy scrounger. A couple of years ago I was physically assaulted by a new work colleague, who afterwards said that she didn't realise it wasn't appropriate to assault disabled people. I have also been the victim of hate crime.</p> <p>*2. Things that should stay the same Question 2: Is there anything else about DLA that should stay the same?</p> <p>*I welcome the intention to keep a universal, non-means tested benefit that can be spent flexibly to meet the additional costs of disability.</p> <p>*As a profoundly deafblind person, I currently have automatic entitlement to the higher rate mobility component of DLA. This automatic entitlement should be retained. Deafblind people have severe difficulties with mobility and it is a waste of resources to require them to undergo an assessment when the severity of the deafblindness inevitably means severe mobility difficulties.</p> <p>*I am also deeply concerned by the government's intention to remove the mobility component of DLA from those in residential care. Although I live independently, I know many people in residential care and losing DLA will have a terrible impact on their lives. Without the mobility component of DLA, they will be unable to get out and about. It has wrongly been claimed that there is duplication of funding between local authorities and DLA mobility for people in residential care. This is wrong. Local authorities may pay for transport for activities listed on a care plan, such as visiting a day centre, but not for other activities such as visiting family or friends. The government has also compared people living in residential care with patients in hospital. This is fundamentally flawed. People in hospital are ill and there temporarily. People in residential care need and want to be able to get out and do things, the residential service is their home, where they live, just like our homes are for us. I therefore, urge the government to reconsider this decision and re-instate the mobility component of DLA for people in residential care.</p>

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		<p>*DLA can be awarded for a limited time or for an indefinite period. It would be wasteful to require people with conditions that cannot improve to undergo regular re-assessments. I therefore urge the government to keep indefinite awards.</p> <p>*3. Additional costs*Question 3: What are the main extra costs that disabled people face?</p> <p>*I face a wide range of additional costs, some relating to specialist equipment and services, and some relating to higher than average day to day living costs.</p> <p>*I rely heavily on a range of assistive devices to assist with mobility, communication and access to information, all of which I have purchased myself. These include a wheelchair, Braille display for a computer, screen reader software for the computer, a scanner with optical character recognition software to enable me to access some printed documents, special software to enable me to use a computer with Braille display as a Braille textphone, a vibrating pager system to alert me to the door bell, telephone and smoke alarm, a mobile phone with Braille display, and much more. The cost of my Braille display alone was £3,000 and this needs regular maintenance and replacement from time to time. Whilst Access to Work funded some equipment for me to use at work, I have had to purchase all of my own equipment for use at home. Whilst theoretically the NHS should have paid for my wheelchair, the waiting list is so long that I had no choice but to purchase my own so that I could continue working.</p> <p>*I also have many additional costs relating to mobility and daily living as a result of my disabilities. For example,</p> <ul style="list-style-type: none"> *• I have to pay the fare for my communicator-guide/support worker, as well as my own fare, when using public transport *• I live in an area with no wheelchair accessible buses so have to pay for taxis to travel locally *• I have frequent hospital appointments a long way from where I live and the cost of paying for my travel, plus the travel for a support worker, mounts up *• I frequently have to pay for interpreters when service providers refuse, or fail, to do so. For example, at hospital appointments the hospital would provide a British sign language interpreter, which is no use to me, but will not provide a deafblind manual interpreter and so I have to pay for this. Service providers refusing to pay for interpreters in this way is unlawful but it still happens. *• In order to visit family or friends, I have to pay for a communicator-guide to travel with me because social services will not pay for these activities. This includes both the communicator-guide's fare and their time *• I live in an inaccessible flat and to get in and out must drag myself on my bottom up and down outdoor stairs, which means I frequently damage clothing *• I cannot read use by dates or cooking instructions on food

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		<p>and consequently frequently have to waste food</p> <ul style="list-style-type: none"> *• I have to wash and replace clothing more frequently than other people due to spills and damage *• I have to do most of my shopping online but am unable to see product pictures and therefore frequently find that products are unsuitable when they arrive but am unable to get to a post office to return them *• I have to use services that are accessible to me and this sometimes means using more expensive services *• I have to buy accessible products, such as washing machines with tactile controls, and this sometimes means having to buy more expensive models *• Etc.*4. Two rates per component <p>*Question 4: The new benefit will have two rates for each component: Will having two rates per component make the benefit easier to understand and administer, while ensuring appropriate levels of support? What, if any, disadvantages or problems could having two rates per component cause?</p> <p>*Reducing the number of rates to two per component will have little impact on how easy the benefit is to understand or administer. Any difficulties with understanding DLA are not because of its structure but because of the misinformation put out by the media and others. What is needed is clear information and action taken to put a stop to, and correct, misinformation.</p> <p>*Reducing the number of rates to two per component will have a negative impact by leading to some people who currently qualify for DLA losing out. Two rates are insufficient to respond to the wide variety of needs.</p> <p>*5. Automatic Entitlement</p> <p>*Question 5: Should some health conditions or impairments mean an automatic entitlement to the benefit, or should all claims be based on the needs and circumstances of the individual applying?</p> <p>*There should be automatic entitlement for people with certain impairments or health conditions. Deafblind people should retain entitlement to the higher rate of the mobility component. The accepted working definition of deafblindness is that a person is deafblind if their combined vision and hearing impairment causes difficulty with mobility, communication and access to information (both written information and information about what is happening around them). The mobility difficulties faced by deafblind people are extreme and they apply to all deafblind people. It would, therefore, be a waste of resources, as well as causing unnecessary stress for deafblind people, if they were made to undergo an assessment. Automatic entitlement for certain groups, including for deafblind people, helps to ensure that benefit reaches those who need it and reduce the cost of assessing people for the benefit.*6. Prioritising support and activities of most importance</p>

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		<p>*Question 6: How do we prioritise support for those people least able to lead full and active lives? Which activities are most essential for everyday life?</p> <p>*Everyone should have a reasonable quality of life. This is not just about personal care, it is also about• the ability to get out of one's home• interaction with others and overcoming social isolation and exclusion• access to information – both written information and information about what is happening around them• having a basic social life, including the ability to be part of one's family and make and see friends• participating in the community and• living a healthy lifestyle*• accessing food and drink, including the ability to shop, cook and eat and drink• maintaining a safe and decently clean home• the ability to cope with unexpected things happening. All of these are essential to remaining physically and mentally well.</p> <p>*7. Variable and fluctuating conditions Question 7: How can we best ensure that the new assessment appropriately takes account of variable and fluctuating conditions?</p> <p>*It is vital that variable and fluctuating conditions are properly taken into account. Those of us with fluctuating or variable conditions may have higher costs during bad phases than we do during less bad phases. However, even during less bad phases we may have costs associated with the uncertainty of knowing when will be a bad phase and needing to be ready for it.</p> <p>*The assessments must give people the opportunity to explain how their condition affects them during bad phases and how frequently these occur. A healthcare professional, who does not know the person, cannot judge on the basis of a one-off snap-shot assessment how someone with a fluctuating condition is affected. Therefore, it is vital that the person is listened to and believed, and that further information is sought from the person's own GP or specialist, who is likely to have a better understanding of the variability of the person's condition than an assessing healthcare professional can obtain.</p> <p>*8. Aids and adaptations</p> <p>*Question 8: Should the assessment of a disabled person's ability take into account any aids and adaptations they use? What aids and adaptations should be included? Should the assessment only take into account aids and adaptations where the person already has them or should we consider those that the person might be eligible for and can easily obtain?</p> <p>*Aids and adaptations generally only partially overcome barriers and are often associated with significant costs. It is vital that disabled people have the money they need in order to be able to purchase and repair aids and adaptations. Therefore, if aids and adaptations are taken into account, their effectiveness and the costs associated with them should be properly considered.</p> <p>*With the exception of equipment I use in my job, I have had to purchase all of my own aids and adaptations, at considerable</p>

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		<p>cost. Although these aids and adaptations are extremely important to me, they only partially solve the problems. For example, I have a scanner, with special software, that I use with my computer and Braille display to enable me to read some printed materials but a lot of print information will not scan and so I still need someone to read a lot of information to me and always need someone to help me fill in forms.</p> <p>*Reliability of aids is another important factor. They do need maintenance, repair and replacement. When an aid breaks, it can result in significant costs whilst it is being repaired or replaced.</p> <p>*It is also vital that, if aids and adaptations are taken into account, that their appropriateness is considered. Many aids and adaptations that work for people who are either blind or deaf do not meet the needs of deafblind people.</p> <p>*I am deeply concerned by the implication that aids and adaptations that a person does not own could be taken into account. If people do not own them, there is a good reason for this. Sometimes this will be due to insufficient money to purchase or repair them, other times it may be because the person is fighting with another service to try to get the aid or adaptation but is meeting with resistance, and sometimes it will be because the aid or adaptation has been tried and found to be unsuitable. To penalise people for what they do not have is grossly unfair.</p> <p>*9. The application process</p> <p>*Question 9: How could we improve the process of applying for the benefit for individuals and make it a more positive experience? For example: How could we make the claim form easier to fill in? How can we improve information about the new benefit so that people are clear what it is for and who is likely to qualify?</p> <p>*It is important that the application process is accessible, fair and as low-stress as possible.</p> <p>*Claim forms and other information should be provided in a range of accessible reading formats and it should be possible to fill in the claim form in a range of different ways. For example, in print, online or by phone.</p> <p>*The person applying, people who support them on a day to day basis, and the person's own healthcare providers are best placed to provide information for the claim process. I am concerned that a healthcare professional, who is not familiar with the claimant, and may know little or nothing about low-incidence impairments, such as deafblindness, or health conditions, such as mitochondrial disorders, will be unable to fairly assess the claimant. The assessment process should seek to be fair and to minimise the number of people who feel the award, or lack of award, is unfair and so need to appeal.</p> <p>*It is essential that claimants retain the right to appeal when they feel that an unfair decision has been made.</p>

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		<p>*I believe that the main reason there is confusion over DLA is that the media and others frequently give out misinformation and this is not corrected or stamped out. It is important that clear and accurate information is provided and that misinformation is prevented from being published.</p> <p>*10. Supporting evidence for applications</p> <p>*Question 10: What supporting evidence will help to provide a clear assessment of ability and who is best placed to write it?</p> <p>*The claimant him/herself, people who support the claimant on a day to day basis and the claimant's own healthcare providers are best placed to provide supporting evidence. Deafblindness is a unique, complex and low-incidence impairment and it may sometimes be necessary to involve a person with specialist knowledge of deafblindness, and its impact, when assessing deafblind people, unless there is automatic entitlement for deafblind people.</p> <p>*11. Face-to-face assessments*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? Are there any circumstances in which it might be inappropriate to require a face-to-face meeting with a healthcare professional – either in an individual's own home or another location?</p> <p>*Deafblind people have difficulties with communication, mobility and access to information. Therefore, for a face-to-face assessment, deafblind people would require appropriate communication support. If the assessment was to take place in a location other than the claimant's own home, deafblind people would also need appropriate support to travel to and from that location. The need to provide this sort of support makes face to face assessments even more expensive.</p> <p>*Deafblind people's communication is often slow, for example, I use deafblind manual, which is approximately a fifth of the speed of speech. This means that additional time is needed for face-to-face meetings. If adequate time weren't allowed for the assessment, deafblind people would be disadvantaged.</p> <p>*Furthermore, simple interpreter errors can result in significant and problematic misunderstandings. This in turn could lead to unfair decisions being made.</p> <p>*I am concerned that a face to face assessment with a healthcare professional who knows little or nothing about deafblindness will fail to give an accurate picture of the extent of deafblind people's needs.</p> <p>*A claimant themselves, people who support them on a day to day basis, the claimant's own healthcare providers and deafblind specialists are better placed to make an accurate assessment.</p> <p>*12. Reviews*Question 12: How should a review be carried out? For example: What evidence and/or criteria should be used to set the frequency of reviews? Should there be different</p>

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		<p>types of review depending on the needs of the individual and their impairment/condition?</p> <p>*It is vital that reviews recognise that, for many people, their condition is more likely to stay the same or deteriorate than it is to improve.</p> <p>*Routine reassessments are a waste of resources if the person's condition will not improve. Life-time or indefinite awards should be retained for people whose conditions will not improve. A claimant's own healthcare providers are best placed to judge the likelihood of a person's condition improving, staying stable or deteriorating.</p> <p>*Reviews should be as simple and stress free as possible and the quality of the decision making must be fair.</p> <p>*13. Reporting changing circumstances</p> <p>*Question 13: The system for Personal Independence Payment will be easier for individuals to understand, so we expect people to be able to identify and report changes in their needs. However, we know that some people do not currently keep the Department informed. How can we encourage people to report changes in circumstances?</p> <p>*If the fairness of decision-making were improved, so that people felt confident that if they reported a change in circumstances they would be treated fairly and retain the appropriate level of benefit they would be more likely to report changes. I have been reluctant to report deterioration in my condition for fear that, despite a very clear increase in my needs, my benefit could be reduced. I do not trust the decision making process and I do not want to have to take it to appeal again as appealing is a very stressful process. Clear guidance about what changes to report, coupled with improved decision making would help to encourage people to report changes in circumstances.</p> <p>*Where a change in circumstances will lead to a reduction in benefit, it may be useful to provide a short adjustment period where benefit is paid at the old level for a fixed period of time to give the person time to plan and reorganise their finances.</p> <p>*14. Advice and information needed</p> <p>*Question 14: What types of advice and information are people applying for Personal Independent Payment likely to need and would it be helpful to provide as part of the benefit claiming process?</p> <p>*I am deeply concerned by the proposal to link PIP to advice. As a person with a complex and rare condition and impairments, the quality of advice I have received has been shockingly poor. I have been blind since childhood and lost my hearing as a young adult. When I lost my hearing, two social workers, a doctor and a university disability adviser all advised me to learn to lipread. Advising a sighted deafened person to learn to lipread may be good advice. But all of the people who gave me that advice knew that I am blind and that I cannot</p>

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		<p>even see a person in front of me, let alone read their lips. I am extremely concerned that advice given during the process of applying for PIP may be equally flawed.</p> <p>*A benefits application process is not the appropriate time to be providing advice. Especially for people with rare or complex conditions and impairments, advice needs to be provided by people with appropriate expertise.</p> <p>*I also feel strongly that, as the proposal is to have a six month qualifying period, advice should be provided by other services, such as the NHS, social services or voluntary organisations long before a person would be eligible to apply for PIP.</p> <p>*15. Requirement to access advice</p> <p>*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, and what would need to be avoided?</p> <p>*As explained above, I am deeply concerned about the proposal to link PIP to advice. Inappropriate advice can be harmful, and if inappropriate advice is given and following it were a requirement of receiving benefit, people with conditions or impairments that are poorly understood will be disadvantaged and potentially put at risk. If advice is made a requirement, it is absolutely essential that it be provided by a person or organisation with good understanding of the claimant's conditions and impairments, how these interact and what the impacts are. For example, deafblind people would need advice from a specialist in deafblindness.</p> <p>*No single organisation could possibly provide appropriate advice for people with all kinds of impairments and conditions.</p> <p>*Most disabled people do their utmost to improve their own circumstances. Often, it is other services, such as social services, that thwart these attempts. Advice will do nothing to overcome these problems.</p> <p>*16. Funding for aids and adaptations</p> <p>*Question 16: How do disabled people currently fund their aids and adaptations? Should there be an option to use Personal Independence Payment to meet a one-off cost?</p> <p>*With the exception of equipment I use at work, which was funded by Access to Work, all of my aids and adaptations were paid for by me. It is very important that DLA/PIP can be used for this kind of expense.</p> <p>*17. Children*Question 17: What are the key differences that we should take into account when assessing children?</p> <p>*18. DLA as a passport to other benefits and services*Question 18: How important or useful has DLA been at getting disabled people access to other services or entitlements? Are there things we can do to improve these passporting arrangements?</p> <p>*DLA is important as a passport to other benefits, concessions and services. In particular, for me, it has been important for</p>

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		<p>obtaining a disabled person's railcard and bus pass. Having automatic entitlement to other things based on receipt of DLA helps to streamline the application process for these other services and benefits.*It may be useful when people are awarded DLA/PIP to tell them what it is a passport for.</p> <p>*19. Implication if PIP were not a passport</p> <p>*Question 19: What would be the implications for disabled people and service providers if it was not possible for Personal Independence Payment to be used as a passport?</p> <p>*If PIP were not used as a passport, it would increase the burden on disabled people when applying for other services or benefits and increase the burden on those service providers. Using DLA as a passport helps to streamline these application processes and ensure fair decisions are made.</p> <p>*20. Combining assessments</p> <p>*Question 20: What different assessments for disability benefits or services could be combined and what information about the disabled person could be shared to minimise bureaucracy and duplication?</p> <p>*Combining assessments is likely to be problematic because assessments for different benefits and services are looking at different things. Therefore, the information gathered in one assessment is not necessarily relevant or adequate for another assessment.*Under the statutory guidance Social Care for Deafblind People, deafblind people are entitled to have their needs assessed by a deafblind specialist. Although implementation of the guidance is patchy, this has helped to improve the social care services provided to deafblind people. Sharing information from a specialist assessment may help to partially overcome some of the concerns described above regarding independent healthcare professionals having little or no understanding of deafblindness.</p> <p>*21. Equality impact</p> <p>*Question 21: What impact could our proposals have on the different equality groups and what else should be considered in developing the policy?</p> <p>*The removal of the DLA mobility component from people in residential care is unfair on those whose disability results in needs that are best met by a residential service.</p> <p>*The proposals are unfair on people whose disability will no longer qualify them for benefit. It is worrying that the starting point for these proposals is to reduce costs, thereby restricting the number of people who are eligible. There will be people with significant additional costs who no longer get any support.</p> <p>*As explained above, the proposals could also disadvantage people with complex or rare conditions or impairments.</p> <p>*Question 22: Is there anything else you would like to tell us about the proposals in this public consultation?</p> <p>*I welcome the intention to keep a universal, non-means tested benefit paid to disabled people to spend flexibly to help towards</p>

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		the additional costs of disability. However, I am deeply concerned by the proposals for how PIP would be managed. I am also concerned by the intention to reduce the numbers eligible to claim the benefit.*Prepared by [REDACTED]
EM738	17/02/2011	<p>I think it is more important that evidence is gathered from hospital records rather than GP's and that this evidence is not written evidence by an individual completing a form but by obtaining a copy of the computer medical history records. Any cost incurred would be offset by ensuring just and appropriate decisions are made.</p> <p>*In addition, whilst it should still be an individuals responsibility to report changes of circumstances false perceptions of abilities may prevent these changes being reported, it is therefore important that there is a robust review inbuilt into an award due to the wide parametres of abilities within the majority of diagnosed conditions. Also the appeals process should include a medical expert at every appeal hearing. [REDACTED]</p>
EM739	17/02/2011	<p>1. Your response: Money & affordable support if no family support is available. The law was changed years ago for disabled access to all areas...nobody took much notice and it seems rarely enforced.</p> <p>*2. Your response: The higher rated recipients have already been through a rigorous procedure with evidence & declarations from numerous health professionals which is time consuming and stressful so leave them in peace. It's the fringe claimants that need to be re-examined.</p> <p>*3. Your response: Carer/Companion, Food/Special Diets, Convenient Transport, Extra fuel bills especially if virtually housebound, Laundry, medication, special equipment and the need to keep everything in working order or to be repaired/replaced immediately not by the local council/social services as their time frame for immediate is when they get round to it particularly when they do get round to it the workmanship leaves a lot to be desired yet they get paid top dollar for doing it.</p> <p>*4. Your response: Either you need it or you don't. Many people receive the lower end and still function perfectly normally and within the normal costs of everyday living. 1 higher rate level to ensure those who genuinely need it receive it. There may be an argument for a set lower rate for temporary conditions over a set period but why not encompass that in a different benefit.. Those who are already assessed as high component long term recipients should be left to get on with their lives with payments left as they are linked to inflation.</p> <p>*5. Your response: Terminal illness diagnosis is a big mental and financial shock that should be maintained unabated to provide some respite and comfort at the end of a persons' life. It should be given as an immediate automatic payment.</p> <p>*6. Your response: Interaction with other people of their own choice in a home/social atmosphere who often will perform a</p>

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		<p>level of care is vital, so the freedom of choice how they choose to cover any costs involved is paramount. Start sending in social based care and restricting how the recipient chooses to spend their life improvement income will lead to a revolt from the disabled community. Anyone who has a disabled family member or friend...which I would guess is about everyone would join the revolt.</p> <p>*7. Your response: Respect the opinions of professional assessors ie doctors/specialists and don't assume everyone is putting it on.</p> <p>*8. Your response: No...certainly not...Aids are used to improve quality of life and very often to make life easier for a carer. Base assessment on a blank canvass.</p> <p>*9. How could we improve the process of applying for the benefit for individuals and make it a more positive experience? For example: SHORTER FORMS LESS SUSPICION WITH ONLY MEDICALLY KNOWLEDGABLE PEOPLE ASSESSING</p> <p>*10. Forget complete self assessment. If a Dr/Consultant says you are ill/disabled I think that it could be true.</p> <p>*11. Your response: Dr/Consultant for illness/disability...Carer/Partner for impact on life</p> <p>*12. Your response: A professional paid to look for flaws to reduce or cancel the benefit is nothing short of scandalous. An unbiased medical report is far more acceptable.</p> <p>*13. Your response: High Care & High mobility combined people should be left alone...they have enough to cope with...it has been awarded following alot of collated evidence of their condition.</p> <p>*Lower awards should be subject to a periodic check,maybe 12 months, with their doctor and possibly called in for a review.</p> <p>*14. Your response: PIP...easier to understand or easier for the Gov't to administer?</p> <p>*If as rumoured they will be administered by local gov't and not on a monthly basis then PIP should not even be considered.</p> <p>*Circumstances changing are basically like the return to work and up to the honesty of the claimant.</p> <p>*15. Your response: Simplification of the forms not the process is needed then people could understand how to claim. An advisor within their doctors surgery who is fully versed in all benefits would be great.</p> <p>*16. Your response: If you are ill or disabled you tend to need medication and visit or be visited by your doctor. Encompass the benefit advisor within a doctors practice.</p> <p>*17. Your response: Basics are supplied to those on low income/unemployed but they tend to be supplied with too many things they don't use. The more important or expensive items are in short supply. If everyone bought their own aids/adaptations within reason they would shop wisely getting value for money.</p> <p>*Important more expensive needs should be met if the person</p>

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		<p>can't afford them.</p> <p>*18. Your response: I can't see any. Disabled is disabled.</p> <p>*19. Your response: DLA has been a lifeline to many people allowing access to the world that they would otherwise only see on tv on their own.</p> <p>*20. Your response: Disastrous</p> <p>*21. What different assessments for disability benefits or services could be combined and what information about the disabled person could be shared to minimise bureaucracy and duplication?</p> <p>*Your response: Assessment of current recipients is a way of saying "we don't believe you". Look at each case on its merits...people have been given their awards based on evidence.</p> <p>*If the evidence looks suspicious call for independent assessment as Gov't sponsored medicals are symptomatic of a dictatorial state.</p> <p>*22. Your response: Get this wrong and another Middle East is on its way</p> <p>*23. Your response: Means test DLA. This consultation form has been designed so that it is so long that most people will give up half way thereby loading the outcome.</p>
EM740	17/02/2011	<p>Dear Sir/Madam, Please find my response to the current DLA consultation attached. I hope that this is in order but please contact me if there is anything else that you need of me meantime.</p> <p>*1. :• Stigma, discrimination and lack of disability awareness with a clear social model emphasis making clear the distinction between (medical) impairment & disability as experienced as a social construct.</p> <p>*• Impairment effects which are themselves life limiting.</p> <p>*• Low expectations of disabled people themselves and others of the capabilities of disabled people. (often as a result of rejection and past failures resulting from no suitable support being available.</p> <p>*• Lack of incentive for employers when considering a disabled employee who may require "reasonable accommodation" that may increase the employer's direct and indirect costs.</p> <p>*• Inconsistent support for vocational rehabilitation using skilled allied health professionals.</p> <p>*• Slow delivery of "self directed support" models of social care practice being rolled out.</p> <p>*• Environmental barriers in homes, businesses, public transport and public places.</p> <p>*• Additional physical and financial costs and efforts needed to participate.</p> <p>*2. :• Qualifying people having control of the awarded money that empowers them to make choices thereafter.</p> <p>*3. What are the main extra costs that disabled people face?Your response:</p>

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		<p>*• Direct costs of both formal support (paid for) & informal support (unpaid) Currently informal costs are often absorbed totally by carers if available however who would not themselves be eligible to qualify for carers allowance and evidence from the Joseph Rowntree Foundation and Care for a Family that there is a knock on negative economic and social effect on disabled people and their families .</p> <p>*• Transport costs. Inaccessible buses or inability to get to & stand at bus stops often mean that taxi's are needed at higher cost (plus it provides a helpful free assistant as known drivers can help take bags. Adapted vehicles required for those with the most severe impairments also often need a large deposit in addition to using all of the existing mobility allowance.</p> <p>*• Increased heating costs.*• Increased laundry costs.*• Increased clothing costs especially if adapted clothing or footwear is needed.</p> <p>*• Cost of equipment and adaptation costs. This extends from adapted bikes/bikes that are often 10 times+ more expensive than bikes for non disabled children through to the means test applied to adaptation costs via most local authorities.</p> <p>*4. Your response:• I am sure it will make it easier to administer but those who struggle to understand it now will most likely still struggle to understand this slight change.</p> <p>*5. Your response:• I am in favour of a robust assessment for each person to ensure people get what they are entitled and to deter malingerers or those with minor impairments.</p> <p>*• This can be compatible with an efficient and not overly distressing process however and having automatic entitlement categories can surely be agreed with medical advice of impairments that are known to always need support to achieve mobility or supervision/support for daily living tasks. It is also important that the provider of these assessments is also judged on the quality of their assessments if they result in paperwork that leads adjudication offices to initially refuse which is a decision then overturned at appeal. Some obvious examples may be:-</p> <p>*• People registered blind. If you go about this consultation seeking to split hairs (eg awarding benefit to someone with a fixed impairment that obviously requires them to need practical help and/or supervision but a reduced benefit or refusing applications from individuals who have a similar impairment but who have developed greater independence by being more willing to take risks etc) Such an approach would contraindicate engagement with rehabilitation or enablement efforts.</p> <p>*• Children with missing limbs or for example permanent non articulating hip joints (such as children born with congenital neurological conditions causing lower limb paralysis and an associated developmental dysplasia of the hips.)*• Individuals with a permanent paralysis or loss of limbs.</p> <p>*6. :• It really depends on the age, capacities and interests of</p>

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		<p>the person. • Activities of daily living that are essential for all people however could be summarised and prioritised as feeding, toileting/continence routines, transfer ability from bed/chair, personal washing/hygiene routines, dressing, medication management and the ability to get around. Then there are a range of other tasks that are more essential or important to some that includes ability to manage household tasks and responsibilities including money management, ability to socialise and engage with others, ability to get and keep a job etc.</p> <p>*7. : • Base the award on a typical day's functioning, consistent with their presentation and known medical history.</p> <p>*8. Your response: Absolutely not for the reason stated above that the only logical outcome will be to demotivate people to maximise their potential if they are to then be "punished" for developing greater independence by developing competency utilising suitable equipment and adaptations of a specialist nature. The ability to discern someone's underlying functional abilities is essential and should be used to base the level of support on if we are serious about supporting inclusion.</p> <p>*The ultimate outworking of this type of thinking would be to say that a person with 2 x ankle foot orthosis and adapted shoes and crutches is now similar to a non disabled person with regards to mobility or that a full time wheelchair user are now as free as a non disabled person now that they have received provision of an NHS issued wheelchair. Such thinking demonstrated great ignorance of the issues involved or true barriers faced.</p> <p>* The alternative can easily be seen as leading to creating an environment that could create a disincentive to a disabled person seeking to engage with enablement services or making decisions to move to more suitable housing with fewer barriers or purchasing and developing competence in using appropriate adaptive equipment.</p> <p>*9. Your response:</p> <p>* • Every person should be able to obtain free of charge from their own NHS funded GP a statement of their medical conditions with clarification of current medication and planned operations etc. That would cover the medical fact finding and could also be used to consider eligibility for Blue Badge applications also.</p> <p>* • In keeping with the intended switch to a social model of award have the form focus on the barriers faced by individuals in undertaking daily living activities including a statement on what adaptations they have had to make to the task or environment in order to maintain independence.</p> <p>* • Individuals should also be able to request a home visit by assessor who would complete an assessment without the need of paperwork being filled in by the applicant. (Whilst contracting this via a provider such as ATOS healthcare is 1 option,</p>

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		<p>alternative models should be considered such as paying local authorities from Benefit Agency money for having the relevant assessment completed and returned by an appropriate health care professional accredited via the Health Professions Council (HPC) such as Occupational Therapists. This would enable the local authority to use the same assessment to consider their eligibility for appropriate support by their services and be income generating thus able to maintain qualified staff able to deliver their other responsibilities.</p> <p>*10. :• The person and or their carers when supported to understand what aspects of mobility and daily living activities are of interest. • If they have recent contact with a physiotherapist or occupational therapist (HCP = healthcare professional) then this report would also help – but like the point above all public services are being squeezed so last thing they need is an additional task when there is no incentive for their employer to have their expensive time spent on this task.</p> <p>*11. :• If the assessor is experienced and independent then there should be only benefit as they could provide an informed functional assessment and be able to provide a clearer picture of capacities even when visiting applicants who were underestimating or overestimating their own abilities.</p> <p>*• Depending upon how integrated this was it could also reduce duplication of assessment for the applicant.</p> <p>*• A difficulty may be the availability of assessors if this was inflexible thus upsetting a child's nursery or school day routine or an adult's working day.</p> <p>*• Another difficulty is the lack of therapeutic relationship that could be established with an unknown assessor. I suspect a medical model of assessment is in mind – with the assessor able to quickly “diagnose” function and “prescribe” a solution/award. In reality peoples lives are more complex than that.</p> <p>*• It would be wise to use a HCP that had knowledge of the person. Impartiality would be assured given their registration responsibilities with the HPC although they should perhaps undertake focused training to ensure they provide a focused report that properly informs the DWP.</p> <p>*12. Your response:• Individuals likely to experience a significant change in their abilities either improvement via natural healing, condition cycle, medical or rehabilitation intervention or deterioration pathways consistent with their known conditions should be identified at initial interview with a review date recommended based upon that professional judgement.</p> <p>*• For all others a review period of 3 years seems agreeable but where someone has a fixed impairment and no current hope of improvement in their abilities then they should have a longer review period if wanted eg 5yrs (with the caveat being that they can request an earlier review).</p>

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		<p>*• In keeping with other fraud initiatives though a random review should be considered upon allegations of abuse (as what has happened with individuals claiming DLA yet participating in very active activities displaying no impairment effects) The benefits cheats helpline could be utilised by whistleblowers.</p> <p>*13. :• Consider making it a criminal offence not to report improvements that would have seen eligibility decrease and/or cease and reclaim monies paid. • Use of the benefit fraud helpline number by whistleblowers. Applicants may “fool” an assessor by putting on a good yet fraudulent act but they will rarely fool all within the communities in which they live.</p> <p>*• Public awareness campaign. • Random sample mailings / calls to those in receipt to remind them of this requirement possibly. • Add the statement to all paperwork sent out to current people in receipt of the benefit. • Publicise examples of individuals who did not report changes in ability after their convictions.</p> <p>*14. Your response: • People need to know the goal posts and process of assessment and be encouraged to judge initially whether they wish to apply knowing this so yes provide this as part of the benefit claiming process. • Money advice workers across the country also need to know what has changed.</p> <p>*15. Your response: • I can do no better than my answer to no 9 above. Relevant HPC accredited staff (appropriately trained/instructed) can provide an independent and fair assessment. Those employed in local services via the NHS or Local Authority will only do so consistently though IF the assessment money could be gained for their resource by doing so. It would also be ultimate people power by giving disabled people the right to “commission” their own independent assessment. That would lend itself to them being able to do so using HCP’s from the independent sector also. Works for optician services.</p> <p>*16. Your response: • Mixed bag of ways across the Country would be the answer.</p> <p>*• In the state sector access to an assessment by an appropriately qualified person can take months. Provision is then limited by local eligibility criteria, financial assessments and procurement arrangements of that authority.</p> <p>*• In the private sector it must also be recognised that provision has seen mis- selling and high pressure sales techniques. The Office of Fair Trading have launched a recent mobility aids study indicating that consumers often find it difficult to make informed decisions. http://www.oft.gov.uk/OFTwork/markets-work/current/mobility-aids/</p> <p>*• Using the PIP to meet one off costs could remove some of the existing problems with provision but not as an alternative to an ongoing benefit that helps the person with their ongoing needs.</p> <p>*17. :• The assessor needs to have child specific experience</p>

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		<p>and developmental knowledge and have an appropriate communication style/skills for both child and their family.</p> <ul style="list-style-type: none"> *• The real underlying needs of the child may be masked by the parent or primary carer actions in meeting the child's current needs. They can often be the most authoritative voice in gaining information about existing routines of daily living however. The specific "difference" in care or mobility capacities against the disabled child and an comparable age *18. • Very useful re previous entitlement to Independent Living Fund, access to Blue Badge (with HRMCC) and concessionary travel card for applicant and / or carer. • Reducing/removing further applications by utilising the "Tell Us Once" principle would be great. *19. : • Lack of linked up entitlement. • Faced with more bureaucracy and form filling and costs shoring up an assessment structure for each separate benefit. *20. Your response: • Blue Badge. • Disabled Persons Parking Place • Concessionary Travel Card • Disabled Road Tax • Employment & Support Allowance • Self Directed Support Payment (more controversial this one) *21. Your response: Not my area of expertise. *22. Your response: • I think it is widely recognised that there are too many people with minor impairments qualifying for the existing DLA benefit. To see someone with congenital cerebral palsy in a moulded seat wheelchair and a user of hoisting equipment currently paid the same allowance as the person able to drive (in their mobility funded car) to play at their local bowling club is ludicrous and grossly unjust. *• The "most" impaired individuals often need adapted vehicles with families having to find large deposits to fund these in addition to having all of their existing mobility allowance taken also. *• It also needs to be recognised that equipment and adaptations in an individuals own home does not remove their impairment so whilst they can be independent at home with appropriate equipment and adaptations, they experience barriers whenever outside or at the homes of others (including on holiday) where such accommodation is not available. *• The Housing Scotland Act Implementation sees individuals on the old Incapacity Benefit faced with a 20% cost towards adaptations in most local authority areas (until they can be assessed for the new Employment Support Allowance rules which may take many, many months). *• This same act has removed local authority funding support for "additional living space" so any disabled persons requiring a downstairs bedroom receives no statutory automatic entitlement to help fund this facility thus having to bare the cost themselves. *• Scotland also stands alone in the UK as the only area that applies a means test to parents of disabled children to meet

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		<p>their adaptation costs. It is left up to each local authority in their Section 72 statement whether to exempt groups such as disabled children from this requirement. Guess how many have chosen to do so in the current climate?</p> <p>*• From experience those hit hardest by this double whammy of 20% top up costs for standard amenities and 0% funding for a ground floor bedroom are those with the most severe impairments and maximum environmental barriers faced in order to achieve the most basic of daily living activities. It is often adults (and often at a stage in their lives where they may be unable to sustain their existing employment because of their decreasing physical or cognitive abilities and disabled children as discussed above.</p> <p>*• In conclusion there has already been, in my own informed opinion, a disproportionate financial burden placed on disabled people and their families in the current “credit crunch” Faced with “normal” rises in living costs (although disproportionately if they have less options about using less heating etc) the additional costs related purely to disabled needs. I would hate to think this proposed change is yet another assault as the social consequences and whole system costs will be unrecoverable and for many crushing.</p>
EM741	17/02/2011	<p>Please see attached file Many thanks for the opportunity to contribute.</p> <p>* 1. Your response: My 10 year old son is severely autistic. He has acute sensory problems and learning difficulties and often exhibits very challenging behaviour. He will never be able to lead an independent life.</p> <p>*2. Your response: My 10 year old son is severely autistic. At the moment DLA provides funds to help him. I see nothing in the proposed new benefit which mentions providing funds to help children.</p> <p>*3. Your response: My 10 year old son is severely autistic. Extra costs have and are being incurred in constant decorating and adaptation of our house, on a bigger and safer car, on replacement of frequently damaged and broken equipment, on nappies, on extra and additional laundry, on purchasing specialist equipment, etc.</p> <p>*4. Your response: My understanding is that the existing DLA benefit has two rates for each component already.</p> <p>*5. Your response: My 10 year old son is severely autistic. He will always be severely autistic. Autism is certainly a condition which should have an automatic entitlement to the benefit.</p> <p>*6. Your response: My 10 year old son is severely autistic. His needs for life will need to be supported by us and others and funded by us and others. The second question is rather wide for this particular forum. *7. Your response: My 10 year old son is severely autistic. There may be variable and fluctuating conditions but he will remain severely autistic. The current DLA assessment more than adequately seeks regular information</p>

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		<p>from us, his health professionals and his educators about him.</p> <p>*8. Your response:</p> <p>*9. Your response: The Emergency Budget Debate of June 2010 made it quite clear that 20% of the DLA budget will be cut even before any review of its existing systems takes place. With that background it is impossible to make the application process a positive one as people already receiving DLA are obviously concerned that any new system is designed to reduce monies paid: where else is the 20% saving to come from if not from people already receiving DLA funding?</p> <p>*This consultancy exercise has not been easy to access or contribute towards. Its length, its language and the time required to complete it are certainly not positive experiences, and neither is the fact that the home page informs us that there are IT problems which may affect responses being sent. If it was so important that our views be heard then this consultancy process would be much better publicised, this form would be much shorter and less time consuming to complete, the language used would be clearer and less repetitive and more closely focused towards the specifics of those completing it, and the opportunity for oral responses would be available.</p> <p>*10. Your response: My 10 year old son is severely autistic. His DLA funding is supported by evidence from his education, health and social services professionals who know him very well. They are best placed to provide this evidence.</p> <p>*11. Your response: My 10 year old son is severely autistic. He is non verbal. He will not engage with a stranger without supervision either in or out of his home. A face to face meeting with a healthcare professional would not be a discussion but they would soon see how autism affects his life. Again, I see no indication in this proposed new benefit that it is available to children.</p> <p>*12. Your response: My 10 year old son is severely autistic. The present DLA benefit has regular reviews already in place. His autism will be severe throughout his life. The existing frequency of reviews needs no altering.</p> <p>*13. Your response: I see no evidence that the system for this new benefit will be easier to understand. You are proposing altering a system that is already understood by those receiving DLA.</p> <p>*14. Your response: My 10 year old son is severely autistic. He currently receives DLA. I see no evidence that children are eligible for this new benefit. I would like to see information telling me that my child will continue to be eligible for DLA or any replacement benefit.</p> <p>*15. Your response: All three components of this question are confusingly expressed.</p> <p>*16. Your response: Disabled people use either their own money or benefit money to fund aids and adaptations. I do not know if a provision exists within the DLA at present to fund a</p>

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		<p>one off cost but it seems a sensible idea.</p> <p>*17. Your response: My 10 year old son is severely autistic. The evidence provided by his family in the home environment, his education professionals in the school environment, and the health and social services professionals who work with him is already being used in assessing his DLA entitlement. I see no reason why this should change.</p> <p>*18. Your response: Quality of life and depth and range of experiences will have been helped by DLA funding, and we will have come into contact with other services.</p> <p>*19. Your response: The personal Independence Payment is not in place and I will not guess at possible implications of its use as a “passport” to other services.</p> <p>*20. Your response: This sharing of information to minimise duplication and bureaucracy is already being implemented. I was at a meeting last week involving social services and other agencies and this not only being discussed but examples of how it was working were given.</p> <p>*21. Your response: What should be considered is whether the existing DLA benefits need to be replaced by a new benefit at all. I see no evidence that this needs to be done, apart from the already cited 20% cut to be made in the DLA budget as announced by the government last June in its Emergency Budget.</p> <p>*22. Your response: My 10 year old son is severely autistic. I can only answer from my understanding of his condition and how it affects his life and our lives as parents. He is currently eligible for DLA payments. I see no evidence that children under 18 are allowed access to any replacement benefit. That is either an oversight or a deliberate change of the entitlement policy. The system currently in place is understood by those benefiting from it. I see no reason to radically overhaul it—apart from making it easier to cut 20% of the existing DLA budget. This may be a cynical response but that does not mean it is an inaccurate one.</p>
EM742	17/02/2011	<p>1. Your response: I can only speak personally and as a person who has been disabled [broken neck with partial recovery] for 45 years. I need physical help with many normal actions as my body is weak [paralysis to most of my right side] and I move very slowly on two crutches. My wife does a lot for me. I am unable to use public transport. However I try to be independent as far as I am able. I have been able to work for 40 years, expand a business that started with 9 people and now employs over 100 people. This has created much in the way of taxes. To my mind there are three key elements that have helped me overcome my problems:• Self motivation• Practical help from my wife who is an unpaid ‘carer’</p> <p>*• The Mobility Allowance as it was called. This has enabled me to work and travel for business purposes. It has also allowed me to travel socially to a reasonable extent.</p>

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		<p>*2. Your response: The Mobility Allowance.</p> <p>*3. Your response: IT equipment [now essential]. Extra over travel costs. Parking costs in many areas. Help with house repairs and maintenance as DIY [eg changing a light bulb is not possible]. House modifications. Shopping – limited choice due to access problems.</p> <p>*4. Your response: At the moment a single rate is fine. I use it largely for mobility in the widest sense as my wife and friends help with 'care'. As my wife and I are getting older [70+] the 'care' element is already increasing. I don't see any disadvantage in having two rates except that needs will change more with age.</p> <p>*5. Your response: I can see that automatic entitlement may be relevant when the degree of disability and need is very unlikely to change.</p> <p>*6. Your response: The ability to work and engage socially to an extent that is as near as possible to those that are able bodied. However there are many areas where this is by definition impossible. I have no answer to the question about prioritisation – it's almost impossible to do that.</p> <p>*7. Your response: I can only think that periodic independent checks every 3 or 5 years might work. This area is very difficult as doctors' opinions vary hugely. Where appropriate a hospital report could be helpful – this comment is made from personal experience.</p> <p>*8. Your response: Yes. Include those aids and adaptations that are necessary for physical needs to minimise dependence on others. Existing working aids should be disregarded.</p> <p>*9. Your response: As I have received the current benefit for a long time I have no comment.</p> <p>*10. Your response: A hospital if someone is in continuing care. Otherwise a doctor who is well acquainted with the applicant's condition and able to articulate that person's needs. An independent doctor may be able to do this but must have a joint responsibility with the applicant's doctor. I fear that such an assessment is open to abuse and could produce an unreliable conclusion. This is an important area of scrutiny and should be open to a third-party assessment but this could be costly.</p> <p>*11. Your response: Clarity and honesty I hope. • I can't think of any unsuitable circumstances beyond those that exist.</p> <p>*12. Your response: • It will depend on circumstances. The default should relate to the starting position ie 1 year for a temporary condition to say 5 years for something that is considered 'permanent'.</p> <p>*• I think the answer is 'yes'. In my case my needs require specialist knowledge and there must be many others in the same situation.</p> <p>*13. Your response: I don't think it is in human nature to report an 'improvement' in their condition. I guess the Department will have to require people to provide a statement that their</p>

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		<p>condition is unchanged and that statement must be countersigned by their doctor or health consultant. A false statement must be a 'crime' and carry a significant fine. This will generate more administrative costs and consume valuable time but overall I think it is likely to produce an overall saving through diminished abuse of the system.</p> <p>*14. Your response: I think that the advice and information should be part of the claiming process and written in plain English. Thereafter the applicant should be given a clear statement about the process that must be followed.</p> <p>*15. Your response: I really don't know. I recall that I was reluctant to seek advice years ago as I was determined to be independent. No doubt there are still people who feel the same now. Whatever do not patronise.</p> <p>*16. Your response: Again I don't know. I guess that people do what they can with what they have or others provide. The NHS has helped friends of mine.</p> <p>*A one-off cost may be appropriate in known unchanging one-off situations.</p> <p>*17. Your response: Growth, change and dependency on parents/guardians.</p> <p>*18. Your response: None at all in my experience but it depends what you mean. I use the DLA in isolation and occasionally need to declare this benefit.</p> <p>*19. Your response: At the moment I cannot think of any but I may have missed something.</p> <p>*20. Your response: I am not qualified to answer this.</p> <p>*21. Your response: I was unable to access page 28 so cannot answer this.*22. Your response: I can see that there may be a benefit in separating 'care' from 'mobility'. From my point of view the 'mobility' element has helped my working life greatly and, in turn, created jobs, produced taxes etc. Now I have retired I am increasingly dependent on others, especially my wife and at no cost to the State. My wife is getting older too and our children live away. I have less need for mobility after retirement but an increasing need for care – this is quite frightening.</p> <p>*It is very disappointing that the web site has not worked properly, as I feel denied access to important information.</p>
EM743	17/02/2011	<p>Dear DLA Reform Team This is my attempt to respond to the DLA reform consultation. I downloaded your main questions, and have spent about a week trying to complete my response, but this task is too much on top of everyday life with the condition for which I receive DLA.</p> <p>*I managed 8½ of your questions, and today cannot remember what it was about or how I worded my answers. I am not able to read it back quickly. This is because of the condition I live with – which itself discriminates enough to prevent me from earning my own living that discrimination from people is surplus.</p> <p>*I have been struggling for 11½ months to get the support in</p>

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		<p>place which my Social Services assessment deemed me entitled to. Each time my DLA needs renewing, the form takes about six months to complete. It is not that I have any cognitive difficulties, only a condition that saps me; to be frank, my Oxford finals caused me less stress than this.</p> <p>*I mention these facts in order to point out that 'the disabled' are individuals. And the 'taxpayers' paying to support them INCLUDE many disabled people. Mine is one of the invisible, long-term conditions which are so difficult to prove to any sceptical observer, and so impossible to lead a normal life with.</p> <p>*I don't imagine anyone will take in the details of the hundreds of responses I expect you will have to this consultation. So to sum up my main worry:</p> <p>*I keep hearing 'support should be targeted at those disabled people who face the greatest challenges to leading independent lives' ... and I am afraid for those of use who face, not the greatest challenges, but challenges slightly less great than that. In other words, if support is targeted at the 'top 10% neediest', what about those at the 11th centile?</p> <p>*For example, I can wipe my own bottom and lift my own spoon to eat; I only sometimes use a wheelchair. BUT i cannot contribute to the household income – I have tried all the possible ways of working I can think of, and found them one after another to be beyond my capability; I can barely cope with everyday life, keep up with my finances, etc; I am increasingly isolated because I cannot socialise at all without help; most important of all, my children are doing without both parents: me because I am not up to it, and their father because he is now a carer. I wouldn't count amount the most challenged, but cannot manage without support. I have not heard this large section of the disabled mentioned anywhere. Yours faithfully</p> <p>*1. 1. Having to fill out the application for benefits, because it is badly designed, badly written, far too long, and changes every couple of years. I have a Master's from Oxford University but struggle with the DLA form; it takes weeks, and during that time I have to cut back on other activities such as being there as a mother - let alone my own leisure and social life. A first step would be to take advice from the Plain English Campaign.</p> <p>2. Transport - esp in rural areas, but also anywhere if getting on a bus means high steps etc, and if sufficient support is not available at stations etc, for carrying bags. The various companies running bus and train services, since privatisation, do not collaborate on timetables so a connection may require hurrying across platforms, which makes that journey impossible; or waiting times and multiple connections make a journey far more tiring than it needs to be, which makes it impossible for someone with fatigue and/or pain problems.</p> <p>3. Parking - so many places have blue-badge spaces that are wide for wheelchair users, but too far to walk for those of us not in wheelchairs.</p>

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		<p>*4. Finances - the disabled have lower incomes. SUGGESTION: blue badge allows free use of taxis (including any minors with the disabled person, perhaps half fare for one carer) - reimbursed to the taxi company. 5. Social Services are unhelpful, not 'joined up', often not knowledgeable, and ridiculously inefficient. I have spent a year battling for support; I'm about halfway to getting all that my assessment deemed me entitled to. Meanwhile I have had to drop almost all my social life, work and leisure because I cannot cope with anything on top of dealing with Social Services. Many, many people have this experience.</p> <p>*2 Having various levels - must not become a yes/no benefit which you either receive or don't receive.</p> <p>*3. 1. Transport - needing taxis because of difficulty walking far, etc. 2. Groceries - often need to pay for delivery, plus need to buy pre-prepared food (ready-chopped vegetables etc) because preparing it at home is difficult or impossible; forced to use takeaways more often than we can afford, because of problems preparing food. 3. Transport and other costs for children, if the disabled parent cannot drive. 4. Obviously, equipment - from profiling beds and wheelchairs, to 'reacher/grabbers', grippers, tin openers, etc. 5. Mail order shipping costs in general, because of difficulty getting to the shops, or inability to carry much. 6. Electricity etc because of extra time spent at home. 7. Paying people to do things I would do if I was able, such as cleaners. 8. Huge mistakes made because of brain fog making finances etc terribly difficult to handle. 9. Having to buy things I would otherwise make - clothes etc.</p> <p>*4. Two rates will probably make no difference to how easy the benefit is to understand.</p> <p>*5. 1. Of course, terminal conditions, and permanent disablements such as blindness, loss of a limb, brain damage, there should be no question. 2. Permanent conditions should be granted lifelong benefit without the need for reassessment. We are already required to tell the DWP of any improvement that makes us less disabled, and not declaring improvement would obviously be fraud - as it already is. A doctor's signature that the condition is *expected* to be permanent should qualify for lifelong benefit. Think of the admin savings.</p> <p>*6. 1. The obvious ones: being clean, fed, and having one's children clean, fed and given enough attention - in one's own home if that is the disabled parent's preference. 2. Having the home clean and tidy, including a presentable garden.</p> <p>*3. Being able to socialise. Most disabled are isolated. In the long term this must cost the NHS more, not only because of depression and anxiety, but also because many physical conditions get worse with low mood. 4. Some kind of status in society, from being good at something - especially important when unable have a job. I cannot afford evening classes, even</p>

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		<p>if they weren't being threatened by having to fight harder and harder for subsidies etc.⁵. Perhaps most important: someone regularly checking (say, yearly) whether things are getting better or worse.— It is easy to get worse gradually and not realise until it's too late. — It is hard to ask for help, especially when we know it will probably mean a long period of negotiation and intrusive questions about personal difficulties.—</p> <p>Regardless of the obstacle of shame, it can be physically hard to ask for help when keeping up with everyday life is already a struggle.⁶. Perhaps a regular meeting with a counsellor for *everyone* on any disability benefit. Problems would be picked up before they blew up (a stitch in time) and save DWP and NHS greater costs. Suggestion: default 4 weekly sessions first, then 3 meetings a year or as agreed between counsellor and disabled person but not less often than annually.</p> <p>*7. 1. BELIEVE WHAT WE SAY.2. Understand that "Well, I could at a pinch, but if I did the cost would be pain tomorrow, or being unable to do these other things..." = "Cannot" for the purposes of everyday life.3. Consult with AND TAKE NOTICE OF organisations such as the Fibromyalgia Association UK, etc, and doctors who work with such patients. Recognise what will help and what won't.4. Allow that the proper support makes a person much more able to do stuff, and if someone improves to the point of needing less or no benefit, follow up a year later to find out if they are still managing, rather than letting the person's condition reach the point of needing lots of support instead of just a little.</p> <p>*8. Of course, just as the sight criterion for a driving test is passed wearing glasses if you need them. BUT "easily" is not the point. "Affordably (and easily)" is the point. £20 for an item is not cheap for most people, especially not parents, especially not on benefits. It would be ridiculous to say someone needs no support, or no money towards support, when they are (or would be) doing ok purely because of equipment without giving them support with paying for that equipment.</p> <p>*9. 1. See Question 1: . A first step would be to take advice from the Plain English Campaign. Or the people who wrote the information for disabled about the digital switchover, which was beautifully easy (= low energy cost) to understand.</p>
EM744	17/02/2011	<p>1. My son is Autistic, he finds it hard to understand the world we live in. He relies on myself and others e.g. school transport, mentors, needing one to one support at all times, to take part in anything. It takes extra money to do so as the level of his needs is much greater than others.</p> <p>*2. My son receives the high rate for care and mobility, without it I would be even more isolated as I use it to help run the car as I get him from A to B. It helps replace clothes on a weekly basis as he chews through jumpers daily.</p> <p>*3. Everything is much more expensive, to access anything, due to the level of support he needs</p>

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		<p>*4. I thought it was like that anyway</p> <p>*5. Individual circumstances</p> <p>*6. Most support is provided by family members</p> <p>*7. No, I feel it is much easier for people in wheelchairs to receive much more support than a child like mine who has Autism, dyspraxia, learning difficulties. I feel because it is somewhat a hidden disability for many Autistic kids it's harder to get the right level of support, putting many families in an unbearable situation</p> <p>*8. Your response:</p> <p>*9. I find the claim form asks the same questions but worded differently</p> <p>*10. Psychologist/doctors</p> <p>*11. Any new situation is extremely difficult for my child</p> <p>*12. It's clear my sons needs will become greater and his condition will never get any better. So I feel it should be looked at individually</p> <p>*13. N/A*14. Explained in detail</p> <p>*15. Older people don't claim because a lot don't know about it or they are worried it might affect other benefits</p> <p>*16. N/A</p> <p>*17. Two days are never the same; you may see them on an OK day, which can sometimes happen. You need to listen to the main carer, taking on board all he/she says</p> <p>*18. Without DLA I wouldn't be able to get a blue badge which I use every time I am brave enough to take him out. Without it, it would be more problematic</p> <p>*19. Life for my son and whole family would be unbearable</p> <p>*20. Unsure *21. Unsure</p> <p>*22. Our lives have been turned upside down. I have to live with knowing the rest of my life and my child's life, the pressures, worries, the high level of support he is going to need is never going to change, having a bit of extra money allows our lives to be a little easier. It would be devastating to my son and myself</p>
EM745	17/02/2011	<p>The questions have been responded to by a group of registered professionals working within the speciality of Rheumatology. A couple of questions have no responses as our current working area means we are not in a position to comment as we have little experience/ knowledge in these areas.</p> <p>*1. Attitudes and beliefs, personality types, previous experiences related to access and response to treatment/ rehabilitation that they have had.</p> <p>*2. The main change appears to be a change of wording and the introduction of a regular review. It is difficult to note the changes or similarities to their full until the assessment forms are available.</p> <p>*3. Cost of attending appointments, purchase of small aids, paying for care, paying for treatments not offered by the service, e.g. maintenance work such as gym work, Pilates,</p>

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		<p>massage.</p> <p>*4. It may simplify it but will it make it less responsive to individual need?</p> <p>*5. We believe no one should have an automatic pass through the system, as this is contrary to the ethos of being responsive to individuals.</p> <p>*6. The core essential activities for all are eating, drinking, toileting, adequate personal care and accessing appropriate medication. In terms of providing support to enable individuals to have a basic level of general well being would need to be assessed individually.</p> <p>*7. Having a suitable review period according to the initial assessment completed based on the type or severity of condition and stability of medications.</p> <p>*8. Yes. It would be difficult to create a list as this would depend on individual need, e.g. a level access shower would result in one person being totally independent and another being able to access a shower but still need assistance. It should take into account equipment that is refused that would have increased independence – again looking on an individual basis as to why the equipment was refused and by whom.</p> <p>*9. The current form appears very repetitive. Maybe consider online applications. The assessment form needs to be detailed enough to gain sufficient information on an individuals need. Ensuring people have access to assistance for completing the application process if required.</p> <p>*10. Reports from Consultants, Therapists, GPs, Occupational Health departments and carers/ relatives in an individuals care.</p> <p>*11. There would need to be a range of healthcare professionals to complete the discussions as a benefit would be if the healthcare professional had an understanding of their condition and the impact of such a condition on every day life.</p> <p>*Equality for all. A face to face could be deemed inappropriate if there is very strong supporting evidence. However does this place certain individuals at a disadvantage if they do not have access to these options?</p> <p>*12. Individuals are to be responsible (according to the guidance) to inform of any changes to their condition.</p> <p>*Reviews could be based on the stability of their condition, on the individual and their condition, dependent on the frequency of consultant/ nurse/ therapist appointments and/or the rate of benefit offered.</p> <p>*13. People will be concerned that reporting changes will mean their benefit is cut, but it is important to make people aware of their responsibility to report changes. Perhaps by encouraging the 'signposting' benefits will be a key component.</p> <p>*14. Information on other benefits that may be available, who will be able to complete the forms and where to go to get this help, when do they get their benefit paid, how long will the process take and when will they be assessed, what are the</p>

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		<p>differences in payment of the different rates.</p> <p>*15. How would this be managed? It's an individual's choice to apply for a benefit.</p> <p>*16. Some equipment will have been provided from Social Services, the hospital or one-off grants (either private or government). Smaller items of equipment are generally privately funded. The eligibility and availability of equipment is dependent on resources and your postcode.</p> <p>*17. Your response:</p> <p>*18. Unclear as to the passporting of individuals on the current DLA and how clear this was made to individuals.</p> <p>*19. Repeat assessments, longwinded process, regular reports from GPs, Consultants, and Healthcare professionals.</p> <p>*20. Your response:</p> <p>*21. Disability, ethnicity.</p> <p>*22. Your response:</p>
EM746	17/02/2011	<p>A response from a disabled person and service user Below is my response to some questions raised within the consultation document.</p> <p>*1. I can only speak for my experience with mental health issues of myself and those I have engaged with. The biggest barrier is the condition and disability itself, but there are also difficulties with discrimination within society; lack of mental health service provision and community support.</p> <p>*I have also personally noticed increased fear of social contact by claimants, and potential reprisals due to misrepresented media attacks on benefit claimants. For example, at times I am afraid to go out with my family to a shop in case someone that may know I am on DLA and incorrectly assume I can walk, therefore it is fraud and they should report me to DWP. Misinformation and media rhetoric can be socially damaging.</p> <p>*2. It is vital that DLA should remain a non-means-tested benefit to assist with the extra costs of living with a disability.</p> <p>*5. It is clear that needs vary depending on the individual illness and circumstances of each individual. Clearly, however, some illnesses by definition cause high levels of disability and assessments would be pointless for the DWP, and cause unnecessary stress to the claimant.</p> <p>*Mental illness may be harder to make automatic entitlements for due to the varying levels of disability caused. For example, a person with schizophrenia may function well when not in an active psychosis, but others may be permanently low functioning or disabled. However, some symptomatic, rather than diagnostic criteria could be used to automatically filter out those who may not need a full assessment.</p> <p>*11. Many of those who have mental illness find it difficult to articulate themselves or explain their difficulties, due to either embarrassment, lack of awareness or anxiety with communicating. I strongly feel that there must be provisions made for these difficulties.</p>

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		<p>*I have suffered from anxiety-induced “Mutism” since I was a child. I have great difficulties communicating in some situations, especially when under stress or with closed questions. There are times when I am unable to communicate at all. There is little awareness about*those symptoms and my doctor has combined it with a general anxiety diagnosis. It will not be obvious by looking at my diagnosis that I may not be able to speak.</p> <p>*This causes a number of concerns:</p> <ul style="list-style-type: none"> *• Will the medical professional be adequately trained to handle the situation if I cannot respond, and understand why? *• Will they give me other methods to communicate my difficulties? i.e. writing. *• If I am too anxious to respond to certain questions only, or expand on them, will the medical professional understand when it is happening to make provisions to make sure all information is being captured? *• An advocate is an option, but I personally would find that hard to set-up and communicate my difficulties to. While my disability provides barriers to finding an advocate, this is also due to the embarrassing content of my difficulties. For example, some things I write on the DLA form that I do not feel I can discuss with my doctor. For example, there is a lack of opportunity and open questions, and because it is often seen is irrelevant and time consuming. *Some of those concerns would be alleviated if a great emphasis will remain on the DLA form with an opportunity to write down all difficulties in day to day living. As a disabled person, I need to be reassured that my difficulties will be recorded and that I may be the best source of that information. *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? *I feel strongly from the evidence that I have seen within the mental health community that disabled people, where able, can be the best source of information on their difficulties. If a face-to-face meeting with a health professional cannot have additional benefit to the information already provided, then it would be unnecessary to put a claimant through the strain of a face-to-face meeting. *I cannot comment of this question with regards to physical disability. *15. Conditionality is wholly inappropriate for a needs-based benefit. Disabled people should be encouraged to live an independent life, not be forced into state conditionality or control. *In my experience, those with mental illness should access services in their own time and in a way that is suitable for them. Conditionality and pushing service requirements does not promote independence, responsibility and a sense of choice for

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		<p>disabled people. Conditionality on individuals who have disability needs may also be seen as bordering on discrimination.</p> <p>*22. I have found that the reasons for the drive behind the proposals have caused a contradiction. The first mention of a reform to the DLA that I recall was during the Chancellor's emergency budget speech about the need for savings and the need to reduce costs. Creating a greater system for the disabled, their careers and the needs of the vulnerable cannot be achieved under a pre-defined cost cutting target if that forms the foundation of the reform.*I would like to echo some comments by leading charities, including Mind (2011) who state1:</p> <p>*"We believe that the stated aim of saving 20 per cent on the future budget of DLA is incompatible with the concurrent objective of creating a new assessment that accurately and objectively identifies who needs additional support from DLA (or Personal Independence Payments). We do believe that savings can be made from DLA; but to aim for a specific percentage of saving fundamentally undermines the objectivity of the assessment process and the clear need to provide support for the disability costs of many people in the UK."</p> <p>*I wholeheartedly agree with Mind's assessment of the proposals which are driven by what they know to be in the best interest of the claimant and disabled for whom they represent. I urge the government to take the dignity of the disabled precedence over the cost cutting targets, if nothing else. 1 Mind consultation document (2011) http://www.mind.org.uk/assets/0001/1805/DLA_Consultation_Response_-_CFMH_Hafal_Mind_Rethink_RCPsych_and_SAMH.pdf</p>
EM747	18/02/2011	<p>I am appealing to the government for there to be NO change in the DLA payments. So many people who are very genuinely receiving the mobility component of the DLA, will become housebound, myself included.</p> <p>* I am a person with a dwarfism condition, which means I have very short arms and legs, ie. I am under 4ft tall. It does not take a lot of imagination, to understand that walking ANY distance for me is physically impossible. I am 65 this year, and am totally dependant on my mobility car. Should this be taken away from me, I will be housebound, unless I pay for taxis, which as I am on a government pension only, I will not be able to afford. This will mean that any ladies groups or meetings that I now am able to attend, I will be deprived of going to.</p> <p>* So I appeal to you once again NOT to make any changes in the DLA payments. Thank you</p>
EM748	18/02/2011	<p>1. Your response: Society discriminates against disabled people! In particular people who have mental disorders – virtually little or no support is available for people with, schizophrenia, bi-polar etc</p>

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		<p>*2. Your response: DLA should only be paid to people who have were born or live in the UK for 10years or more. This would stop Eastern European benefit gangs from operating in the UK</p> <p>*3. Your response: Being able to socialise which includes mobility – function to be part of society (normality) using buses, and trains/tube is extremely difficult and in many cases impossible. Will need private transport.</p> <p>* 4. Your response: 2 components will discriminate against people who have mental disorders. The test is heavily based upon mobility – and indeed favours those who need walking aids – which does not stop one working. It is the brain which drives the body not visa visa.</p> <p>* 5. Your response: Those with chronic disorders e.g severe schizophrenia, cerebal palsey etc should have automatic entitlement. Based on professional reports from their medical records. These people are geniune and are usually supported by family carers.</p> <p>* 6. Your response: Those who are the most vulnerable are supported by family members (carers) it is the carers who should be given support. £53per week which equate to £1.52ph is an insult. Acitivies – social support – should not be isolated, as many are.</p> <p>* 7. Your response: It is impossible to cover for every single account of a sick persons fluctuating condition. Doctors or health support workers with whom the sick person is registered. Not gov doctors – with tick box list.</p> <p>* 8. Your response: The assessment should take into account a persons mental ability to carry out everyday tasks. Many people with disabilities drive cars and play sports go to Stanmore Mike Heafy centre. * 9. Your response: The claim form is misleading, and the questions are repeated but in a different manner and are very confusing. Forms are too long. The DLA form is some 59 pages.</p> <p>*10. Your response: The persons carer, GP and or other health professional will provide the best assessment and also the persons own statement.</p> <p>*11. Your response: better if discussion takes place with persons doctor as man not hve health professional. Face to face in home would be better, person is more relaxed, but, good days and bad days exist for those who are mentally unwell.</p> <p>* 12. Your response: Common sense ! if one has a broken leg, obviously one does not need to be on sickness benefit for 5 years. If one has a life long condition e.g cerebal palsey, severe schizophrenia there is little hope one will be able to lead a normal life. Look at the condition and set the review accordingly.</p> <p>*13. Your response: you can't and the fact that you impose £50 fine to those who incorrectly fill in your laborious complex and</p>

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		<p>confusing forms is shameful</p> <p>*14. Your response: advice is crucial, but rarely given. Applicants are treated like poorly.</p> <p>*15. Your response: support charities e.g Princes Trust</p> <p>*16. Your response: What about people with mental health conditons, who don't get any consideration for their needs??????</p> <p>*17. Your response:</p> <p>*18. Your response: very poor. Cuts to local services, cuts to support charities where is the support?????</p> <p>*19. Your response: ?</p> <p>*20. Your response: If one applies for job seekers, process involves telephone interview, follow up appointment at job centre, more forms to fill in and id checks. Then same person becomes ill and is told, now you are on a different benefit e.g sickness benefit, you will have to go through the process again as this benefit if handled by a different dept.</p> <p>* 21. Your response: The policy does not take into account those with mental disabilities and nore does it involve the support of carers.</p> <p>*22. Your response: This will do nothing to stop those form overseas claiming disability benefits and claiming for children who do not live here. Eastern european gangs run these rackets. African lady claimed for 8 children, she only had to show their passports. These policies will not stop this, the changes will cost the government about one billion to implement and will create extreme hardship for geniune sick/disabled. You state changes will help the most at need, but do not outline how those in greatest need will be helped.</p>
EM749	18/02/2011	<p>1. Being unable to access events and resources at the same level as others. My daughter can not just go to the library as she can't read any of the books. She can't go swimming as she can't see far enough ahead to feel safe. She can't ride a bike because of her sight problems. This also is why she will never be able to drive. Where we live there is one bus an hour (if we are lucky and it doesn't drive past) which stops at 7 at night so she won't be able to just 'pop' to the shops or visit friends. She will be socially isolated as she won't be able to go out. She won't be able to get a job without lots of adaptations and without a way to get there! There is still prejudice amongst employers that because she can't see it will be too much work for them to make adaptations.</p> <p>*2. Your response: Children shouldn't be subjected to medicals; its invasive, inaccurate and distressing.</p> <p>*3. Your response: The costs of adapted resources: educational, personal, work related, home related. For example my daughter can't pour hot water herself as she is partially sighted. She can use a liquid level indicator but that cost has to be paid by us. Likewise she can't read the scale on kitchen scales or measuring jugs so suitable equipment is paid for by</p>

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		<p>ourselves. Other people have the costs of personal care (ie incontinence pads etc) which are not provided free. Being partially sighted my daughter is always spilling food etc so the washing machine is always on (she's 12 so that is not normal). Likewise she needs several uniforms as she will often need a new one every day and it would be negligent (in the eyes of the school as well as our own) to not give her them.</p> <p>*4. Your response: No. Disabilities are complex. Two rates are going to mean some people will not receive what they need because they are not severe enough for the top component but are a lot more severe than the lower component.</p> <p>*5. Your response: Some impairments are going to be ongoing, e.g. visual impairment, deafness, physical so entitlement will not change much over time. In these instances surely it is less expensive to have an automatic entitlement?</p> <p>*6. Your response: If people need help to access work/ education, then they need the priority, especially since 'work is good' seems to be the new slogan. Yes some people may need priority for care, but they also get a lot of support from other sources- nhs, social services. If there is none of this support then these people should have priority. e.g. partially sighted people get little help from the nhs (other than sight tests) but with DLA help can get enough resources</p> <p>*7. Your response: Listen to the person with the condition! Use doctors/professionals who have regular contact with the person as they will be a lot more reliable and aware of the conditions than anyone else.</p> <p>*8. Your response: No. DLA is often used by people to buy/rent these aids. Without DLA these aids, because of their cost, would not have been purchased, therefore it is paradoxical to include them. Plus aids or adaptations are not suitable for all people so to assume that they could use them is judgemental, likewise aids can not always help as well as they are believed to. You should only include aids people use regularly, ie everyday. Unless you are going to supply without charge and with full training then any aids should not be 'assumed' as being suitable- they often aren't!</p> <p>*9. Your response: Make the form shorter. Have example booklets aimed at different people- e.g. VI, deaf, wheelchair users etc- this is what we would expect to see. None of the examples ever seem relevant so its hard to know what you need to put.</p> <p>*Make the guidelines clearer so people can more directly answer with the information the assessor is looking for.</p> <p>*Maybe have two forms- a primary one which will cover overall eligibility and then 1 or 2 shorter forms to cover the mobility and care components at a later date.</p> <p>*10. Your response: Parents of children, family carers who are with the person the majority of the time. Professionals, including teachers, who actually know the person, especially with</p>

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		<p>children who often have many distressing hospital visits already. This would make assessment more accurate and quicker.</p> <p>*11. Your response: The professional will not know you and they often don't understand the condition. They don't know what it is like to 'live' with the condition. There is a difference between coping medically and living with something. Also if there are complex needs then one professional will not be qualified to cover all of them. Professionals often do not see past the clinical medical side of the diagnosis, if there is one. Some conditions change so it is hard to be accurate if the person is having a 'good' day. My daughter is photophobic and very sensitive to glare. However, in most well-lit buildings, like hospitals, then this rarely shows. It would be inappropriate and cruel, as well as 'not in the best interest of the patient' to have her walking in and out of a dark to brightly lit room to demonstrate this. Most professionals I have met do not realise she has this as part of her condition or appreciate how it impacts her life- she can't walk across a market square if the sun is at the wrong angle or the clouds are glaring with light around them. Sunglasses don't help as glare goes around them and for that instance is effectively blind. This would not be picked up in a face to face meeting!</p> <p>*Children should not be subjected to professionals at their home- it's far too invasive and could make them feel there is no 'safe' place.</p> <p>*12. Your response: Reviews should be every couple of years in a changing condition, e.g. where people might get better. Where there is no change in the condition reviews should be further along as this would reduce costs and stress. Different types of review would be better than the current system which is essentially reapplication.</p> <p>*13. Your response: By not taking it away from people until the changes are sustained over a period of time, e.g. 6 months as relapses do occur and it can take people time to get into 'normal' life without support. Also it is hard to know what and when to inform, especially if there are a lot of changes within the period.</p> <p>*14. Your response: Yes. If they don't know all the information at the start they can't make an informed choice. Information about the process, examples of what information is needed and how to fill it in as well as eligibility criteria and what future reviews will involve and when they will be. Also advice about support and where to get further advice (especially independent advice) are always helpful.</p> <p>*15. Your response: Yes, but it needs to be impartial, or independent, advice. Forcing people into doing anything or buying expensive things just because they were 'advised' to and were afraid of losing their DLA/PIP if they didn't should be avoided. Trials of equipment might be a better idea and then</p>

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		<p>review them with the advice giver. Involve the person to make the choices and they are more likely to accept the advice and support.</p> <p>*16. Your response: Yes. Mainly funded themselves. DLA may sometimes be used towards some aids and adaptations- ie using the money to fund something. Same should be possible with PIP. People are different, disabilities are different, therefore PIP needs to be adaptable and flexible to deal with all this!</p> <p>*17. Your response: They are young. They often don't realise how different they are, how they are different and why. If asked they won't be able to equate how they cope with a 'normal' person. They often struggle and get on with things because they don't know anything different. Not involving parent carers would be a serious mistake as they are better placed than their children to say how 'not- normal' they are. They know what their children need to help them lead independent lives.</p> <p>*18. Your response: DLA allows me to get Carers Allowance. If she was no longer entitled I would lose that too which is a double-whammy. It would mean I have to work and she would not be able to do all the things she does after school etc as there would be no one to take her. Her DLA goes towards an after school VI club teaching independence skills and guides for her social skills and independence as socialising with others this is a particular problem. If there was no DLA then these would have to go. Many services run by councils are also eligible only if you receive DLA/Carers. There needs to be another system whereby those with a physical disability (VI, deaf, wheelchair) only need to show their medical status to access these services.</p> <p>*19. Your response: A disaster. DLA allows me to get Carers Allowance. If she was no longer entitled I would lose that too which is a double-whammy. It would mean I have to work and she would not be able to do all the things she does after school etc as there would be no one to take her. Her DLA goes towards an after school VI club teaching independence skills and guides for her social skills and independence as socialising with others this is a particular problem. If there was no DLA then these would have to go. Many services run by councils are also eligible only if you receive DLA/Carers. There needs to be another system whereby those with a physical disability (VI, deaf, wheelchair) only need to show their medical status to access these services.</p> <p>*20. Your response: Using PIP info/form as a passport to other services, even if not eligible for PIP. Sharing information- securely!- between government and councils only.</p> <p>*21. Your response: Many people will be put off applying. It needs to be easier to access different information/form types.</p> <p>*22. Your response: Just a lot of people are very fearful about these changes and the future. Especially those who have the</p>

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		<p>lower rates because their disability is not severe enough for the higher rates and know they will lose this money in the future. Disability costs are a lot higher than looking after a child, but people with children all get money without this stress and worry.</p>
EM750	18/02/2011	<p>1. Your response: Access to services, modification to not support al disabilities</p> <p>*2. Your response: Disability does not go away at pensionable age and should not be stopped on reaching that age</p> <p>*3. Your response: Paying for services that healthy individuals can do or utilise themselves and the disabled can't, i.e. Public Transport, Daily life activities, cooking, cleaning, entertainment etc.</p> <p>*4. Your response: acceptable</p> <p>*5. Your response: no automatic entitlement</p> <p>*6. Your response: Transport and access to services, home support</p> <p>*7. Your response: Accept the individuals description of their capabilities, and if there is doubt , observe the activity</p> <p>*8. Your response: Adaptations which are intrusive or dominate an individual through their use, or has limited benefits should not be taken into account</p> <p>*9. Your response: forms should be available that reflect the disability/medical condition, i.e. physical, neurological etc so that question that are not relevant are required to be answered and confuse the issues</p> <p>*10. Your response: The individuals medical support team.</p> <p>*11. Your response: Some conditions are complex and are beyond the experience of some health professional day to day experience</p> <p>*12. Your response: The nature/cause of the disability, if improvement is possible or is the condition life long</p> <p>*13. Your response: ?</p> <p>*14. Your response: ? Individual specific</p> <p>*15. Your response: ? Individual specific</p> <p>*16. Your response: ? Individual specific</p> <p>*17. Your response: they are still at a stage where their bodies are developing and there is greater potential for them to develop there abilities to accommodate disabilities, this potential should be identified and assisted</p> <p>*18. Your response: DLA is important, it prevents individuals resources being diverted from other needs assisting in moving to a more normal life standard</p> <p>*19. Your response: standard of life reduced</p> <p>*20. Your response: ? Individual specific</p> <p>*21. Your response: restricting Benefit to pre pensionable age is making an assumption that the need stops when that time occurs, and it is likely that financial resources will already be reducing</p> <p>*22. Your response: no</p>

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EM751	18/02/2011	<p>Responses to questions- Ch5.**1)Barriers & problems are manyfold in that until you have had personal & ongoing experience of living with a disability it is mind numbing in how society and authority receive you and try to portray you.</p> <p>* This can be said of individuals as employees in the workplace ALONGSIDE ,professional people who often only pay lip service to disability issues providing they do not have to consider employing you in facing their prejudices despite the advent of the DDA.</p> <p>* At one interview I was told that I was a Health & Safety risk because I have to wear a foot/leg splint (which, is not visable)and would be required to walk up and down stairs in the workplace during the course of the duties. I was absolutely appalled at this especially as it was in a healthcare setting .</p> <p>*Likewise , some charitable organisations who, proport to be in a supportive & advocacy role often let the disabled person down as I again have personal experience of by "falling through the net" on more than one occasion and at last was completely abandand by a government disability charity.!!</p> <p>*The employment advisors for some of the organisations have very poor insight and understanding that when you come up against obstacles & hurdles they should stand shoulder to shoulder with you & help you to fight your corner in order to remain in the workplace or within a course when/if new medical problems arise alongside your disabilities which,thus cause you to leave and probably never return to work.</p> <p>*Likewise, in everyday activities which, can range from any physical formal exercise as you may be advised to do to shopping to driving to being able to safely take your children to school which, are normal tasks to non-disabled people.However much you as an individual & as a family adapt and accept the changes in your life some sections of society never cease to fail in that they have no perceptive grasp on how disabled people struggle on a daily basis within a community to be accepted. After ten years in this position myself I am still having to educate many areas in the community including retailers in the form of having to make formal complaints in a constructive manner in order to be treated with the same dignity & respect that everyone else is entitled to as ignorant ,likeminded public harass & bully the disabled.</p> <p>* With regards to any future employment prospects I do not see this as a viable option on a personal level as after a further five years since last employment the system & world of work have washed their hands of me since the age of 43yrs from ill- health retirement. I now co-ordinate a support group voluntarily and am very concerned as are many of our members of working age just, what will happen to us all within the next two years which, is a very concerning future.*I trust this will be helpful in collating your responses . [REDACTED] for: Fibromyalgia in [REDACTED]</p>

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		support group.
EM752	18/02/2011	<p>1. : Lack of money, increasing lack of accessible jobs (local councils are BIG employers of disabled people but many like myself are facing redundancy in a few weeks thanks to government cuts), lack of level pavements with dips in them, lack of disabled parking spaces at the tops of hills where town centres often are</p> <p>*2. : Most of it should stay the same</p> <p>*3. : Transport (taxis in London for example), petrol, travel insurance, specialist equipment, adaptations to vehicles</p> <p>*4. : Presumably all the people now receiving one of the rates will receive less or nothing, which isn't fair. *5. : Yes, those with severe, life-long conditions</p> <p>*6. : Work, education, leisure, volunteering, socialising, shopping, family activities are all essential. DLA is the best way to prioritise support</p> <p>*7. : For conditions which are curable (many are the opposite, degenerative) there could be regular reviews depending on the type of condition. Reviews have a cost, so they should not be so frequent that the cost erodes any savings eventually gained by deeming someone well enough to no longer qualify for DLA.</p> <p>*8. : Absolutely not—the aid can never fully replace the ability that's missing, and aids themselves can cause problems such as sores, discomfort, technical problems, repair and replacement costs, stress, etc.</p> <p>*9. : The claim form could be shorter and less repetitive. *The information should be in plain language with examples given</p> <p>*10. : Information from doctors, therapists, counsellors and other professionals</p> <p>*11. : The face to face discussion must provide any support the person needs, such as interpreting, signing, pictures, etc. It should not be required for children, and may not be appropriate for people with some mental health conditions</p> <p>*12. : A doctor's assessment of the likelihood of improvement or degeneration and the approximate time scale would be useful evidence.</p> <p>*13. : By asking them politely to do so in an annual letter</p> <p>*14. : It would definitely be helpful to provide information about other support that DLA can lead to, such as blue badges and discounts available like the Odeon Carer's Card and leisure schemes run by local councils</p> <p>*15. : DLA is a benefit to replace the abilities that most people are naturally blessed with; it should not be used as a type of coercion</p> <p>*16. : DLA is already used to pay many costs—it should not be stretched further</p> <p>*17. : Children should be primarily assessed on the basis of reports from health, education and social care professionals. If the child and parent are happy about a one to one session,</p>

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		<p>fine, but otherwise this should not be required</p> <p>*18. : Very, see 14 above</p> <p>*19. : Devastating</p> <p>*20. : Personally, I'm happy for anything to be shared, but those with 'stigmatised' conditions like mental illness may understandably be more reluctant. I will soon be applying for ESA since I'm extremely unlikely to find a job I can physically perform in the current climate, and I would be delighted if I could simply go to a website and request that all my DLA details be transferred over to ESA. Such a system would definitely save time and money.</p> <p>*21. : Any change is extremely difficult for many minority groups to understand, especially if English is not their first language. I know of a brilliant Portage worker being made redundant at the end of March who is an absolute lifeline for a group of BME families with disabled children. She would be the perfect person to explain any changes in DLA to them, but she won't be there and she won't be replaced...</p> <p>*22. : This government goes on and on about the huge debt inherited from the previous government, but we never hear about the wonderful programmes it created for vulnerable people—the Carers' Grant and Aiming High for Disabled Children, to name just two—that are now being torn apart. DLA is one of the few supports left to us; please don't let it be torn apart as well.</p>
EM753	18/02/2011	<p>Dear Sir, I have attached your questionnaire to this email as your system seems to have a problem. Yours faithfully,</p> <p>*1. : Lack of suitable access to retail and leisure facilities and shortage of disabled parking at these facilities.</p> <p>*2. : The system, as it is, helps me pay for extra help and adaptations that make my life more bearable.</p> <p>*3. : Additional help around the house and necessary adaptations to my home and car.</p> <p>*4. : Not enough flexibility in fine tuning the benefits to suit the level of disability.</p> <p>*5. : Some conditions are clearly permanent and the prognosis will always be negative, therefore, a further qualification process will only add to the existing stress of the condition. Automatic entitlement can be valid in certain circumstances.</p> <p>*6. : The existing system attempts to address this issue, no alternative system can possibly improve on such an objective issue.</p> <p>*7. : Decisions must be open to appeal and review and not set in stone when conditions like MS are so variable and the symptoms are so devastating.</p> <p>*8. : Again, a flexible approach to the condition and its variability should be built into any assessment and medical experience of illness progression should be noted.</p> <p>*9. : A total review of one of the most difficult and cumbersome forms in existence should be undertaken. It is such a laborious</p>

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		<p>piece of documentation it ceases to correctly identify the real from the fictional.</p> <p>*10. : Medical, employment and home visit evidence should suffice. Ideally backed up by any Social Services input from OT's or local authorities.</p> <p>*11. : The ability to have a level playing field response. Some healthcare professionals are much more effective than others.</p> <p>*12. : The use of an existing and local service such as the Pensions Service would make best use of limited resources and give a more accurate overview of local conditions and facilities that are available.</p> <p>*13. : A more welcoming and user – friendly communication that will encourage interaction.</p> <p>*14. : A simple checklist that leads people through the qualifying criteria.</p> <p>*15. : Link the new system up to an existing facility that everyone is familiar with such as local authority council information or NHS General Practice.</p> <p>*16. : I do not think that the PIP system should try and be all things to all people. A simple but fair payment process should be its only aim.</p> <p>*17. : Children's' assessment is best dealt with by input from both parents and healthcare as children's' disability will always be dealt with as a team affair.</p> <p>*18. : The relationship between DLA and allied facilities seems to work quite well most off the time. A closer link with the local OT service could improve matters.</p> <p>*19. : As long as the existing system did not suffer, damage could be limited.</p> <p>*20. : The Pension Service working closely with the local authority and the NHS in Tayside perform a valuable service for information but obviously not assessment. The ability for a more co-ordinated assessment does exist.</p> <p>*21. : Common sense and sensitivity.</p> <p>*22. : More often than not a major consultation and review of this type merely creates another bureaucratic system which in itself costs more than it attempts to save and, inevitably, will be changed or replaced at a later date.*The stress a review like this creates for already stressed, disable and ill people outweighs any benefit.</p>
EM754	18/02/2011	<p>Dear Madam/Sir, Here are my responses to a few of the questions in your consultation document. I have not answered them all as it is very tiring and my days are very short as I spend large proportions of each day asleep in bed.</p> <p>*Question 1 a) my Disability</p> <p>* feeling ill, tired and lack of energy, having to live with pain 24/7and other symptoms that come with the disability and associated chronic conditions;</p> <p>* having to put up with additional symptoms that are side effects of medication because drugs are not advanced enough to be</p>

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		<p>side-effect-free;</p> <p>*b) National Health Systems inefficiency Disabled and long-term ill people use the NHS to a greater extent than others, therefore they fall victim to inefficiencies proportionately more than the rest of Society. examples:** repeat prescription system leaves me angry, frustrated and exhausted every month . GP staff make mistakes almost every month and I am often without medication for many days;</p> <p>* the long amount of time it takes to get an appointment with a hospital specialist and the fact that you cannot see them to talk about side effects of their medication, treatment or new symptoms until 6 months have elapsed, even if you need to see them after one week or month;</p> <p>* hospital referral system that means you go back to the GP rather than be referred on by the consultant. This means that enormous amounts of time are spent waiting to receive an appointment and not being treated, and follow-up letters often do not arrive or get lost at the GP surgery</p> <p>* hospital outpatients system means that receptionists do not always have diaries available for the next 6-month period, causing distress and delays at certain time of the year</p> <p>* lack of appointments for mental health problems - like many others I have been waiting without treatment for two years to see a counsellor</p> <p>* waiting two weeks for a GP's appointment when it has also taken me a week to get to the surgery due to illness; being refused an appointment when I went to the surgery when I was very ill because I did not have an appointment. Sadly I cannot plan to have an illness two weeks in advance</p> <p>*c) Assistance at home Disabled and long-term ill people need help to manage daily living tasks before even thinking about joining in with other people and living full, active and independent lives</p> <p>* some disabilities mean that a person needs full-time assistance, others result in the disabled person being very slow to complete tasks which also cause great fatigue and additional pain so bed-rest is need after undertaking simple housework tasks such as washing up, or doing some light shopping</p> <p>* lack of help round the house to enable one to have time to join in with other people. Personally I have much less time available to go out and socialise: my disability and the side effects of medication makes me sleep around 16 hours a day. As a result on many days I just cannot get out as there is no time and no energy. Some days shopping at the supermarket is all I can manage, the next day I empty the bags and the day after put washing in the machine, and the next day I take it out and hang it up. Dog gets a walk once a week rather than once a day as there is no time and not enough energy. The house looks like a dirty tip, so I would never be able to invite anyone back.</p>

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		<p>* help to carry shopping - pains in my upper arms joints and hands prevent me lifting and carrying. I, like many other disabled people, have to buy smaller sizes of dry goods so cannot benefit from bulk discounts.</p> <p>*d) Travel Lack of suitable vehicles and lack of flexibility of the official Motability scheme</p> <p>* I cannot use motability scheme cars as I need a vehicle where I do not have to bend down to get in or out (eg). The Motability Scheme offer is too narrow and does not reflect the disparate needs of disabled people * My own van has just broken down for good, but I cannot afford to buy another, and I have neither the time nor enough energy to travel to view local second-hand outlets</p> <p>* Motability scheme is not flexible - I live in an area where people throw stones at my car, kick the doors in and throw rocks stones. Motability insurance, I believe, would ban me from having one of their vehicles.</p> <p>*e) friends and relatives Due to disability many disabled people are isolated at home and lonely. The disability means that there is a progressive loss of contacts and ever fewer friends and family to visit, let alone rely on for daily support.</p> <p>* I have been unable to keep up past friendships by going to clubs and societies and weekends away. So I meet few people each week and having been disabled for over 20 years there is almost no one left that I know.</p> <p>* My nearest relatives are elderly (in their 70's and 80's) and want me to visit to help them. I cannot do this. * f) other people Society is still not aware enough of the needs of people with disabilities. Disabled people, who probably need more advice and support than some other people, should as a right be given advice by fully qualified people in both voluntary and official organisations like other members of society, rather than well-meaning, but untrained volunteers. The result of this unintended discrimination can be chaotic and distressing, and contrary to the Equalities Act.</p> <p>* Organisations hold participation meetings, consultations and fact-finding groups at 9.30am. Many people need assistance to get up and ready in the morning, some need carers to escort them when out and/or take medication that results in 'hangover' effects for some hours after getting up; all such people have difficulty in making arrangements to get to early morning meetings. The result is that decision-makers are not made aware of their needs and so inadvertently discriminate against large numbers of disabled people.</p> <p>** The general public do not know to make allowances for memory lapses (part of the disability or a side-effect of medication), slowness in manipulating small items, dropping things on the floor etc</p> <p>** voluntary advisors are not always trained to give correct advice; the problem is exacerbated as charitable and local</p>

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		<p>Council-based organisations are reducing support services. For example a lady with learning disabilities is employed as a 'junior apprentice', her role is to advise other learning disabled people how to get into employment. She has neither the life's experience, at 22, nor adequate training to give a comprehensive service.</p> <p>*Again, I have been seeking advice from my local Council's 'Staying Put' section whose role is to help disabled people stay in their homes. Financial cut-backs have caused one of the two building surveyors and one of three administrative staff to be made redundant within a month. As a result an untrained clerical member of staff has been giving me financial advice - I am now in a financial mess because on three occasions over the past 5 month she has given me incorrect financial advice. The same unqualified staff member is now giving me town planning advice - and I know she is incorrect. She is, however, well-meaning.</p> <p>*The same local council employs someone as 'harassment' officer; she is neither trained in legal matters nor in counselling. When I contacted her for support over a matter of harassment (which has been going on for nine years), she raised her voice at me over the telephone and accused me of doing the harassment.</p> <p>*Another personal example: I contacted an organisation which uses volunteers to arrange help around the house for people like myself. It is now 10 months since I made the initial request and nothing has happened. When I contacted their head office the manager excused the lack of communication by telling me that the local office is staffed with volunteers.</p> <p>* Question 2 Disability Living Allowance is a good benefit although the methods of obtaining it are haphazard and result in a high proportion of successful appeals, but cause distress and financial hardship during the very long appeals process. Aspects that should be kept, with modifications, are:</p> <p>** flexibility so that ones can use the money for whatever is urgent at the time</p> <p>** not needing to account for every penny one spends - no accounting, no receipts: this would be beyond me to organise</p> <p>* * attending a medical to check limitations but with medical personnel who are specialists, in accommodation that is accessible to people with a variety of disabilities</p> <p>** appeals system, and giving the results of the appeal only a few minutes after one leaves the room.</p> <p>** having a list of disabilities that will never go away, which gives everyone a basic understanding of the nature of problems of living with disabilities and a mixture of disabilities.</p> <p>* What parts of Disability Living Allowance do you think we should change?</p> <p>*All systems need periodic review and amendment in the light of the results of this review to become and remain efficient,</p>

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		<p>effective and well-regarded by the public in general. Examples of possible modifications are</p> <ul style="list-style-type: none"> ** Not asking people with chronic or genetic conditions to travel long distances to talk to an examiner who does not understand the ramifications of one's disability, who sometimes does not listen to responses and who 'makes mistakes' when writing up one's answers. * giving, say, one month's notice with reasons before any benefit is to be withdrawn * making the appeals process less arduous and more adaptable to a person's own circumstances. Currently this is very time consuming, and makes one very anxious and depressed. The forms took me 3 months to complete, it took 11 months to get my benefit restored, and three years to pay off accumulated interest on debts. * Question 3 As disabilities are unique to the person, so money is spent on whatever is required by each person: *Examples, personal and general: <ul style="list-style-type: none"> * transport to and from appointments * caravan purchase and maintenance: needed to get away from harassment by neighbour; I sleep for longer than a b&b would accept. * larger vehicle: forced to change car from low insurance model as the driver's seat was so low it generated additional pains. Have driven a series of decrepit small vans that are expensive to run but have high enough driver's seat, electric windows and power steering. This results in a higher level of maintenance costs as breaking down is catastrophic in the short and longer-term * aids and adaptations that are not available on the NHS or available but are not the right model for the individual and/or their life-style * professional decorator as cannot do painting and decorating anymore * someone to clean floors every two weeks as I cannot mop and Hoover or bend down a lot * gardener: I used to grow most of my own fruit and vegetables. Now do not have the stamina or strength and cannot bend down properly to even do normal gardening * someone to wash or Hoover the car and caravan * larger sizes of all clothes and shoes as I have put on weight due to lack of exercise and eating to ease my ulcer brought on by medication (a well-known side effect), and weight-gain as a side effect of medication. * household gadgets that enable me to manage in the house such as a robot vacuum cleaner, small light steam cleaner as I cannot hold cloths or brushes to scrub; convection dual microwave to heat up pre-cooked foods; special clock that vibrates as the medication makes me sleep through normal alarms; very small mouse for computer (normal ones are impossible to manipulate); electric blanket used all

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		<p>year round; extra room heaters; dishwasher as I cannot stand for long due to pain</p> <p>* more sheets, night-shirts and towels as I go through phases when I sweat profusely at night and have to change these every day</p> <p>* additional use of electricity to power extra aids, extra washing-powder and conditioner etc due to frequency of needing to do washing</p> <p>* more hot water for washing clothes and sheets, and also due to need for deep bath every day, and sometimes during the night, as a form of pain-relief and easing stiff joints and muscles; also for hair-washing as I have long hair (less cost in hairdressing bills) and sweat a lot (partially due to medication); also have a scalp condition and need to wash out scalp medication</p> <p>* duplicate items for caravan as I cannot lift and carry everything from the house to the caravan prior to going away, and vice versa on return</p> <p>* more frozen foods such as frozen rice, vegetables and fruit as I get too tired to go shopping, and too fatigued to cook from scratch</p> <p>* gluten-free, lactose-free etc foods which are much more expensive. Food sensitivities make it very difficult to eat many 'normal' foodstuffs.</p> <p>* scanner for computer and fax machine as I do not have enough energy to go out to make copies of important correspondence</p> <p>* food and vets bills etc for cat and dog as company and also to make me feel safe when walking in streets as I limp sometimes and this is a high crime area</p> <p>* house maintenance and adaptations such as raising floors, widening doorway, ground floor bathroom etc</p> <p>* more space heating as many disabled people are forced to stay indoors more than a person able to work or get out regularly</p> <p>*Question 4 How can two parts possibly cover all the graduations that exist in disabilities in any meaningful way? How effective can support be if disparate individuals are squeezed into definitions that do not reflect the reality of survival for so many disabled people.</p> <p>*It is generally accepted that each person with a disability is an individual. How a disability affects each person is unique, and many people have multiple disabilities that react with each other differently.</p> <p>*For example I can walk a little way if I keep stopping for a rest, but am in extreme pain all the time and the pain and the number of steps I can take at a time varies from day to day. However after about 30 seconds of standing (such as in a shop queue or for a bus) I have to sit down or I collapse and burst into tears due to the pain. There are relatively few people who have this combination of mobility problems.</p> <p>* Question 5 If everyone was articulate, self-aware and</p>

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		<p>confident I would agree with the latter statement. However this is not always the case.</p> <p>** People with mental health problems may not be able to articulate properly at the time of asking; people with problems communicating (such as someone on the autistic spectrum) may never be able to tell a stranger of their physical or mental limitations.</p> <p>** Some people are too shy or lack confidence to talk about themselves so would never be able to ask for help. I personally find it very difficult to open up to a stranger about many of my symptoms due to my personality - I automatically strive to create a good impression and often brush off symptoms as not creating limitations, and also make a joke of it all</p> <p>** anticipating, and then dreading, in-depth probing of personal details may in itself cause a worsening of a person's health, physical and mental.</p> <p>* * a physical examination by someone who does not know the patient's health situation, or who is not a specialist in the area, may cause pain or damage unwittingly. Yet without a physical examination how can an examiner ascertain the extent of the pain/damage - one solution may be to communicate with the person's specialist, but not their admin clerk.</p> <p>* * someone with a combination of physical and mental health problems, and difficult external life situations might have a see-saw of symptoms that they might not be able to describe accurately. Many health and disability symptoms are not stable but vary drastically, often on a daily or more frequent basis. Interview answers can therefore vary according to which time of day to which day or week/month it is.</p> <p>** someone who is anxious and/or has extreme fatigue, for example, may want to get the interview over in as short a time as possible so may not mention important points</p> <p>** very often a person will not know what the important and critical aspects of their disability are, and may not even have spoken to their GP about the details.</p> <p>** flexibility should also include the ability to gift the money back to the Treasury if the person wishes it and their GP agrees (to prevent a needy person feeling guilty but allow a person with other income to express their wish to donate the money elsewhere).</p> <p>** preventing benefits becoming a post-code lottery would become impossible</p> <p>*Question 7 Having regular repeated examinations is not the answer. Removing benefits is one side of a coin, the other is ensuring each person has an alternative, adequate and long-term means of financial support</p> <p>** As said above, just looking towards an examination may create great anxiety and result in worsening of symptoms. Just getting to a strange venue may create stress, anxiety and fatigue. Having to climb flights of stairs may bring on asthma</p>

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		<p>attacks, cause breathlessness in some and extreme pain to others. ** Venues may be impossible to access due to parking or lack of wheelchair or other needed physical modification. Having to go down an unlit alley or the presence of a guard dog outside are apparently minor difficulties which could cause great distress to an individual.</p> <p>** recognition of long-term improvements in health is good - but only if the person can then be integrated into wider society without creating additional problems. Taking a person off benefits does not necessarily mean that they will be found acceptable by an employer, nor will it make every employer agree to put in improvements that eliminate barriers to access. These could be as simple as eliminating a flickering light-bulb or giving all employees and managers a course, and follow-up sessions, in disability awareness. The commute to a job may be the factor that prevents a person taking up a job - every person is different.</p> <p>* * flexible benefits should also mean that deteriorating health automatically entitles a person to more support in the form of money and/or the assistance they need to have a meaningful life.</p> <p>*Question 8 Aids and adaptations that suit the person and help them manage on a 24/7 and a long-term basis, that are available, (financially and in a practical sense) should be made available for everyone. However, are there any aids that assist 24/7?</p> <p>* A light manoeuvrable wheelchair may be of use for getting to and from a vehicle, but might not be useable around a flat or going on a walk around a hilly area with the rest of the family. An armchair chair that helps a person to stand up at home will not be available on a bus, in a cinema, restaurant, hotel or conference room. A prosthetic leg might help commuting, but not be of use in the middle of the night when a person needs to get to the toilet urgently. A deaf aid might not be successful in a noisy train, or at night when it is taken out when they are needed urgently (say in a crisis at work).</p> <p>*Aids break down and need to go for maintenance. They often depend upon costly accessories such as batteries, spare wheels and lights as well as cheap, but difficult to find, items such as rubber ferrules for a walking stick, sterile plastic bags and tubes. Time, energy and money are needed for both use and maintenance.</p> <p>*Whatever the aid the person uses they are still disabled with all the associated physical and mental discomforts and problems.</p> <p>*Question 15 I believe that many aids should be given to people as a right. Currently I can use DLA although it is not high enough of all my additional adaptations. At the moment I do not need to be given permission to use this benefit for aids etc as is implied in the way this question is framed ('allowed to use')</p>

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		<p>*Should a person pay for their oxygen cylinders and incontinence pads? It is not a person's fault that they are, or become, disabled. A disabled person may have many skills and talents to contribute towards society, even if it is just to be seen going out and about so that others know it is possible to live with a disability or so that disabled people are so commonly seen in every context that the general public learn not to stare, mock or make fun of those who are 'different'.*With the current system of DLA if I had a motibility car and an au pair to help around the house (which I do need urgently), I will have used up more than the top rate of DLA gives me. I would not then have the funds purchase appropriate aids. My life would be more confined to the house and I would become even more depressed and physically weaker as I would not be able to eat the correct foods nor exercise occasionally by walking the dog. House maintenance would be non-existent and areas that are dangerous could collapse on someone.</p> <p>* Question 17 I benefit from the Blue Badge scheme and have used the Warm Front scheme.</p> <p>*a) Warm Front - the water freezes on the windows inside my house in the winter. The insulated loft has meant that it freezes on fewer days each year.</p> <p>*However Warm Front are very inflexible so there are still areas in my house that are cold and draughty; Warm Front is limited in what work they can carry out under the grant. For example I have a large grill (about 1 metre in length) in my garden that leads into the basement. The wind comes through the basement and up the stairs to remove any heat. This lies outside Warm Front remit. An elderly friend could not have her walls insulated because her flat is tucked inside the roof of a house.</p> <p>*b) Blue Badge Scheme. I find it painful to stand and so queuing for a ticket at the station became a nightmare. I generally had to sit on the floor in the ticket office whatever state it was in, and people thought I was very peculiar. Standing at the counter to purchase the ticket brought excruciating pain. With a Blue Badge I walk straight through and get to medical appointments in London with appreciably less pain and sweat. Thank you from the bottom of my heart. signed, [REDACTED], London</p>
EM755	18/02/2011	<p>1. : Choices are still limited for some disabilities. Some people like my son cannot live an independent life as he has severe Autism. He needs 24 hour, seven day a week care. I think we should make sure people like my son have the right support, the right place to live (even if this means residential), and the right people to look after him.</p> <p>*We need to understand that there are some people with disabilities that cannot work and cannot live on their own, but still need to have things to do to fill their day, like going out and about and continuing their education appropriate to their</p>

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		<p>disability. We need to remember that not all people are capable to access their local college and need specialist placements.</p> <p>*We need more scheme's to help people access their communities, like the bike scheme that is being run for disabled people in are local country park (excellent idea). We also need to understand that some people, for example people on the Autistic Spectrum, are working on a much younger age level and really want to still access play parks etc but cannot do so as they are set up for under 5's. Perhaps we should do more to create adventure play grounds for everyone to enjoy regardless of age. We need to do more to help people understand people with disabilities. Why not start talking about it in PSHE classes at school. Prompt disability in a positive way.</p> <p>*2. : The three parts of the care component. Make sure that nobody will lose out by your changes.</p> <p>*3. : With regard to my son, he is very destructive. Breaks things, rips off wall paper etc it gets very costly to have to replace things all the time. My house looks like a war zone at times. We could do with an extra room in our house because of how my son is. It would be great if money was available for this. It doesn't have to be a big extension just some extra space. Although there is money available to adapt your home there is no money for this sort of thing even if you own your own home.</p> <p>*4. : I do not think just having two rates would make it easier. The only way you will make it easier is to change your forms. I understand why you are doing this but I think more people will have a chance of getting DLA if there are more options?</p> <p>*5. : Yes please, can you make sure severe Autism is included in this. Your forms are a complete nightmare to fill in. I think people like my son should automatically get the highest support. I shouldn't have to go to your tribunal for us to prove our son has severe Autism. Surely it would cut down on expense in the long run.</p> <p>*6. : I have always said that people in most need like my son need to have a certain level of funding. It would be good if this came direct from government to take away all the grief our local authority gives us when trying to get the right support. It's important that people in authority understand the disability before they sort out the right support.</p> <p>*I am sure my local authority sees him as a burden to them.</p> <p>*It's important that young people access education even if this means accessing an expensive provision. That everyone has choices. We must also take into account that as a lot of ASD young people are at a much younger age level mentally they need to be able to access education longer. This means they need to stay in college longer than the two years offered at the moment. Most importantly we have specialised colleges in every area to help the more severe.</p> <p>*7. : I think this is all about knowing the condition or disability and how it can affect the person. It's also about making sure</p>

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		<p>that the person looking at the claim form understand the disability they are looking at.</p> <p>*8. : I think this should depend on the disability. With Autism my son does use aids in the way of pictures and cards which he needs every day. When he was younger we used a larger buggy to get him around which was essential. These are very expensive to buy. We were given one from the local authority. The buggy was on its last legs and the strap to hold him in didn't work very well but at least we had one. We couldn't afford to buy one.</p> <p>*Because of my son's challenging behaviour we could really do with a wheel chair to use when we are out and about as a family to make it a lot easier when he goes into melt down. We don't have one because we cannot afford one.*I am tired of having to fight for everything. I am tired of being made to feel guilty for asking and fighting for what my son needs. We should look after disabled people.</p> <p>*Although I know that there is money available from the family fund, we use this money for a holiday. (Although with my sons challenging behaviour it doesn't feel like a holiday). That means they won't fund anything extra we need.</p> <p>*9. : Having forms more appropriate to the disability. Having not to have to put how many minutes it takes to do this and that. Rewording it and perhaps, for those with limited understanding having more tick boxes. *Improving the way you give out information is very important. A lot of people do not understand they can claim DLA and even when they do they have been turned down because either they have filled there form in wrong or the professional you contact fills the form in wrong. They don't know they can reapply.</p> <p>*Putting information on websites like yours and NHS websites is good, but it should also go to the people that are diagnosing the disability, doctor surgeries and voluntary groups, and places like the citizen advice bureau.</p> <p>*10. : My son's first and third paedritrian would have been great at giving clear supporting evidence but not the second one as she didn't understand my son's condition.</p> <p>*Not sure what will happen when his 18 and transferred over to adult services. There seems to be no expert in this field and the Local Doctors do not have a clue. They are really nice and do try but have no understanding of Autism.</p> <p>*11. Your response: Some people with Autism would find it hard to do face to face meetings. Some people with Autism can appear more able than they are. With my son you would be able to tell quite quickly that he had Autism. Not sure how he would be having the meeting at home. I think the person holding the meeting must have a good understanding of Autism. I think it's really really important that the parent or carer is in the room at the same time. In fact it's going to be impossible to ask him the type of questions you will need too.</p>

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		<p>*The benefits to this would be, providing the person coming in to the home understood Autism that they could see how severe he is.</p> <p>*12. : With my son's condition has stayed at severe, not changed at all really so it wouldn't matter how many reviews he had it will still be the same. That said he now has epilepsy as well now so reviews should happen at key times in their lives.</p> <p>*I think it would be good to have different types of review depending on the disability as they are all different.</p> <p>*13. : It's important to know what changes we need to tell you. Plus with some disabilities like Autism/Asperger syndrome or a learning disability, they would need help to understand the need to do this.</p> <p>*14. : People will need to know who can apply. How to fill the form in, what type of information you are looking for, and yes it would help to provide this as part of the Benefit claiming process. Make it easy to understand.</p> <p>*15. : Some people do not realise they can claim. I think if you are entitled to the help you shouldn't be made to feel guilty for applying. People need to know where to get help if they need it. You will need to make sure there are independent people out there to help people. The form at the moment is very long and can be confusing. It also can upset the carers as you are seeing your young person's disability in black and white, and all the problems that they have, this can be very upsetting.</p> <p>*16. Your response: Any extra aids my son has needed or needs are paid for by us. It would be nice to get some extra help with this as being on a low income means we cannot always afford to do this.</p> <p>*If you do put extra help in for this can this be relate to the persons disability and not necessarily to the house hold income. It would be great to help the families that are just over the £16000 limit for some benefits and don't get the much needed help especially if you own your own home.</p> <p>*17. : When our children are diagnosed very young, as my son was, we are not allowed to claim higher rate because you say that they would need this care any way. Which is not right. Children with severe Autism need extra care, and parents and carers need a lot of help (which we do not get)</p> <p>*This has a knock on effect on benefits especially as our local authority will not issue a blue badge unless you are on higher rate mobility. Having a Blue Badge makes a big difference especially if your young person has challenging behaviour and you also have other young children to look after. Keeping everyone safe is a nightmare, whether going to the shops or Doctors or Hospital for appointments.</p> <p>*You need to understand the disability.</p> <p>*18. : Make sure that if there other entitlements you are entitled to that it's written into the pack we are given. Also to let any support agency know what's available. A lot of the time you find</p>

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		<p>out by accident or by word and mouth.</p> <p>*19. : we would lose money which would be terrible as the family is on a low income because of the caring responsibilities.</p> <p>*20. : It's difficult to get a system that suits every disability as one size does not fit all. I guess for my son as soon as he was diagnosed with as severe Autism he should be entitled to high rate care and mobility. The family should then be informed that they should let the Tax Credit people know as they will get extra money. I also think that when he's 16 years – 18 years that ESA or whatever other Benefit he is entitled to automatically starts and a form is sent out to the family to help them fill it in. It's no good relying on Social Workers (if you are lucky enough to have one) or connexion workers as they do not know what benefits you are entitled to.</p> <p>*21. Your response:</p> <p>*22. : I think the most important thing is to make sure that people do not lose out if they are entitled to DLA. Make the forms easier to understand. Make sure there is help out there to fill in the forms, and everyone knows they are there. Extra help is needed for those filling in the form with a disability especially if they themselves have Autism because of their lack of understanding. I think you should also understand that there are people with disabilities that will always need 7 day a week 24 hour care, and this should be available to them even if this means a residential setting. I also think that we need to have a stand set for each disability, and that the government make sure that the people with disabilities are being cared for in the right way. Not always put in the cheapest accommodation and provision. It should be the right provision although I know the country hasn't got make money it shouldn't always be down to money.</p>
EM756	18/02/2011	<p>1. : My son and daughter are both teenagers with autism. They both suffer from severe levels of anxiety which is extremely debilitating because this prevents them from participating in normal, everyday life. They have social and communication difficulties coupled with sensory impairments which leave them isolated, vulnerable and naive. They do not leave the house unaccompanied because they are both anxious about the unpredictability of everyday life. They both need supervision day and night. If they do go out they are supported. Autism is an invisible disability so they both look normal so people expect them to act and behaviour accordingly.</p> <p>*2. : The assessment process. A face to face consultation would not highlight the level of disability that someone with autism faces on a daily basis.</p> <p>*3. : Care and support to facilitate them leading an active and independent life.</p> <p>*4. : Sounds good in theory however it is crucial that assessments award the right rate to provide the correct level of</p>

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		<p>support.</p> <p>*5. : Life long disabilities like autism should mean automatic entitlement.</p> <p>*6. : Personal care needs are vital.</p> <p>*7. : Re assessment</p> <p>*8. : Yes, they should be taken in to account as they improve quality of life.</p> <p>*9. : Make the forms shorter and in plain English.</p> <p>*10. : From health professional who know the individual. From family members who have to live and cope with the individual.</p> <p>*11. : For people with autism, face to face communication is often difficult and extremely stressful. It would not give a true picture of the extent of their disability.</p> <p>*12. : Indefinite awards with people with life long disabilities.</p> <p>*13. : Don't know</p> <p>*14. : What the process involves, how to apply and how to appeal!</p> <p>*15. :</p> <p>*16. : Yes.</p> <p>*17. :</p> <p>*18. : Vital. Communication between services.</p> <p>*19. :</p> <p>*20. : Don't know</p> <p>*21. Your response:22. Your response:</p>
EM757	18/02/2011	<p>While feeling that the entire reform of DLA is being driven by political dogma with the sole aim of reducing annual costs rather than delivering an improved service to the many disabled people who rely on it, the limits of time and energy afforded by my disability mean that I have chosen to focus solely on one aspect of the impact of the proposed changes.</p> <p>*It has been proposed that the conditions upon which Higher Rate Mobility are currently granted be modified to take into consideration the use of mobility aids. I am not in principle opposed to this, provided it is enacted with flexibility and a true understanding of the impact of mobility disabilities that is not generally possessed by people without mobility impairments. However DLA, and particularly HRM, function as gateway benefits in allowing access to other benefits, rights and processes and as someone with a considerable mobility disability (though not currently in receipt of DLA), there is considerable fallout from this decision in terms of side-effects outside of DLA that I am concerned may not be adequately recognised and addressed unless attention is drawn to them.</p> <p>*Eligibility Criteria: the main condition for receipt of HRM has historically been inability or near inability to walk, generally cited as meaning having considerable difficulty or distress in covering 30 to 50m, whether through physical inability to cover the distance or the pain or other effects of so doing. However, is 30 or 50m a useful distance? In most of the disabled parking bays in local towns 50m won't even get you onto the street. The</p>

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		<p>closest bank to a disabled parking bay is 150m away, the local Job Centre is 200m from disabled parking, even the DWP Medical Assessment Centre is more than 100m away from the closest bay. 30 or 50m is a limit designed to restrict the number of people qualifying for HRM, not to match actual access needs. If access is now to be based around actual mobility, then shouldn't the test be based around the real distances that disabled people need to access local amenities as an equal member of society? A wheelchair user may be able to cover 100m with ease, as a crutch user with a pain-based disability I can rarely cover 100m without considerable pain. I have long advocated that the gateway aspects of HRM should be moved down to a Middle Rate Mobility that reflects difficulty with realistic access needs rather than the arbitrary, budget-related test imposed for HRM, with the reform of DLA and the intention of having only two rates, perhaps those gateway aspects should move to a Lower Rate separate from any financial element.</p> <p>*Zero-Rated Road Tax: This is no doubt useful to disabled people on a tight budget, however there has been a recent disturbing tendency for some local councils to abuse the zero-rated road tax disc to discriminate between Blue Badge Holders who hold their badge via DLA and those who hold it via the discretionary criteria allowed to local councils, even though those holding Blue Badges via the discretionary criteria may have equivalent, or worse, access difficulties. If Zero Rate was eliminated and the monetary value instead folded into HRM (recognising that disabled drivers generally need larger, higher rated vehicles) then the divisive abuse of this benefit would become impossible with the simultaneous benefit of a reduction in administration.</p> <p>*Disabled Parking Badge: The Blue Badge is vital to my life, without it I would be all but housebound. If forced to I could pay for parking in a non-disabled public car park, but however low the charge I would not be physically able to use it. Even though not a wheelchair user I am absolutely dependent on flinging my car door to its widest and struggling in and out with legs that frequently won't bend however much I might want them to. It is often assumed that wide disabled parking bays are only required by wheelchair users, but this is not the case, many non-wheelchair users are absolutely dependent on the availability of wide bays, or on the use of roadside parking on single or double yellow lines as a substitute. Even without limitation in walking, this difficulty in accessing vehicles makes the Blue Badge vital to many disabled people, but it is a limitation not reflected in current HRM guidance, never mind any tightened guidance under PIP and it is only the flexibility of council discretionary criteria that currently allow it. Yet councils are instructed that their discretionary criteria should use the HRM criteria as guidance. While there may be cost-based</p>

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		<p>arguments for restricting the mobility criteria around HRM, those arguments do not apply to the zero-cost Blue Badge System and it is important that the changes do not inadvertently lead to Blue Badges being taken away from people who can't access society without it.</p> <p>*Motability: Motability is a benefit that draws much abuse and jealousy down on disabled people from those who see only the benefit and not the need. Receipt of HRM is currently the gateway for access to Motability, with HRM payments signed over in part payment. My question is why the linkage? Yes, HRM payments enable many disabled people to afford their Motability payments, whether for cars or for powerchairs, but the need for disability adapted vehicles is not restricted to people in receipt of HRM. My own license restricts me to automatic vehicles because of my disability, in time I may even need adapted controls, and there is certainly a case that a powerchair would considerably improve my life right this moment, yet I don't currently receive HRM, so can't access Motability. Equally the proposed changes to DLA mean that many current HRM recipients may find themselves falling short of the revised criteria and therefore no longer able to access the cars or wheelchairs on which they have been reliant. Yet the linkage between HRM and Mobility is an artificial one, both schemes could continue independently of the other. If we are going to see disabled people losing their previous eligibility for HRM, then why not provide continuing access to Motability for them even if they no longer receive the subsidizing benefit, and why not shift the eligibility for access to Motability to cover anyone with a medically restricted driving license, opening the scheme up to the many disabled people who need adapted vehicles but currently fall short of the HRM criteria. This would be a clearly, unarguably improved system, something not true of the other proposed changes.</p> <p>*Wheelchair Provision: While not in theory part of the DLA gatewayed benefits, provision of wheelchairs and other mobility aids to disabled people by the Wheelchair or Rehabilitation Services of individual PCTs is something which must be considered because of the revised basis on which mobility will be accessed. When I enquired about obtaining a wheelchair through my PCT's Wheelchair Services I was told that as a part-time user I would get no more than a basic chair and cushion, yet as someone with considerable difficulties in sitting that would actually be worse for me than no chair whatsoever, to be useful to me a wheelchair needs to have an individually tailored cushion and back, but Wheelchair Services will not meet that need. Similarly I frequently come across people who can barely walk within the home, have almost no ability to self-propel, but report that Wheelchair Services refuse to provide a powerchair, and insist that because they have some residual ability to stand they must use an unusable manual chair. This is</p>

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		<p>bureaucracy elevated to a Kafkaesque level, and adding to it an assessment for HRM depending on an imaginary wheelchair that PCTs will not provide would simply compound the insanity. If HRM assessment is to assume use of a mobility aid, then the system for the provision of mobility aids must be simultaneously reformed to ensure that those aids are available, not simply imaginary.*Other Gatewayed Benefits: DLA is currently used as an eligibility criterion for things as diverse as reduced rate access to concerts and events, entry to disability accessible camping and toilet areas at festivals, discretionary rate travel on trains and no doubt others. Blue Badge eligibility sees similar usage and also allows discretionary rate passage through various toll bridges, tunnels and motorway sections. These facilities are zero-cost to government and it would be inappropriate for the redesign of DLA to remove access to them for disabled people who find themselves falling outside the revised PIP eligibility criteria. Their disabilities and need for these concessions will not change simply because Parliament elects to pass a new act.</p> <p>*Conclusion - If the government is intent on changes to DLA then individual disabled people like myself can express our thoughts and concerns in the consultation process and oppose those changes in the political system, but we may not be able to stop the process, no matter the validity of our arguments. However, even if the changes are forced through the government still has the opportunity to demonstrate that it does truly understand the impact of the changes by working around the periphery of DLA to minimise unnecessary negative consequences. In many cases those peripheral benefits can be maintained without any fiscal cost and there is therefore no reason that this should not be done.</p>
EM758	18/02/2011	<p>1.: • Lack of money• Discrimination & misunderstanding. • Lack of opportunity• Lack of modifications to facilities• Lack of parking places</p> <p>*2.: • Assessment by GP and consultants and psychologists / therapists etc already involvedwith the particular case - introducing a new random professional with no understandingof the circumstances or the history or the medical complexities makes no sense at all!!!</p> <p>*3.:• At home more of the time - so higher heating & lighting & telephone costs*• Extra laundry for medical reasons - electricity, detergent, wear & tear on clothes & machines etc etc</p> <p>*• Special diet foodstuffs to avoid symptoms / expensive food supplements such as fish oils & gla to reduce symptoms</p> <p>*• Not being able to use mega big supermarkets so paying higher costs for more accessible local small shopping</p> <p>*• Needing bigger better cars to carry wheelchairs or walking frames or because better suspension and maybe air conditioning are needed for medical reasons - these cost more to buy, more to repair & service, more to tax and take much</p>

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		<p>more fuel!</p> <ul style="list-style-type: none"> *• Needing someone to help with mundane tasks like cleaning the bathroom or hanging the*laundry. *• Needing a companion when going to a theatre, cinema, tourist attraction, museum, etc <p>*4. Bad idea !! VERY BAD IDEA!!! This is essentially a cost saving exercise for government</p> <ul style="list-style-type: none"> *by excluding people on the lower level - but that small sum can make all the difference to *a struggling family or individual - and because DLA acts as a passport to other things *those meanly taken out of the bottom rung of DLA will loose other entitlements and *services too... <p>*5. Your response: • Yes of course there should be automatic entitlement for some conditions – somebody</p> <ul style="list-style-type: none"> *with a serious condition should not be having to go through the indignity of repeated *assessments!* • There are also variable conditions which need ongoing assessment. *• And there are conditions like ME & Fybromyalgia which have good days and bad days and dreadful days. <p>*6. Your response: • Give them a decent income to have self respect without someone constantly prying into their affairs.</p> <ul style="list-style-type: none"> *• Make sure that their physical needs are met including sufficient heating and special diet foods etc.* • Attend to their educational, social and spiritual needs to avoid mental health problems. *• Assist mobility!! Current idiot plans such as removal of the mobility component for people in care homes will create prisoners with consequent expensive mental health problems - and will also prevent access to medical care beyond the GP as hospital consultants don't have the time to go visiting care homes!!! <p>*7.: • DON'T USE A SYSTEM THAT REMOTELY RESEMBLES THAT CURRENTLY USED FOR ESA WHERE DOCTORS (frequently foreign with limited linguistic understanding of the client!) WHO DON'T UNDERSTAND THE MEDICAL CONDITIONS INVOLVED MAKE CRASS ILL INFORMED DECISIONS AND LAND PEOPLE IN EXPENSIVE</p> <p>*TRAUMATIC APPEALS PROCESSES</p> <ul style="list-style-type: none"> *• THE ONLY PERSON IN A POSITION TO COMMENT INTELLIGENTLY IS THE GP WHO SEES THE PATIENT ON GOOD DAYS AND BAD DAYS AND WHO KNOWS THE CARERS *• ALSO TAKE INFO FROM NURSES, HEALTH VISITORS, PHYSIOTHERAPISTS, PSYCHOLOGISTS AND OTHERS INVOLVED IN ONGOING SUPPORT *• ASK FOR COPIES OF HOSPITAL LETTERS - THESE ARE GENERALLY COPIED TO THE PATIENT THESE DAYS AND

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		<p>TELL THEIR OWN STORY</p> <ul style="list-style-type: none"> *• TALK TO THE CARERS - THE CARERS OFTEN ARE THE ONLY PEOPLE WHO REALLY KNOW - BECAUSE THEY ARE THERE WHEN THE PROFESSIONALS ARE NOT!!! *• GET INFO FROM THE WEBSITES OF THE ORGANISATIONS CONCERNED WITH THE CONDITION SO THAT THE DECISION MAKER HAS SOME SEMBLANCE OF UNDERSTANDING OF THE CONDITION *• STOP INCENTIVE PAYMENTS TO ASSESSORS FOR DECLINING BENEFITS – that just encourages short sighted ill informed idiocy!!! <p>*8. Your response: • Aids and adaptations help but don't mean that needs evaporate!!</p> <p>*• For example on the radio yesterday Clarissa Dickson Wright was appealing for a charity that helps blind people - a young blind man had aids that enabled him to make a cup of tea - but it took him half an hour per cup If some idiot assessor now ticked a box saying he could make tea and was therefore no longer entitled to DLA, he wouldn't have much of a life!!!! How could he attend to social, educational and employment matters if it took him 3 hours a day to make 6 cups of tea - would he even be awake long enough to cook dinner?????</p> <p>*• Another example is my son who has a Mac computer from student finance England so he can use complex software in bed when he is too unwell to attend his studies – does this mean that under proposed changes he should be denied mobility payments because he can now communicate with his tutors from his bed???? And don't forget that when he is working at home in bed I have to run the central heating all day long!!!</p> <p>*• Needing and using aids and adaptations still takes time and energy and often involves pain which in itself can cause fatigue and depression.</p> <p>*• And aids and adaptations in the home may well not be there in employment, educational or social situations</p> <p>*9. Your response: • Allow more sections for narrative or description - it is often difficult to fit the information into the boxes!!!</p> <p>*• Allow more spaces for names and contact details of therapists etc - having to choose one out of several leaves the assessor with limited information - ALL therapists etc involved should be invited to contribute to the assessment or review - rather like all teachers & medics & therapists etc contribute to a review of a Statement of Special Educational Need</p> <p>*• Put posters & leaflets in GP and hospital and health centre waiting rooms giving information</p> <p>*• Give good clear information online but don't rely on online information only as some disabled people & their Carers are not Internet savvy</p> <p>*10. Your response: IF YOU ARE LOOKING FOR INFO FROM</p>

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		<p>ONE SOURCE ONLY THIS HAS TO BE THE GP WHO SEES THE PATIENT ON GOOD DAYS AND BAD DAYS.... THE GP SHOULD BE THE PERSON DOING THE ASSESSMENT!!!!</p> <p>*• Info from GP • Info from school head or SENCO in case of disabled child • Info from all therapists and psychologists involved*• Info from CARER as well as from disabled person • Info from any voluntary or community organisation (including sometimes religious organisations) providing support • Info from local Carer support professionals or organisations if relevant - it is often the case that those supporting the Carer best understand the extent of the individuals need for support!!!! • Copies of all hospital letters • Info from organisations relating to the disability or condition</p> <p>*11.: • This sounds like a costly time wasting exercise to bring in a new tier of bureaucracy – I thought the coalition wanted to REDUCE paperwork and organisations not increase them... • The only person with the background info to do this efficiently is the GP!!! • Assessors with scant knowledge of underlying conditions and no knowledge of the</p> <p>*disabled person will make extremely damaging and ultimately expensive mistakes!! • I foresee increased mental health trauma & costs from getting this so very wrong - not to mention potential loss of quality of life or loss of actual life...</p> <p>*• PEOPLE WITH AUTISM & ASPERGER'S SYNDROME DON'T LIKE MEETING STRANGERS!!!!!!</p> <p>*12.: • By the GP In the GP surgery at a quiet time - by appointment and after the GP practice nurse or practice manager or clerk has collated copies of hospital letters and reports from therapists, psychologists, schools, employers, voluntary organisations and above all CARERS!!!</p> <p>*• The primary Carer should also be seen & interviewed - separately - by the GP or practice nurse!</p> <p>*• If the person cant get to the GP surgery then the GP or practice nurse should visit them at home!</p> <p>*• Timing of reviews depends on condition - a lifelong condition such as loss of limbs or Autism won't change and needs review only every 5 or 6 years if at all. • For changeable and variable conditions review periods will vary according to the condition and could be anything from 6 months to 3 years. After a while if conditions persist review periods should be lengthened !</p> <p>*• The GP is a professional and will be quite capable of deciding which aspects of the disability or illness the GP or the GP nurse should investigate more thoroughly.</p> <p>*13. Your response: • Put the onus on the patient to inform the GP practice manager and the GP practice manager to inform the department following a face to face meeting between the GP or GP nurse and the patient !</p> <p>*• People don't like reporting change for better or worse to an anonymous voice on the phone who can easily misunderstand - much easier via the GP practice!</p>

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		<p>*14. Your response: • Clear guidelines on what exactly is and isn't included and a list of voluntary organisations (eg MENCAP) who could help them with their applications. • Put an onus on the voluntary organisations concerned with disability to help people with complex application processes</p> <p>*15. Your response: • Local! • Condition aware! • Best delivered in conjunction with the GP practice. • AVOID A NEW RANGE OF PROFESSIONAL ADVOCATES HELPING DISABLED PEOPLE WITH CLAIMS - these will inevitably arise under these proposals – delivery through the GP service will render this inappropriate and unnecessary !!!</p> <p>*16. Your response: • Currently with great difficulty through a variety of means including trusts & charities, student finance England, local authorities, friends and relatives, selling homes or treasured possessions, bank loans, credit card debt Etc etc etc • Yes please one off payments would be a GREAT IDEA!!!</p> <p>*17. Your response: • Children are different from adults so the parent Carer will be the chief voice. • If the child is questioned directly remember that children and ESPECIALLY teenagers want to pretend to themselves and their friends that they are healthier and less disabled than is really the case!!</p> <p>*• Again the only person who can really do this is the GP as the GP sees child and Carer on a regular basis and knows the impact of the child's illness or disability on the child and the Carer and the whole family !</p> <p>*18. Your response: • Useful for getting disabled blue parking badge which in turn acts as a passport to other entitlements</p> <p>*• Useful for disabled student assessment • Useful for getting recognition from the local authority • If you are intending to remove many people from DLA you will make everything more complicated • Just keep DLA pretty much like it is but transfer assessments to GP surgeries and let passporting continue especially for people on the lowest level of DLA who are often missed by other services!!!</p> <p>*19. Your response: • Generally more paperwork and bureaucracy for the disabled person and higher costs to local authorities and government in processing the same information multiple times - basically a job creation scheme for local authorities & government who already don't have the funds to employ the staff they already need for essential services - they don't*need more paperwork to be generated!!!</p> <p>*20. Your response: • Let the GP do it all then records will all be in one place!!!!</p> <p>*• There could be a STATEMENT OF DISABILITY NEED - like the current statement of educational need - drawn up by the GP after reports from all concerned and discussion with patient and Carer - this would be agreed and signed by both GP and disabled person and could be forwarded to all relevant agencies and departments - a longer more detailed version and</p>

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		<p>contributing reports would be held by the GP practice and available on application with the signed case by case consent of the disabled person.</p> <p>*• It should be reviewed & updated periodically as in question 12 above or annually as with the SEN statement.</p> <p>*21. • Your response: • I can't find page 28 and there is no mention of it in the executive summary and I don't understand the question....</p> <p>*22. Your response: • In general I think the proposals are poor and will lead to more bureaucracy and more tribunals and more people earning salaries as professional and legal advisers and representatives at endless tribunals!</p> <p>*• I think my proposal for a STATEMENT OF DISABILITY NEED as in 20 above is worthy of consideration.</p> <p>*• I think that the only people who could take the lead in assessments without creating senseless and cumbersome administrative and quasi legal bodies are the GPs supported by their nurses and practice managers.</p> <p>*• I think that there is grave danger that people with 'invisible disabilities' such as M.E./ chronic fatigue syndrome, Fibromyalgia, Mental Health Difficulties, Diabetes, Autism & Asperger's Syndrome and other Autistic Spectrum and Neurological Differences will be failed by the system and will not get the help which we need - leading to HIGHER COSTS for emergency medical intervention, long term mental health problems, deaths from self neglect due to poverty and inevitable suicides.</p> <p>*• I am an OAP and a graduate with professional qualifications and experience in a related area, i have a long term health problem for which I am not currently eligible for DLA although it does increase my cost of living, I have an undergraduate son with Asperger's Syndrome & complex medical issues receiving higher rate DLA and a school age daughter with M.E. and ADHD receiving lower rate DLA and an aged infirm mother receiving lower rate attendance allowance so I DO have considerable knowledge and experience on which to base my comments.</p> <p>*• I can be contacted on [REDACTED] or [REDACTED] if you require further information or if I can assist you by attending meetings or reading and reviewing documents and further proposals relating to this issue.</p>
EM759	18/02/2011	<p>Regarding this consultation, I've not been able to go through the questionnaire, however would like to make the following comments*DLA IS over-complicated, I agree, but the document does NOT highlight the common issues that me, my wife (who I've been looking after and helping with her claims) and many others have faced as detailed in our situation below.</p> <p>*She has diagnosed chronic back problems, feet and leg problems + numerous other issues which affect her mobility and mean that she requires a lot of personal care every day</p>

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		<p>*We have filled in the DLA claim form, every time we made a claim for her, with full, accurate honest details of the issues she has and the care she needs. The case has been rejected every time so far because:</p> <p>*a) Claim handlers simply cannot add up the figures they are given. There's always a response saying less than an hour of care is needed per day, when the accurate figures WHEN ADDED UP show around 3 or more hours per day</p> <p>*b) The medical assessors have been incompetent (same problem with ESA assessors) and also ignore the key facts. One assessor came round who was old, deaf, full of cold, did not hear what we said so we had to keep repeating it, and ignored the facts anyway!</p> <p>*c) When we've complained and appealed, the DWP staff are unhelpful and take no notice of the facts again.</p> <p>*d) They always send the forms and letters out way after they date them – significantly reducing the amount of time to complete or respond by their deadline. If you miss a deadline, even by just a day for this reason and/or due to poor health during that period – they do not care and take no notice of the situation!!</p> <p>*e) They would rather push everything through to the Tribunals Service than sort it out themselves</p> <p>*f) GPs also have a poor attitude, probably brought on by the complexity and unfairness of the DLA system. Their view is why should we bother providing the facts to support a genuine claim, when DWP will only turn it down anyway!</p> <p>*We hope that these issues will be taken seriously and addressed in the reforms. Scrapping the whole of DWP and starting again with people who are capable of making fair assessments, would be a start. I seriously think you should replace the DWP by some of the people who have disabilities and are struggling to claim or to get work currently. At least they would have a better understanding of what is genuine and what is fair.</p> <p>*My wife, with many genuine issues and who is eligible according to the rules – cannot get DLA. Yet, my ex-wife who just has poor eyesight (but is not partially sighted) and who was told the right things for the DLA form, did get DLA.....surely that is not fair Regards</p>
EM760	18/02/2011	<p>Dear sirs I attach my response to the DLA reform consultation. I hope I've done everything correctly. It's in Word format.</p> <p>* 1. : Lack of proper legal protection/advocacy, lack of money and jobs, bad attitude towards disabled people in society, including employers, lack of good access, not enough accessible public transport, fear of crime/hate crime, redundancies and the recession.</p> <p>*2. : GPs know the applicants and therefore should understand the issues faced by them. How can someone who doesn't know you assess you? Cars are a necessity to many, so</p>

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		<p>Motability is vital. People living in care homes, etc., should still get the mobility component of the new benefit.</p> <p>*3. : Transport, wheelchairs and other equipment, clothing, laundry, adaptation of cars/van conversion, employing personal assistants</p> <p>*4. Your response:</p> <p>*5. : If your condition is unlikely to improve (or never to), at least significantly, this should be taken into account. Mental health should also be taken into account, and memory problems.</p> <p>*6. : Work, seeing friends and family, visits to hospital/outpatients/podiatry/GP, collecting prescriptions, shopping, trips out (theatre, sporting events, etc.) attending places of worship.</p> <p>*7. : Even fluctuating/variable conditions can be lifelong, so they should be treated as such; i.e. depression, bi polar disorder, etc.</p> <p>*8. : Just because someone has, for example, a wheelchair or prosthetic limb, it doesn't mean that it is the equivalent of having fully functioning limbs. For example, it often takes more time and energy getting to places than it would for non-disabled people. Also, not all wheelchairs and scooters fit on public transport, and many of these rely on batteries which can go flat.</p> <p>*9. Your response:</p> <p>*10. : This may vary from day to day, so it can be very difficult to assess ability.</p> <p>*GPs, district nurses, Occupational Therapists, Special Educational Needs Co-ordinators, teachers, relatives.</p> <p>*11. : As mentioned before, how can someone you don't know possibly assess your condition? How can people be selected two will be compassionate and listen carefully and use common sense? Whoever does the assessments should not just be in it for the money – it needs to be a vocation for them. Some people get very flustered when being questioned by people, especially strangers, so they would not respond well to being interrogated.</p> <p>*Some people are very loath to talk to strangers – for example, some on the autistic spectrum. There are others who find communication difficult anyway, so another way may need to be found. There are some people who may present a danger to themselves or others.</p> <p>*Some people have chaotic lifestyles, which means that it may be hard to conduct a meeting with them as they may not remember, or they may not be in a fit state to be interviewed. They may not wish to be met at their own home.</p> <p>*12. Your response: It may prove difficult to schedule reviews for people with some fluctuating or varying conditions, including some mental health conditions. Some conditions are completely stable and never change and this needs to be reflected. However, some conditions deteriorate rapidly.</p> <p>*People have different communication needs, and some may</p>

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		<p>need more time and patience when interviewed. Others may need to respond using technology such as PCs, communication grids/boards etc. and this takes more time as well.</p> <p>*Others still may need interpreters – i.e. Deaf or Deaf/blind people.</p> <p>*13. : There could be sanctions, such as fines for non-disclosure of changing circumstances – but see my answer to q. 11.</p> <p>*14. : How other benefits may be affected, what other benefits they can get, including Blue Badge, wheelchair vouchers, Motability cars, etc.</p> <p>*15. : You cannot force people to seek help – people can be proud and stubborn. People will often only seek help when they are desperate.</p> <p>*16. : There is the NHS wheelchair voucher scheme, which allows many disabled people to get discounts for wheelchairs; this is useful if lightweight or specialist wheelchairs.</p> <p>*17. : Again, care must be taken regarding who conducts the interviews, as parents and children may be wary and nervous about the process and what it could mean for them.</p> <p>*18. Your response:</p> <p>*19. : If, for example, the Motability scheme were to end, many people would be trapped in their own homes.</p> <p>*20. Your response:21. Your response:22. Your response:</p> <p>*Changing the way people are assessed may prove to be costly to administer. The consultation has only run for 9 weeks, despite Government guidance suggesting that 12 weeks is appropriate, it also creates problems for people who have alternative communication needs.</p>
EM761	18/02/2011	<p>1. These are many and varied. To be able to participate in society and lead a full and active life there are the problems caused by my medical condition that need extra money to be able to compete on an equal level with others (eg extra items needed for me to be able to attend a day at work (or anywhere) without problems, money needed to get me to work). There are also the barriers raised by the environment which mean I cannot use 'standard' methods to get to places but I have to pay extra to enable me to get there (eg paying for taxis as there is no accessible direct way of getting to where I need to be). In addition there are the barriers raised by other people's reactions (or lack of reaction) which means that I have to find money to be able to deal with issues that get thrown directly at me (eg companies refusing to make allowances for my access needs).</p> <p>*2. It should remain free from means testing. And it should comprise the two distinct areas – mobility and care.</p> <p>*3. As listed above, these can be many and varied. Travel is obviously a major one. So is equipment and the extra items needed to be able to attend a day at work (or anywhere). This is made more expensive when you have to pay more for</p>

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		<p>smaller, discrete items so you are not taking a suitcase to work with you every day!.</p> <p>*4. There should be no difference to the ease of understanding in changing 2 rates in one component and 3 in the other, to 2 rates in each as long this information is clearly stated.</p> <p>*I'm less convinced that reducing the 3 levels to 2 will ensure appropriate levels of support within that component.</p> <p>*I believe different disabilities at different stages could necessitate the 3 levels if not more to reflect these differences.</p> <p>*5. As medical conditions can vary greatly, (some affect all sufferers in different ways), some claims do need to be looked at. However, there are some conditions which should receive an automatic entitlement as the stress of going through the application process can worsen the condition irreversibly.</p> <p>*6. The answer to this depends on the individual. I have always worked, not because I am more able to work than others but because I know I will become totally useless and my condition will get much worse if I'm not working for as long as I possibly can.</p> <p>*Other activities will be essential for some other individuals. It isn't possible to have a generalised answer that will cover all individuals relating to all disabilities</p> <p>*7. There has to be an acceptance that there is such a thing as varying and fluctuating conditions and don't just take the results of one visit when there is such a condition. It is so disheartening to be accused of lying because you happen to be having a good day. However it would be good to look into other, non intrusive, ways of confirming that this is the case, rather than putting the individual through a large number of stressful visits</p> <p>*8. The assessment should take into account the whole person. If that happens to include any aids and adaptations it should note that, but that is all. The aids and adaptations are just part of their needs like shoes and clothing!</p> <p>*The assessment should only take note of aids and adaptations where the person already has them. It's a complicated process of considering those that the person might be eligible for as it's a highly skilled and long term decision as to exactly what aids and adaptations would be useful to the individual, and whether they would be of appropriate assistance or indeed would be a hinderance.</p> <p>*9. The claim form needs to be as brief as it can be, with lots of assistance to reassure the claimant.</p> <p>*10. This depends on the individual and the condition.</p> <p>*11. This depends on the individual and their condition and whether this will be a healthcare professional who is known to the individual, whether the individual is happy to talk to this person and how much information is given in advance of any such process.</p> <p>*12. Reviews should be carried out quickly and efficiently but</p>

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		<p>without undue pressure on the claimant. They should also be carried out in a sensitive way without making accusations towards the claimant.</p> <p>*The evidence/criteria to set the frequency of reviews ought to take into account the condition concerned and whether there is a need for frequent reviews.</p> <p>*There has to be different types of review as the individuals are all different and the range of conditions are all different.</p> <p>*13. There needs to be security that when you report changes in circumstances your case is not going to go right back to the beginning and be completely reassessed. Contact also needs to be simple, straightforward and accessible.</p> <p>*14. Full details of how to apply for this payment and full information about what it is need to be made easily accessible. Information is absolutely vital as part of the benefit claiming process so that the application can be filled in as appropriately as possible rather than having to try and guess what is wanted.</p> <p>*15. A 'requirement' is a very harsh word rather than being encouraged and simple to find and utilise. This may sound obvious but such a system would need to be fully accessible.</p> <p>*16. There are as many ways for disabled people (or their families) to fund their aids and adaptations as there are disabled people. (And several of them are not able to do this.) Not knowing more about the Personal Independence Payment (information!) I don't know what would potentially be lost if it is used to meet a one-off cost. In principle it sounds like a nice idea but would need more information.</p> <p>*17. Your response:</p> <p>*18. DLA has been useful to get other services but I've found it's normally by luck that people have found this to be the case. I'm back to saying more information is needed out the to inform people of what is available and how.</p> <p>*19. Your response:</p> <p>*If it is not possible for this to be used as a passport to other benefits and services it is likely to leave disabled people without vitally needed services and extra stress from having to do separate applications. This stress will negatively knock on to the medical condition.</p> <p>*20. Your response:</p> <p>*Only necessary information should be shared and they should be clearly told who information is being shared with.</p> <p>*21. Your response:</p> <p>*22. Your response: I'm afraid I've already been banging on about remembering each disabled person is an individual. Remember also that there is a huge range of disabilities many of which can cover a wide range of affects and severity, even changing throughout the person's life. Information must be out there and accessible so that people know about the process and what is available. I am aware there has been some abuse of DLA but that is no reason to make things impossibly hard for</p>

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		genuine claimants who are trying to live an equal and fair life despite the problems that may have been thrown at them medically through no fault of their own.
EM762	18/02/2011	<p>I am responding to the Disability Living Allowance reform paper (Cm 7984)) as an individual: the father, and Secretary of State's Appointee, for my daughter [REDACTED] who is a disabled person living in state funded residential care. My daughter was brain damaged at birth, resulting in quadriplegic spasticity and learning difficulties.</p> <p>*My daughter has had DLA for over 20 years, though initially it was Attendance Allowance and Mobility Allowance separately awarded. Our Mobility Allowance award was based on attendance at a review.</p> <p>*She also attended state provided residential education, and for the last 14 years has lived in a state funded residential home, so my interest in this reform started from the announcement of the intention to withdraw DLA mobility from such residents.</p> <p>*On this particular aspect, like many other individuals and organisations, I consider the proposal to withdraw DLA Mobility for residents of state-funded homes to be based on a fundamental misunderstanding of the basis of the care. If enforced in isolation, it will result in a severe reduction in both care standards and the quality of life for the majority of recipients. The major arguments were well expressed in the House of Commons debate on 14th February.</p> <p>*I have studied the Consultation document and read the statics therein with interest. I have downloaded the current claim form and notes, and studied them. I understand why reform is considered necessary.</p> <p>*The situation around DLA is acknowledged as complex, where DLA is one aspect of a total care package, where many other organisations; notably local authority Social Services and the NHS make significant contributions. Changes to the DWP's DLA payments can't be made in isolation: you must consider the effect on Social Services and NHS resources.</p> <p>*If you are considering fundamental change to this and all other allowances or payments, as Disability is essentially a health matter, why isn't DWP handing over this funding to Health or Social Services?</p> <p>*My plea is that no changes affecting current recipients are made until the replacement provision has been agreed with all affected or contributing organisations, and is in place.</p> <p>*I attach a personal response to the questions asked in the Consultation paper</p> <p>*1 With mental disability, the barrier is the inability to comprehend what is happening around them at a level that enables them to participate as equals with the rest of society With physical disability, the barrier is depends on the disability: loss of lower limbs, the problem is mobility: no upper limbs, the problem is feeding and no ability to communicate other than</p>

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		<p>verbally. There is also every possible shade of grey between the two extremes</p> <p>*2 Why do you want to keep DLA in any shape or form? It was Attendance Allowance and Mobility Allowance, two separate schemes that were much easier to understand. I think there is a misconception that is easier to administer as a single allowance. Para 12 of the consultation paper is pretty good</p> <p>*3 Assistance, to cope with normal essential functions Transport, to access all other support areas such as health care, shopping and activities. Holidays can only be taken in places that provide assistance in suitably designed accommodation. Even when provided by charities this is expensive – approx £1000/week in 2011.</p> <p>*4 Is this paper predicated on the concept of “son of DLA”, not on the idea of “what do we need?”</p> <p>*4a Will having two rates per component make the benefit easier to understand and administer, while ensuring appropriate levels of support? Possibly, it depends on how it is administered</p> <p>*4b What, if any, disadvantages or problems could having two rates per component cause? Defining conditions that segregate the levels</p> <p>*5 Perhaps, if the claim is supported by a Social Services or NHS reports. All other claims must be based on assessment, even if the costs of the assessment panel appear high.</p> <p>*6 Essential activities are washing, toileting, dressing, eating and drinking and the means of moving between these phases of life. Then access to health services and social activities</p> <p>*7 Have a competent assessment and review process rather than rely on self description of the condition.</p> <p>*8 No, because the disability does not go away with the supply of the aid/adaptation, these items only mitigate the effect of the disability. If they break or wear out the disability is still there. You must also consider who supplies the aid/adaptation.</p> <p>*8a What aids and adaptations should be included? None</p> <p>*8b 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? You can help the claimant by pointing out available aids</p> <p>*9 Pass responsibility to NHS who already have all the relevant information of a claimant’s condition</p> <p>*9a My daughter was awarded Mobility Allowance 20 odd years ago after examination by a medical panel. I have just read the current claim form and think it is bad, and very subjective. Question like” How long do you need help on the toilet for”, whereas the need for assistance arises because help is required at all.</p> <p>*The form should be limited to personal details, and leave the assessment to medical staff.</p>

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		<p>*9b First you must fully define the new benefit and be clear why you are providing it.</p> <p>*10 Sponsorship from local authority social services, NHS or other organisations that are financially involved with the total care package</p> <p>*11 Excellent</p> <p>*11a For a generalised answer, Para 30 of the consultation paper sums it up well.</p> <p>*11b 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? As above, Para 30 of the consultation paper sums it up well. If people can attend hospital appointments, they can attend a review panel.</p> <p>*12 How should the reviews be carried out? For example:</p> <p>*12a What evidence and/or criteria should be used to set the frequency of reviews? Dependant on condition and/or elapsed time</p> <p>*12b Should there be different types of review depending on the needs of the individual and their impairment/condition? The scope of the review should be consistent – the format could be altered to suit circumstances.</p> <p>*13 The system for Personal Independence Payment will be easier for individuals to understand, so we expect people to be able to identify and report changes in their needs. However, we know that some people do not currently keep the Department informed. How can we encourage people to report changes in circumstances? By making it beneficial to the claimant– make it a requirement for continued payment, *14 Para 37 sums it up well</p> <p>*15 Don't think this is a good idea. Other involved organisations, local authority or charity will manage this better</p> <p>*16 A wide variety of sources: NHS , local authority, charities (lots of them) and, currently, DLA. PIP should not be tied down to specific items otherwise, when circumstances change there will need to be a review, and I doubt if the DWP will be able to staff that adequately.</p> <p>*17 Paras 39 and 40 are good summaries, but for children, need to consider the effect of the disabled child on the rest of the family and how PIP can be used to minimise the effect on the lives of other children.</p> <p>*18 Successful application for one benefit always aids application for another, whether DLA came before or after Local Authority Social services or Education department activity</p> <p>*19 It would cease to be both Personal and related to Independence</p> <p>*20 Health, social services, education department information should all be accessible and shared between all authorities. It will prevent duplication, and it could ensure better and more appropriate care. It would remove the need for the claimants to</p>

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		<p>try and describe their own condition for DLA/PIP claims</p> <p>*21 Can't see any.</p> <p>*22 Why is DWP continuing to handle this? Why, as it is so health related, isn't it being handed over to Health to manage and run? Because Health will carry out condition assessments regularly, in one form or another.</p>
EM763	18/02/2011	<p>At this time of writing and after much careful consideration of your output on this reform, I note that the latest headline from Community Care magazine reveals that ministers are cluelessly silent on how many benefit claimants will be affected by your proposed reforms that will cost an estimated £675m over a three year period, adding to the global turnover of Atos Healthcare.[1] It is clear to me that the ministers responsible seem to neither know or care about the real hardships of the disabled people affected, and do not really want to know my opinion. So as a slower reader and writer than most, I shall reserve my own responses for a different audience that will be more appreciative of my own 'expert witness' account and less inclined to promote an investment banker to the House of Lords as Welfare Reform Minister after his supposed three weeks of research and writing on the matter of welfare reform made him such an expert.[2]</p> <p>*ESA tribunal victor December 2009, kept waiting two months for payment of back money due to system overload, and later sentenced to re-assessment by Atos Healthcare for a lifelong disability</p> <p>*Note*[1]*http://www.communitycare.co.uk/Articles/2011/02/18/116311/ministers-dont-know-how-2bn-benefit-cut-will-affect-users.htm</p> <p>**[2] http://www.telegraph.co.uk/news/newstopics/politics/1577313/Welfare-is-a-mess-says-adviser-David-Freud.html</p>
EM764	18/02/2011	<p>This is my response to the consultation, I have not been able to respond to all questions due to time restraints.</p> <p>*1. No response</p> <p>*2. Disability Allowance should not be means tested</p> <p>*3. No response</p> <p>*4. No response</p> <p>*5. Of course some conditions should have an automatic entitlement. It is a misuse of time and resources on assessing someone with say, severe mental disablement, to find out the "impact" on their ability to get around or to carry out daily living activities.</p> <p>*It is inexplicable to me that you would remove the automatic entitlement for the six current conditions, when the very nature of these conditions means that have such a significant impact on the individuals ability to function. This is why they are exclusions in the first place. These are the very people who you say you are trying to target. It means within the Personal Independence Payment there is no recognition of the plain fact</p>

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		<p>that there are a range of disabilities that are so severe that the individuals ability to get around, or to carry out key activities. This does not represent a simplification of the process, but a complication. The likely result is that some of these people, who are in the most need will fail to qualify due to the application procedure.</p> <p>*6. How do we prioritise support to those people least able to live full and active lives? With transparent, clearly communicated entitlement criteria. An easy application process that takes full account of the evidence provided from main carers. Evidence from care and support agencies (if involved) should be considered. Naturally the reports from the individuals G.P. and any health specialist should be considered.</p> <p>*7. By taking account of the individuals report of their condition and ongoing GP/ specialist reports, rather than the report or observation of someone who sees them only once, at a particular time.</p> <p>*8. NO. The use of adaptations and aids should not be assessed as part of this process, this is the role of trained occupational therapists and health care providers to assess the aids and adaptations that someone should/ could use, and to look at their individual circumstance, ability and home/ community settings. It may look on paper like a particular aid might help someone but there might be a perfectly good reason why they do not use it. I cannot see how the application process for Personal Independence Payments will allow for this detailed and specialist process.</p> <p>*9. Make the qualifying criteria clear and simple, so that people know what criteria they have to meet. They can then make a clear decision as to whether they should apply or not. This would take the mystery and subjectivity out of the process.</p> <p>*There is far too much repetition at the moment, the form asks a number of questions in different ways, as though trying to elicit different answers to undermine the validity of the claim. You ask for reports from GP's and Specialists, and then insist on sending along another person to make an assessment of their health, this is more repetition.</p> <p>*10. Your response: The whole picture needs to be considered and along with the individuals account, you should also give the main carers evidence more weight. Evidence from care and support agencies (if involved) should be considered. Naturally the reports from the individuals G.P. and any health specialist should be considered.</p> <p>*11. In my near 20 year experience of supporting people with severe and enduring mental health problems and those with moderate to severe learning disabilities, any face to face discussion with an unknown healthcare professional brings only stress, confusion and distress. This process represents more duplication, and more complication of the process. They have already shared a large amount of personal information in the</p>

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		<p>application form, and given you access to private and confidential; information from their healthcare providers, and potentially information from other sources yet they are required to go over this again, with a person whom they do not know. Some people, when put in this pressurised situation may say whatever they think they are supposed to, and may have little or no insight into the impact of their condition, and be unable to describe it. *It is an intrusion to make people have a home visit, and this should not be continued.</p> <p>*12. No response</p> <p>*13. No response</p> <p>*14. You should concentrate on the provision of advice and information about the Personal Independence Payment, and anything else that it acts as a passport to. Leave the provision of advice and information to the plethora of agencies and professionals who are already out there i.e Social Work, Citizens Advice, Advocacy, Welfare Right Advisors, support agencies... the list goes on. Otherwise you are creating more duplication.</p> <p>*15. No. This would infringe on personal choice and force people into situations that they do not necessarily wish to be in. Supportive relationships/ advice giving only works if the individual chooses to engage. By compelling people to use an advice or support service, you would undermine the supportive relationship, create tension and waste resources that would otherwise be directed to individuals who need and want services. By making the payment of the benefit conditional individuals who have entitlement will be excluded because they cannot or do not want to meet the conditions.</p> <p>*16. No response</p> <p>*17. Cannot comment on this area</p> <p>*18. There is no clear signposting on award of DLA as to what the other entitlements might be. This should be highlighted at award stage, in all communications and there should be reminders to prompt people following award.</p> <p>*19. No response</p> <p>*20. The process of applying for cash benefits should not overlap with assessments for services. They are separate. You should not have to disclose everything to everybody to be able to access the Personal Independence Payment.</p> <p>*21. Your proposals will have an unfair impact on those people with a disability who live in a care home. You are discriminating against people with disabilities who live in a care home. These disabled individuals who need help to get around will be unable to do so by the removal of the mobility component. They will be unfairly differentiated from those who do not live in a care home. See answer to Question 22. for further information.</p> <p>*22. I am shocked by the proposals to remove the mobility component from people who are in residential care homes. I can only presume this decision has been made on financial</p>

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		<p>grounds only, rather than any understanding of what a care home is and the types of people who live there. People of all ages with a learning disability, a mental illness or physical disability live in care homes.</p> <p>*People who live in care homes are amongst the most vulnerable individuals in our society, hence why they are there. Their disability has such an impact on them that they are not able to live independently. There is no similarity between being in hospital and being in a care home. You go to hospital for medical treatment for ill health for a defined period of time, you are in a care home because that is where you live for an indefinite period of time, possibly the rest of your life. The removal of the mobility component will effectively imprison people in the place they live. You should be allowed to go out if you live in a care home – surely? I can assure you that the additional costs of providing support and transport to people if they lose this entitlement will not be provided by the care home itself. So people will simply not go out anymore. With this action you are saying that people with a disability who live in a care home do not have the right to get out and about, hardly supportive and enabling as you claim these reforms are supposed to be. You are discriminating against the most vulnerable disabled people.</p>
EM765	18/02/2011	<p>1. :I answer as someone suffering from a complete spinal cord Disability Living Allowance reform – injury (SCI), I am paraplegic – paralysed completely from the chest down. There are of course countless barriers but a lot stem from a lack of understanding of my condition – even from the medical profession if they do not have specific training in SCI. Perhaps if everyone got to spend a week in a wheelchair, no cheating! – society would begin to change. I cannot be fully independent because of every time I see a kerb/flight of stairs with no ramp or lift, or cobbled/uneven ground, or a grassy field with no path, or a sandy beach that I can in no way access, despite having a six year old child who would love to have a paddle or build a sandcastle</p> <p>*2. :The qualifying time. The separation of mobility and care components.</p> <p>*When people have a permanent condition, this negates the requirement for reassessment.</p> <p>*3. :too many and varied to list here, also many are hidden. But for example – heating – my body temperature needs to be regulated fuel – my Motability car is my only way of travelling around taxis – for the occasions when I cannot drive, I do NOT have the option of public transport as I can't access it where I live. mobility aids – my NHS wheelchair is too heavy and cumbersome for me to lift into my car so I had to buy my own chair wheelchair maintenance home adaptations</p> <p>*holidays – extremely difficult and costly to find wheelchair friendly accommodation. Travelling with my son and husband –</p>

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		<p>hotels do not have wheelchair adapted family rooms so we always have to pay double as we have to book two rooms. People with more severe injuries have to pay for a carer too. Domestic help – I cannot physically manage around the home as I used to. Jobs I used to do myself now involve paying someone – from a cleaner to a joiner.</p> <p>*4. Your response:</p> <p>*5. :In the case of lifetime conditions, such as a complete spinal cord injury, which has no chance of improving, eligibility should be automatic.</p> <p>*6. Your response:7. Your response:*</p> <p>8. :No! People need to be assessed on their abilities on a level playing field, regardless of any aids and adaptations. Otherwise it would be like judging a runner who is barefoot against one who is wearing training shoes. How can a wheelchair, essential to get around, be seen as part of my ability? I only need it because of my disability.</p> <p>*9. Your response:</p> <p>*10. :only someone with specialist spinal knowledge, such as a spinal consultant, can be involved in the assessment of someone with a spinal cord injury (SCI)</p> <p>*11. : Again – anyone involved in assessing someone with a SCI MUST have specialist spinal knowledge. In many cases, the patient knows far more than the doctor – my own GP freely admits this and values my input and opinions on my treatment.12. :Again – there is literally no need for a review in the case of a complete spinal cord injury – i.e. when the cord is completely severed. This cannot improve, there is no treatment.</p> <p>*13. Your response:14. Your response:15. Your response:</p> <p>*16. : I use my DLA to fund my aids and adaptations, because I was forced to buy a wheelchair privately due to the fact that I cannot lift my NHS wheelchair into my car.</p> <p>*17. Your response:</p> <p>*18. :Motability is the obvious one here. It is essential that PIP provides the same passport to Motability as DLA. If people become ineligible for Motability due to the introduction of PIP huge problems will be the result.</p> <p>*19. :see 18. The result would be large numbers of people previously able to get out and about independently becoming effectively housebound if their Motability car was removed and they, like I, could not access public transport locally.</p> <p>*20. Your response:21. Your response:</p> <p>*22. :I feel it would have been fairer to admit that the Government is seeking to save some money here.</p> <p>*I also feel that this consultation was wrongly introduced at Christmas time, when people are distracted and busy, and don't have as much time as usual to respond. It was also 10 weeks long – too short, particularly if you take off the two week holiday. I repeat what I stated earlier – let's see those</p>

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		<p>promoting the changes spend a full week in a wheelchair, and then give their opinions on how easy it is to cope. This is not a facetious remark but a genuine challenge.</p>
EM766	18/02/2011	<p>Neither Reasonable Nor Fair Response to Consultation on replacing Disability Living Allowance (DLA) with a Personal Independence Payment (PIP), on behalf of people with Severe ME</p> <p>*This is a response to the consultation on behalf of people who are severely affected by the neurological disorder myalgic encephalomyelitis (M.E.). It is estimated that 1 in 4 people with M.E. are severely affected. This response has been jointly prepared by the 25% ME Group, a UK charity supporting people with severe M.E., and Stonebird, a web resource aimed at sharing some of the experience of living with severe M.E. All of those involved in drafting this response have direct experience of this disabling disorder, either as a patient or as a carer. What do we mean by 'severely affected'? Those who are severely affected have severe restrictions in their mobility and ability to carry out essential daily tasks and attend to personal care. There are profound cognitive problems as well as functional disabilities. At its most extreme, people with ME are totally bedbound, in constant pain, unable to tolerate light or noise, and may even suffer paralysis and require to be tube-fed. So this is a response on behalf of people who have a high level of disability.</p> <p>*We believe that it is completely misguided of this Government to replace DLA with PIP under the premise that it is in the best interests of disabled people and society as a whole. The replacement of DLA with PIP, in our opinion, will result in taking cash from vulnerable people who rely on this money to meet additional costs arising from disability, and as such the introduction of PIP is likely to endanger health and exacerbate disability.</p> <p>*PIP repackages prior proposals to 'reform gateway' to DLA by presenting these under a new 'brand', with the concurrent introduction of yet further barriers to qualification, and presented in an ideological wrapper of dubious validity. We note with concern that the changes previously announced were aimed at cutting expenditure by reducing the number of successful claimants, with projected savings of £360 million in the fiscal year 2013-14 and a further £1,075 million in 2014-15. The intention was and remains to make fewer awards of benefit.</p> <p>*We oppose plans that will see disabled people put through a flawed assessment system introduced in order to achieve deliberate and punitive cuts in expenditure, whilst purporting to be in their best interests. We are not convinced that the PIP reflects a serious attempt to understand people's needs and problems arising from having a disabling disorder.</p> <p>*We note that there is considerable expense associated with</p>

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		<p>implementing these unnecessary reforms. This example of the government's maladaptive thinking on '21st century disability' is a waste of taxpayers money that is highly unlikely to benefit the public purse. Not only will there be a spike in costs associated with implementing a new system, but savings achieved through granting fewer awards of benefit and/or lowering the amounts payable to successful claimants will be offset by the higher costs incurred by carrying out regular assessments and by other public services, including costs uncured in response to deterioration in the health and wellbeing of disabled people through the introduction of these punitive reforms.</p> <p>*The government's case for 'The need to reform Disability Living Allowance' as presented in Chapter 1 of the Consultation Paper is paper thin at best; similarly the arguments that are presented in favour of the PIP proposals in subsequent chapters. Our response incorporates a critique of some of material.</p> <p>*We have reservations regarding the capacity of these Consultation Questions to fairly and thoroughly assess views on the PIP system.</p> <p>*Ø Some of the Consultation Questions do not relate well to the government's plans as set out in the relevant section of the Consultation Paper – so that a person reading the Question in isolation may well fail to appreciate the nature of the change that they are being asked about. Relatedly, some are ambiguous. Some have covert implications and could even lead people to unwittingly argue for the opposite of what they wish to see.</p> <p>*Ø Some significant changes are not addressed in the Consultation Questions – perhaps because this consultation is not framed at considering the wisdom of replacing DLA with PIP, but rather at informing 'secondary legislation on the detailed design, including the new assessment process'. We note with concern that the government has already set up a 'group of independent specialists in health, social care and disability' and has consulted with this group prior to the present phase, meaning that primary legislation has been drafted on the basis of a closed consultation. We deplore the lack of a public consultation on the fundamentals of this change.</p> <p>*Notwithstanding that the present consultation is pitched at the details of implementing replacement rather than the fundamental question of whether or not to replace DLA with PIP in the first place, we strongly request that DLA be left in place. DLA in essence is currently meeting the needs of people with ill health and disability. Some aspects of DLA would bear modification, and many people with M.E. – including people who are severely affected - have reported difficulties in accessing benefits to which they are entitled, including DLA. However, there is no compelling case to introduce a completely new system. As matters stand, neither the consultation process</p>

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		<p>nor the present consultation document represent a reasonable or fair basis upon to which to be making decisions that will have far reaching consequences for people whose lives are adversely impacted by ill health and disability.</p> <p>*Critique of Approach to Reform*This Consultation Question is prefaced by several paragraphs headed 'Our Approach to Reform'. We preface our responses to the Consultation Questions by presenting a critique of the stated approach. This is not only relevant to Question 1, but underpins many of the other Consultation Questions and this critique lies at the heart of many of the responses we have provided.</p> <p>*If PIP is intended to 'contribute to the extra costs of overcoming the barriers faced by disabled people to lead full and active lives' what assistance is to be provided if it is simply not possible for the relevant barriers to be overcome? Against this yardstick, will the most debilitated people qualify for PIP?</p> <p>*Ø It is profoundly unhelpful to fail to acknowledge that people who are very ill and very disabled simply cannot live full and active lives in the normal sense. How do you define what is a full and active life in a meaningful way without considering the context of a persons disability including, where this is relevant, the impact of severe illness? You must surely clarify what you mean by 'full', 'active' and 'independent' lives and accommodate the situation of those people who need facilitation within this context.</p> <p>*Any move towards 'a benefit that helps contribute to the extra costs of living independently' must take into account the needs of people who simply cannot live physically independently and require assistance to meet basic needs. *Ø The concept of 'independence' is highly subjective. Independence to someone with Severe ME may be perceived as a tiny irrelevant life, compared to the normal way of interpreting independence.</p> <p>*Ø When the consultation paper speaks of 'independence' what does it mean? Physical independence? Emotional independence? Mental independence? Does 'independence' encompass personhood? Or is it simply intended to imply independence in the sense of living in the normal world doing ordinary practical everyday things?</p> <p>*Ø Attaining independence, as an attitude of mind, takes into account the facilitative role of the carer so that an individual who is bed-bound can still have a presence in the world through the hands and feet, ears and eyes, limbs of the carer. The achievement of independence must include this interpretation to be balanced and relevant to all.</p> <p>*The PIP appears focussed on the situation of people who are disabled but otherwise in good health. The consultation document does not address the situation of a sick person.</p> <p>*Ø Living with a severe long term illness brings very significant related costs arising from ongoing care and support needs. For those who are tormented by symptoms that are very difficult to</p>

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		<p>bear in themselves and that interfere with everyday functioning - as in Severe ME – any fair system must include the impact of this as a relevant issue in determining financial aid.</p> <p>*Ø It is not appropriate that the benefit will continue to take account of the social model of disability' while completely ignoring the concurrent and very real and relevant implications of the medical model of disability. If the social model is skewed to only look at ability and independence, then it leads to a completely wrong interpretation of the social model. The social model was never intended to negate the very real impact of disease. These models are complimentary and not mutually exclusive in their explanatory insights. The total reliance on the social model in framing government policy represents a facile misinterpretation and is patently unrealistic.</p> <p>*Ø It is not legitimate to separate the symptoms and reality of illness from a person and deny their impact. For example, even if suitable physical access arrangements are made this does not yield inclusion, capability, independence and the same freedom to live in the world that a normal able healthy person enjoys.</p> <p>*We are extremely sceptical at the assertion that awards of PIP will be based on 'fairer, objective assessment'. We can see no evidence to support this. And, while the objective of fair assessment is one that all would share, it is doubtful that these matters can ever be decided on a purely 'objective' basis. What, specifically, is implied by 'objective' in this context?</p> <p>*We welcome some of the aims of the PIP, such as basing qualification on need not income. However, both this and most of the other aspects outlined here [Para 5] already apply to DLA. Only one objective is clearly new: 'taking account of the support that disabled people can access to help them live independently'. We are concerned as to what this might imply.</p> <p>*Ø Is it possible that, as well as ruling out help for people who experience insurmountable barriers to living independently, PIP will also rule out assistance for people who are able, with support, to minimise or decrease the very real barriers and have already made arrangements to do so - for example, through access to aids and equipment?</p> <p>*Assessment Process*No evidence is presented to back the argument that the existing DLA process "is based on unclear criteria and often does not make the best use of available evidence." Nor that "As a result, awards can be subjective, inconsistent and do not always focus support on those who need it most." In so far as this is the case – and DLA decision making has been subject to criticism in terms of failure to grant due awards – it is by no means clear the abolition of DLA and replacement with PIP will help surmount such problems. Quite the opposite. And, while there are aspects of the DLA application form that are problematic there has been no serious attempt to address the difficulties when raised with the DWP</p>

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		<p>over the years.</p> <p>*Against this background, it is remarkable to see the DLA application process being slated in order to provide a platform from which to present the 'need' for the changes that the government want to see. We have expressed concerns (see above) about the capacity of PIP assessment to meet the stated aims of being 'fairer' and 'objective'. To summarise:</p> <p>*Ø We do not believe that it is possible to be completely 'objective' in assessing disability.</p> <p>*Ø We have serious concerns as to how moves towards 'objectivity' will translate in practice for claimants with Severe ME, as the NHS carries out no specialist biomedical testing, hence there is no 'objective' record of biomarkers. It is worth emphasising that over 5,000 published research studies, going back to 1934, have demonstrated a range of biomedical abnormalities in a proportion of the patients studied.</p> <p>*Ø As a result of the NHS failure to conduct appropriate specialist testing, all too often the only evidence about how this illness is impacting on ability comes from the patients themselves. Indications are that such accounts hold little weight with assessors, and that this is already a considerable difficulty experienced by people with severe ME in accessing Disability Living Allowance. These PIP changes could well mean that successfully claiming benefit will become even more difficult for people with severe ME.</p> <p>*Ø A lot of the disabling symptoms of ME – e.g. noise sensitivity, chemical sensitivity - are not necessarily visible and cannot be objectively measured, even in a snap-shot way.</p> <p>*Similarly, the PIP system might transpire to be 'easier to understand' - but that doesn't necessarily mean that it will be fair and rational. *Likewise 'transparent': one may be given a clear explanation of why one has or has not qualified, without the criteria employed to reach the decision having been appropriate and fair. *Critique of Case for Change and PIP Approach</p> <p>*This question is prefaced by a short presentation of the government's case for abandoning the DLA system. This rests on a mixture of patently spurious and more opaque reasoning, including:</p> <p>*Ø 'The definitions currently used are subjective....' What are these 'subjective' definitions? In what sense are they 'subjective'? In so far as they are 'subjective', is this a flaw that could and should be remedied, or an intrinsic reflection of the enormous variety of ways in which different disabling disorders impact on different people's lives?</p> <p>*Ø '...and reflect views of disability from the 1990s, not the modern day.' The notion that the case for change is manifestly apparent through a clear distinction between 'the 1990s' and 'the modern day' is risible.</p> <p>*Ø It is asserted that 'care' and 'mobility' "do not necessarily remain the best proxies for cost." This is a fundamental issue in</p>

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		<p>the present context, and some specifics of the ‘conflicting evidence on the factors that affect the extra costs that disabled people face in the 21st century’ and implications of same require to be indicated. On what points does the evidence differ? Also, we note that one of the DWP working papers to which this statement is referenced relates to international evidence on the cost of disability, and suggest that it is specifically the extra cost of disability experienced by people living in the UK that is pertinent to shaping the UK benefits system.</p> <p>*Also problematic is the case repeated mantra of focussing ‘on those who face the greatest challenges to leading an active and independent life’ / ‘individuals whose impairments have the most impact on their lives’ - and similar, throughout the Consultation Paper.</p> <p>*Ø What does this imply? The present system operates on the basis that varying levels of DLA award are appropriate, with higher payments awarded to people with greater care and mobility needs. In Chapter 1 of the consultation paper this very feature of DLA is acknowledged - and used as ‘evidence’ of the need for change on the basis that DLA ‘is too complex’.</p> <p>*Ø Against this background, we envisage that concurrent moves towards ‘simplification’ and ‘focus on individuals whose impairments have most impact’ implies the removal of benefit from people whose disabilities, while not the greatest, nonetheless bring additional support needs and barriers and have a very real impact on cost of living.</p> <p>*1. People with Severe ME: Problems and Barriers</p> <p>*A major barrier that people with severe M.E. face to leading independent, full, and active lives is having an illness with symptoms that severely limit their capacities. These symptoms are exacerbated by activity, rendering this barrier particularly thorny. We also face barriers of prejudice, barriers deliberately created by endorsing a deeply flawed psychosocial model of causation, barriers resulting from the associated pursuit of totally inappropriate and counter productive service models, and the barrier of denial of how severely physically ill we are. Also, as with many other disabling illnesses, the physical environment is hostile to our needs, due to a profound hypersensitivity to all stimuli that has massively debilitating consequences. People with Severe ME experience multiple disabilities within the environment that may appear initially invisible such as multiple chemical sensitivity and acute noise sensitivity.</p> <p>*The mindset that any and all barriers can necessarily be overcome and that disability benefits should be solely geared towards this purpose is potentially toxic for very sick and debilitated people, and quite simply wrong. With severe M.E. it is impossible to live a full and active life. The intensity and complexity of symptoms, including acute hypersensitivity to all</p>

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		<p>forms of environmental stimuli, makes physical independence - in the sense of living freely in the world - almost impossible.</p> <p>*It has been officially recognised that there is no known cure for M.E. At the same time, approaches to activity intervention that have been trialled for 'fatigue' are being misapplied, much to the detriment of people with M.E. For example, in a survey of 25% ME Group members the vast majority of those who had undergone graded exercise - 82% - reported that it had made them worse. Furthermore some patients were not severely affected before trying 'Graded Exercise Therapy. So an intervention that is commonly considered – both in the NHS and on the part of DWP assessors – to be helpful to overcome the barrier of disability for people with M.E. is in fact greatly exacerbating the problem.</p> <p>*2. We agree with the aspects that will remain unchanged under PIP, as set out in paras 8-11 of Chapter 2. It is particularly welcome that 'The new benefit will not be means tested or taxable, and payment will not depend on having paid National Insurance contributions'.</p> <p>*However, we argue that few if any of the changes that the move to PIP does entail are necessary or even desirable. We address the case for and against specific changes throughout this response, alongside the relevant Consultation Questions. Some key points include:</p> <p>*Ø It is essential that people are able to continue to provide evidence from their own GPs or other medical professionals, and - crucially - from carers. This is particularly important for people with severe M.E. in view of their cognitive disabilities and profound physical difficulties, and the consideration that there is a strong possibility that a person with severe M.E. will deteriorate as a result of the effort required to participate in face-to-face assessments.</p> <p>*Ø Where there is no cure or treatment that substantially ameliorates the person's disorder and a poor prognosis, then DLA awards for life should have been granted and such awards should be maintained under the new system. The person should automatically be awarded PIP without having to go through more interrogation, forms and exhausting procedures and having to prove their disability yet again, when they have already proved it to the satisfaction of the DWP for DLA.</p> <p>*Ø People who have already been awarded DLA should not lose out financially by the transition to a new allowance at a lower rate of benefit, or none at all.</p> <p>*There are also some important issues relating to entitlement that appear to have been decided already. Some other matters that will have far reaching impact on disabled people's lives are still under consideration but not through the Public Consultation. These include:</p> <p>*Longer Qualifying Period and 'Prospective Test'</p> <p>*It is planned to increase the present three month qualifying</p>

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		<p>period to six months and introduce a new prognosis requirement. These are problematic for people with M.E. because of poor cognisance of likely duration (long) and prognosis (poor), alongside difficulty in providing a case specific definitive prognosis in respect of an individual person with M.E.</p> <p>*DWP medical examiners should be made aware that ME is included in the NHS National Service Framework (DH 2004) as a long-term neurological condition, "Substantial improvement in ME is uncommon and is less than 6%" (Anderson et al. 2004); and, "Full recovery... is rare" (Cairns & Hotopf, 2005) anyone severely affected for more than 5 years has a poor prognosis of recovery (DH 2002)</p> <p>*Ø Six months is a terribly long time to live with a disabling disorder and no financial support to help with what may be very significant costs arising as a result, costs which are often accompanied by reduced income.</p> <p>*Ø The concurrent introduction of a 'Prospective Test' in the form of a requirement that a person be expected to continue to satisfy the entitlement conditions for at least a further six months means that those who are impacted by disability for anything up to a year will not be granted any financial assistance to help with the additional costs. This is unacceptable.</p> <p>*Ø It is likely that these changes will impact adversely on people with Severe ME, not because it isn't a long term disorder – many patients experience decades of ill health and related high levels of disability - but because this possibility isn't necessarily officially recognised.</p> <p>*Substantive Changes to the Components</p> <p>*The mobility component is to be reframed in terms of 'ability to get around'; and a second component will cease to relate directly to 'care' but instead will concern 'ability to carry out key activities necessary to be able to participate in daily life' and is to be known as 'the daily living component'. It is notable that the public consultation paper does not seek views on this change. This is but one example of a very fundamental change that is not the subject of a Consultation Question. – it would appear to be a fait accompli without any form of public consultation.</p> <p>*We are very concerned about this government's focus upon what people can do, rather than what they can't, and the associated focus on the social model and exclusion of any consideration of medical model of disability.</p> <p>* 3. Extra costs faced by people with Severe ME: some examples</p> <p>*Diet. In Severe ME there are often complex dietary needs due to ongoing gastric issues. Special dietary needs can include, for example, a requirement for gluten-free food, dairy-free food, and/or organic food.</p> <p>*Nutritional Medicine Supplements. For the most part the NHS</p>

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		<p>will not pay for nutritional medicine supplements. These can help greatly in addressing problems relating to mitochondrial and other basic body functions. For a person with severe ME these are often taken at higher than average dosages (or recommended daily amounts) because a therapeutic dosage is required. Such preparations tend to be expensive and specialized and cannot just be brought cheaply across the counter. For many people with severe ME they are a huge and regular expense.</p> <p>*Household. Many people with severe ME experience allergies and chemical sensitivities, necessitating the purchase of specialised cleaning products, washing powders, soaps etc. Every single chemical can have a devastating impact in Severe ME, such that people have to source very expensive, very pure organic products. Specialist furniture, chemical free paints and decorating materials may also be needed.</p> <p>*Personal Hygiene Products. In severe ME there is acute hypersensitivity of the nervous system, commonly with associated multiple chemical sensitivity. This means that things like toilet rolls, tampons, cotton wool pads, need to be bleach free and organic. This is another high, regular cost.</p> <p>*Clothing and other Textiles. Due to hypersensitivity/allergy and resulting skin rashes, expensive organic clothing or particularly expensive makes of clothing and types of cloth may be all that is tolerated by people with Severe ME. This is also the case with bed linen and towels. Cheap everyday alternatives are not a viable option for people so affected. Duvets, pillows, and seating may need extra padding, extra soft textures and organic quality (due to chemical sensitivity) which all mean extra costs, costs that are necessary for the person to try to achieve a tolerable level of physical comfort.</p> <p>*Utility Costs. Heating bills may be higher because it's important to maintain a warm environment. Frequent baths are often needed to cope with the pain. The amount of cooking from scratch required to create special diets significantly increases fuel costs. Experiencing frequent profuse sweats means that clothes and bedlinen need washing more often. Some people with severe ME have incontinence, increasing washing needs and adding to higher electricity, gas and water bills. Severe ME can be very socially isolating and many people find that access to social contacts via e-mail and other on-line opportunities is a welcome lifeline. Computing costs to try and maintain access to the outside world are an ongoing expense.</p> <p>*Aids, Equipment, and Adaptations. Purchasing and maintaining aids and other equipment is an ongoing cost. The person's home may require to be adapted.</p> <p>*Domiciliary Services People may need to pay for providers of services such as hairdressing, chiropody, osteopathy to come to the home, which incurs extra costs. They may require to employ a gardener.</p>

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		<p>*Carers There are direct and indirect costs of employing carers or having the help of family, friends, and neighbours.</p> <p>*4. It is proposed that two rates of benefit will be payable in respect of each of two PIP component. Apparently 'this will simplify the overall structure, making it easier to understand, and reflect the range of individual needs'. *Easier to Understand and Administer?</p> <p>*We do not agree that there is an issue of complexity that requires to be addressed as a result of having three levels in respect of DLA 'care' component and two for 'mobility'. Yes indeed, by the laws of arithmetic, that gives rise to 11 possible combinations of award. This is utterly irrelevant to complexity for claimants though – it isn't as though claimants are expected to perform this calculation. Each recipient will receive one of these combinations and one only, intended to reflect their level of need. This is so not rocket science and scarcely 'complex' nor in any way difficult to understand.</p> <p>*Neither would we have thought that having three rates for care component represents an onerous burden to administer. Nor that moving reducing this to two rates will provide greatly enhanced ease of administration.</p> <p>*Ensuring Appropriate Levels of Support?</p> <p>*We are extremely sceptical that the change to a two rate structure for one of the components will be competent in 'ensuring appropriate levels of support'. On the contrary, there will be less flexibility to appropriately reflect the varying degrees and impacts of long term impairments and resulting extra costs, and almost certainly an associated loss of income for many claimant (this emerges from subsequent sections of the consultation paper).</p> <p>*Disadvantages and Problems*We note that the consultation paper gives no indication as to how PIP rates will compare to the present levels of DLA payments. We are of the view that there should be the equivalent rates of payment as there are now – or better - and also that no one should lose out because the number of rates at which benefit can be awarded have reduced.</p> <p>*There will be loss of much needed and highly valued income to sick and disabled people if the new PIP system results in a poorer level of payment than the same person would have received or had been receiving through DLA. There is a lack of detail in the public consultation paper as to how the qualifying thresholds in terms of degree of impairment and need will differ. However, we note with concern that "It is likely that some disabled people with lesser barriers to leading independent lives will receive reduced support..."</p> <p>*5. The proposal is to end automatic entitlements to all but people who are terminally ill.</p> <p>*The case for change as presented in the consultation paper – that 'This will deliver a more personalised service that ensures</p>

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		<p>resources are targeted where they are most needed' – is highly contentious.</p> <p>*No attempt is made to identify factors mitigating against this change - notably, the potential for adverse impact on health of going through the mechanics of the assessment process itself, and the associated stress; and the cost to the public purse of assessing people who would previously have been automatically entitled.</p> <p>*In our view this Consultation Question implies a false dichotomy. Automatic entitlement presently applies only to certain severe disorders, such that a person with the relevant disorder can reasonably be expected to qualify for the relevant component at the rate specified in view of need and regardless of any variation in personal circumstances.</p> <p>*Not only is the list of conditions / impairments to which automatic entitlement applies extremely short, but no disorder confers automatic entitlement to an award of both care and mobility components of DLA. So it is highly misleading to imply that automatic entitlements are a major feature of DLA. We find this aspect of the consultation paper particularly galling, as the reaction to well nigh any and all attempts by people with M.E. to have the DWP address difficulties that people with M.E. experience in claiming DLA has been to ignore the specific points raised and simply reply that entitlement is not based on suffering a particular disorder, but on how the disorder affects the person.</p> <p>*We would like to see the range of automatic entitlements increased rather than reduced. We would also like to see a 'semi-automatic' entitlement for people who are severely ill and disabled. In such cases, completing the forms and having supporting reports from people such as the persons doctors and carers should be sufficient. Severely ill and disabled people should not have to worry about having to undergo assessment procedures which can be very taxing for them to the detriment of their health. This would apply to people with Severe ME. (More on this at Questions 9 and 12.)*6. Prioritising support 'to those people less able to live full and active lives'</p> <p>*Those who are most ill and most disabled should be a huge priority, in order to ensure the least stress on their life and the maximising of opportunity to manage even the simplest of things. The appropriate way to prioritise support to those people who are least able to live full and active lives is to accord them the highest rate of the relevant benefit. It is not to remove or reduce benefit that is already paid to people who have a lower level of need, who likewise require assistance to meet the additional costs resulting from having a disabling disorder, albeit that the additional costs are likely to be lower than for a severely disabled person.</p> <p>*That, however, is exactly what is envisaged:</p> <p>*"It is likely that some disabled people with lesser barriers to</p>

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		<p>leading independent lives will receive reduced support, but this has been justified by the policy aim to focus support on those with greatest needs.” (Overview of Potential Equality Impacts, p28)*The ‘justification’ presented here is no justification at all. Not only is there is no suggestion that people who have highest needs will actually be better off under PIP than DLA but, even if this were the case, such a policy aim would not ‘justify’ removing assistance from others. It would appear that many will be denied the benefit of financial assistance by implication that their need is not great enough, whilst the current system acknowledges that it is. This is both illogical and damaging to people's lives.</p> <p>*At the same time, the perspective that steps to be introduced PIP – or any other system of changes, for that matter – “should ensure that priority is given to those individuals who need to overcome the greatest barriers to living full and active lives” fails to recognise that people who are very ill and very disabled cannot live full and active lives in the normal sense of these words.</p> <p>*Activities that will be Assessed - As with ‘prioritising support’ there would appear to be a loaded aspect to this question. Of course activities that are ‘most essential’ for daily life have to be taken into account. But this is not to say that only the most essential activities should have a bearing in determining eligibility for PIP.</p> <p>*There is a real difficulty if the</p>
EM767	18/02/2011	<p>The proposed changes to DLA sound laudable. They may, however, result in higher government costs; my family has had experience of some strange medical opinions, given by well-paid visiting doctors who do not always abide by the rules. My daughter had to attend a hearing, heaven knows the cost, but the decision was thankfully repealed. There are people who look “quite well”, especially if they are of the mental capacity who “struggle on”, rather than moan. I am now 66, but lead a useful life, teaching until I was 49. I am superbly cared for by the NHS, seeing five consultants across Britain – I know I cost the country rather a lot already. I could not manage without my DLA benefits, but realise I may have passed away by 2013, and will be too old anyway to be forced into work! The government must realise that we should be presumed unwell until proved otherwise – there are serious conditions that are not terminal. I fear that you will spend a fortune on medics motivated by money, not patient care, and as always the idle will continue to bend the rules, whilst the decent unwell will suffer. My daughter sadly inherited some of my health problems, including an immune deficiency. We almost lost her at 7, and when she was 21 she was lucky to survive chicken pox which turned to viral meningitis/pneumonia. She has never totally recovered and has been under expert care of the Immunologist at St. James's Hospital, Leeds for fifteen years. This is without all the ancillary</p>

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		<p>health problems she suffers, and her many hospital visits. She managed to obtain her degree but has never worked because, even ignoring all the pain in her joints, frequent infections, Reynaud's, low blood pressure and a few other "difficulties", she sometimes spends the day in bed, or surfaces and has to return to bed. She is only seen out and about, as I am, on a "best" day – we try not to make our problems obvious to other people, and certainly don't want pity – but understanding is essential. We have a superb GP and medical staff, all already linked, (without passports), physios, OT's etc, are all part of our system. It doesn't apply here amongst the Celts but if a GP is being given the responsibility to run the whole PCT, surely he could make a decision on whether a patient deserves P.I.P.? Sadly in any organisation there are individuals whose professionalism is questionable but I feel that the new system will cost more than it saves. My daughter makes a huge effort with voluntary work but that is only possible because nobody is reliant on her turning up! Without motability she would never get anywhere. By spending a fortune on heating, and living careful lives very aware of our illnesses we try our best to stay out of hospitals which would cost the state far more.</p> <p>*Reforms are needed – we don't go cleaning windows with bad backs, but we are not sure this has been reviewed in a gradual, considered way. If a patient frequently sees a top U.K. consultant, on a long term basis, how many more expensive checks will they need? Those who want to work will make the effort, the problem is those who want extra money for nothing. Others deserve financial help to survive their physical situations. I agree, "it is time we had a disability benefit which is easier for individuals to understand and provides clear and consistent awards", it must be very fair, just and compassionate.</p>
EM768	18/02/2011	<p>I am writing in response to the consultation. Unfortunately my health precludes me from making a detailed response. However, I am very concerned about the consultation document, which in my opinion is biased and not supported by robust data. I am also surprised that some of the 'statistics' quoted have not been challenged by the Statistics Authority. For example, the numbers quoted on the increase in claims does not take into account demographic changes and does not appear to be based on real terms?</p> <p>*I quote some other examples: chapter 1</p> <p>*p1 "...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> <p>*The only person I have heard state this was one of your Ministers – if a survey was done following this the data would be contaminated.</p> <p>*P16 "...For example, some view the benefit as a form of compensation for being disabled, some don't view themselves</p>

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		<p>as disabled and others incorrectly believe that their DLA payments will stop if they return to work. The 11 possible different rates of the benefit also make the benefit complex to administer.”</p> <p>*There is not data source for this, on what basis did you state this?</p> <p>*P17 “... A significant proportion of DLA recipients believe that DLA is an out-of-work benefit. Applying for DLA is widely linked with the process of leaving or being out of work due to disability. A common assumption among people receiving DLA is that entering or returning to work will lead to a review of their circumstances and a loss of the benefit. “</p> <p>*The research referenced here is qualitative research, so cannot be used to state 'a significant proportion' – do you have any real quantitative to support this?*Chapter 2 p 3 and 4 “... The assessment will be objective, “</p> <p>*It is not possible to have an objective assessment of pain or most common mental health conditions.*Q5</p> <p>*p22 “... a new, fairer, objective assessment of individual need. We want the new assessment to be objective and evidence-based, to ensure that support is targeted to those individuals whose health condition or impairment has the greatest impact on their day-to-day lives. “</p> <p>*Yet you have given the contract to ATOS, whose decisions have been overturned too many times, and whose complaints system is a farce.</p> <p>*http://www.heraldscotland.com/news/home-news/demand-for-fairer-benefits-tests-as-two-die-1.1085915*In my own case the ATOS examiner scored zero, ignoring evidence and making several errors on the form. I complained to both DWP and ATOS, neither of whom provided any satisfactory response. At the tribunal 10 months later, I was scored at 24. However, in spite of my ongoing health problems.</p> <p>*I nearly did not attend the tribunal because it was too stressful. In that case I would have become one of the numbers you and the media are using to 'prove' we are benefit scroungers.</p> <p>*The data used to calculate the percentage of cases overturned by tribunals should be longitudinal – your current statistics underestimate the true figures due to the long gap between assessments and tribunal hearings.</p> <p>*P31 “. We will, therefore, periodically review all Personal Independence Payment awards. “</p> <p>*A waste of money; why review people who have deteriorating or permanent conditions?*Unless there is evidence condition could change (get better), reviewing all claimants is a waste of money that could go to the disabled!.</p> <p>*Finally, why was the consultation document issued just before the ONS' survey? Will you be taking the findings from that survey into account?</p> <p>*http://www.guardian.co.uk/society/2010/dec/09/disabled-</p>

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		<p>people-missing-out-jobs-courses*I DO NOT THINK THE DATA AND ANALYSES IN THIS DOCUMENT ARE FIT FOR PURPOSE, AND I BELIEVE THE INAPPROPRIATE AND MISLEADING ANALYSES WILL BIAS THE RESULTS.</p> <p>*I AM ALSO DISAPPOINTED THAT, IN ADDITION TO INACCURATE STATEMENTS BY MINISTERS, THE WIDELY INACCURATE REPORTING IN SEVERAL PAPERS, SUCH AS THE DAILY MAIL HAVE NOT BEEN OFFICIALLY CHALLENGED. HOW CAN YOU HAVE AN UNBIASED CONSULTATION IN SUCH AN ATMOSPHERE?</p> <p>*ON THE SPECIFIC QUESTIONS</p> <p>*Q1 FAILURE TO IMPLEMENT THE EU DISABILITY LEGISLATION ON ACCESSIBILITY. AND THE WIDESPREAD ENCOURAGEMENT OF DISABILITY HATE CRIMES OVER THE LAST FEW MONTHS.</p> <p>*Q2 A CIVILISED SOCIETY SHOULD NOT BE MAKING STATEMENTS THAT IT CANNOT AFFORD TO SUPPORT PEOPLE WHO HAVE GREATER NEEDS OR MAKING THE INNOCENT PAY FOR CORPORATE FAILURES. MOST OF THE PROPOSED CHANGES SEEM TO BE ABOUT TRYING JUSTIFY CUTTING SUPPORT FOR DISABLED PEOPLE NOT IMPROVING THE SYSTEM.</p> <p>*Q3 – A NAÏVE QUESTION. COSTS VARY SO MUCH DEPENDING ON THE DISABILITY, EG MENTAL HEALTH VS MS. I DON'T BELIEVE IT IS COST EFFECTIVE TO TRY TO COST OUT INDIVIDUAL NEEDS; THE CURRENT GROUPING IS A SUITABLE COMPROMISE.</p> <p>*Q4, WHAT IS THE BASIS FOR THE NEW GROUPS? WHAT RESEARCH SUPPORTS THESE?</p> <p>*Q5 IT WOULD LEAD TO EXTRA UNNEEDED COSTS ON ADMINISTRATION TO COST EACH APPLICANT. TAKING MONEY FROM DISABLED PEOPLE TO PAY FOR EXTRA ADMINISTRATIVE COSTS IS NOT ACCEPTABLE. SOME HEALTH CONDITIONS WILL OBVIOUSLY NOT IMPROVE.</p> <p>*Q6 !!</p> <p>*Q7 AND Q10 RELY MORE ON EVIDENCE PROVIDED BY THE CLAIMANTS' OWN DOCTORS. (I SCORED ZERO ON THE IMPACT OF MY ASTHMA BECAUSE I WASN'T HAVING AN ASTHMA ATTACK DURING THE ATOS ASSESSMENT.)</p> <p>*Q8 AND Q16 WHO PAYS FOR THE ADAPTATIONS? MAINTENANCE? REPLACEMENTS? DON'T MOST OF US BUY THEM OURSELVES?</p> <p>*Q14 HOW TO DEAL WITH ATOS, AND HOW TO MAKE AN EFFECTIVE COMPLAINT.</p> <p>*Q19 THIS WOULD HAVE A SERIOUS IMPACT ON BOTH FINANCES AND HEALTH. MANY DISABLED PEOPLE ONLY HAVE A LIMITED AMOUNT OF ENERGY TO DEAL WITH LIFE, AND THE MORE THEY HAVE TO DO WITH ADMINISTRATIVE MATTERS, THE LESS LIKELY THEY ARE TO HAVE ANY DECENT QUALITY OF LIFE.</p>

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EM769	18/02/2011	<p>Please find attached my submission to the DLA Reform Open Consultation - feel free to contact me (via this e-mail address) if there are technical issues, if any further information should be required, or similar. I would also like to take the opportunity to offer my very sincere thanks to those involved for giving people this opportunity to contribute to the proposed reform.*Regards</p> <p>*1. In my own case, the context and content of the vast majority of typical social interaction itself is inappropriate to my abilities.</p> <p>*This essential difference is problematic only in that, rather than being acknowledged and accepted so that reasonable adjustments can be made, it remains unrecognised – the natural result of which is my unintentional exclusion.</p> <p>*This being the case, it acts a barrier preventing me from participation in any real sense, to the extent that I am unable to achieve the independence which is a necessary foundation towards living a full and active life.</p> <p>*3. Identifying 'extra' costs in my own situation is difficult as – surviving on incapacity benefits and the charity of my immediate family, combined with the exclusion mentioned above – I am so inactive socially that I have virtually no out-goings.</p> <p>*4. I fail to understand the logic regarding why people, their disabling impairments, or the circumstances that result from these necessarily naturally fall into these categories – and so I can only assume that they have been created for the convenient designation of pre-determined amounts of support by default.</p> <p>*While the notion has already been discounted, it would perhaps actually be easier to administer a benefit that didn't attempt to mechanistically impose such categorisation upon its applicants, and which instead responded in a more direct – and less impersonal – fashion to the disabled and their needs.</p> <p>*An additional advantage would be that such a benefit, being tailored to each individual claimant, would also be more effective in terms of ensuring appropriate levels of support were provided.</p> <p>*6. Comprehensive personal assessments are the only satisfactory way to accurately prioritise support, as the pre-requisite clear picture of needs can only realistically be accomplished through fully-rounded examination of the disabled, their behaviour, and the resultant circumstances – in specific relation to any and all impairments.</p> <p>*The reason that the current process is, apparently, inadequate – both in terms of assessing the needs of the disabled, and also in terms of allowing the authorities to prioritise these accordingly – is due to the 'fragmentation' which occurs from attempting to gain understanding of these needs by requesting information through a series of set questions, inevitably limited to specific areas only.</p> <p>*Such fragmentation is inherent to this format of data collection,</p>

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		<p>and will happen no matter how many more sections are added, no matter how much detail these sections require, and with the further result that the claim form – which has already been acknowledged as laborious to fill out, and unwieldy to process – becomes increasingly further overlong.</p> <p>*It is not surprising that assessors and other professionals struggle to achieve satisfactory prioritisation of support, as they are given the virtually impossible task of ‘putting these pieces back together’ to try and create a full impression of a human being, complete with associated lifestyle, before they can even begin to compare these impressions.</p> <p>*The alternative is being forced to regard impairments in an isolated fashion, and so to attempt to process ‘needs’ as an abstract notion, detached from the concrete reality of a life – the fact that various special needs do not manifest in substantial enough extent to be adequately considered in this form is what has resulted in them remaining unaddressed.</p> <p>*In contrast, personal assessment would allow a dialogue to form between claimant and assessor which can shift focus accordingly, ensuring that the claimant can adequately convey their needs, within the context of their daily existence, while also actually reducing the resultant workload when it comes to the unenviable task of assimilating this information in-order to define priorities.</p> <p>*In terms of ‘essential’ activities, there is obviously a ‘base-line’ of necessity, which, if an individuals impairments impinge upon, must be addressed purely out of an obligation of social responsibility – their ability to survive at an acceptable level, ultimately, regarding factors such as diet, clothing and accommodation.</p> <p>*But this area naturally overlaps with other services and provision (such as Income Support, for example) with no sound reason why such provision should be entirely separate specifically for the disadvantaged – though their potential difficulties in accessing it should be acknowledged and responded to.</p> <p>*There is also the further fact that the majority of our society exists above this base-line of ‘survival’, and while not every disability necessarily will impinge upon it, this doesn’t negate the fact that people with such conditions remain fundamentally disadvantaged.</p> <p>*It contradicts the essential principles of an equal society, with equal opportunities for all, that there should be lowered expectations regarding the potential living standards of the disabled, directly as a result of their natural disadvantages in terms of operating within such a society.</p> <p>*Yet that is the inevitable result of prioritising only the ‘least able’ disabled – this narrowing of the overall focus of support means that the needs of the ‘more able’ disabled – who, by definition, are not ‘fully able’, by whatever means this is</p>

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		<p>assessed – become unacceptably neglected.</p> <p>*By contrast, if a distinct ‘stream’ of services was available for the disadvantaged – directly comparable to those on offer to the ‘fully able’ majority (and presumably interlocking with these) but designed in-order to provide access as appropriate to each individuals specific abilities, which they can then choose to access as they see fit – this could fulfil the obligation of providing equal opportunities.</p> <p>*This would negate the need for scrutinising the disabled in-order to definitively specify whether they should be regarded as an individual who is categorically ‘less’ or ‘more’ able – and would instead allow such individuals to be treated as having a specific composition of abilities and inabilities in relation to any and all impairments, which can then be addressed appropriately.</p> <p>*It would also have the added benefit (a rather substantial one in my opinion) of affording disabled people a chance to define for themselves what activities (beyond simply surviving) are ‘most essential’ to their everyday lives – rather than discovering that others have already made this decision for them.</p> <p>*(This can also be taken as a response to Question 11)</p> <p>*7. Sustained contact with the individual would better ensure appropriately accounting for variable and fluctuating conditions than the more irregular process of repeatedly filling out claim forms in-order to reapply for support at infrequent intervals – as is currently in place.</p> <p>*Such ‘continuous assessment’ might be best achieved through face-to-face or phone contact in many cases, and also naturally suggests it could be beneficial developing an on-going connection with a specific individual (i.e. from the DWP).</p> <p>*(This can also be taken as a response to Questions 12 & 13)</p> <p>*9. While it has been acknowledged that the current claim form is extremely substantial, it still fails to offer adequate opportunity for effectively conveying certain recognised impairments, or the impact they can have upon personal circumstances and individual abilities.</p> <p>*Obviously simply giving people a ‘blank sheet’ to fill in about their condition and life is not a solution, but I’m not sure that the extra effort – on both sides of the equation – of forcing people to fill out details which aren’t necessarily of relevance is helpful either.</p> <p>*Perhaps a more ‘open-ended’ claim form could exist, but be implemented only as the initial part of an application – so that an appropriate assessment process could then be established in direct response to this, involving further selected forms, interviews, specialist consultations and so on.</p> <p>*The nature of this form – of giving the disabled a chance to outline the difficulties that they face from their perspective, before having to complete an entire application that conforms to the full range of governmental criteria involved to even be</p>

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		<p>considered (as is currently the case) – would mean that it would naturally be a more ‘inviting’ proposal, and so a greater number of ‘tentative’ claims may be made.</p> <p>*If the appropriate material were readily available for distribution (or similar), then these tentative applications could be responded to with more detailed information specifically targeting the relevant areas in regards to what benefits are available, the process through which individuals are deemed eligible for these and so-on.</p> <p>*(This can also be taken as a response to Questions 14 & 15)</p> <p>*19. If Personal Independence Payment were isolated from other services then potential recipients would be more likely to regard it as a stand-alone form of fiscal ‘compensation’ for a perceived inferiority.</p> <p>*The more that Personal Independence Payment can interlock with other services and related benefits the more likely it is to be regarded as an acknowledgement of disadvantages which potentially impinge upon personal functioning – and which invariably negate equal access to opportunities for self-development and social contribution – combined with a coordinated effort to overcome these.</p> <p>*22. I was hoping that having responded, to the best of my ability, to questions raised in regards Disability Living Allowance and the issues being encountered with specific relation to reforming this benefit, I could be afforded a chance to have my experiences as a claimant taken into consideration.</p> <p>*I can appreciate that, for those reading these submissions, time is undoubtedly a particularly precious commodity and so I will attempt to be as succinct as possible – I hope that this I not inferred as an attempt at being overly brisk.</p> <p>*My experiences of DLA were that my needs as an individual diagnosed with what is, as I understand it, a recognised disabling condition (Asperger Syndrome) were not adequately addressed, as my impairments as a result of this condition were discounted as negligible.</p> <p>*While this is a potentially reasonable conclusion, in my case I feel that it was reached through my claims regarding these impairments being refuted, by having evidence presented that substantiated these claims rejected, and with significant contributions from carers – both relevant specialists and immediate family members – being refused.</p> <p>*Further to this, appropriate medical submissions were discredited, misinterpreted and inaccurately weighted, all with the apparent intent to refuse the truth about how my impairments affect me – and so contribute towards defining my ability and resultant circumstances – when, I feel, this is rather glaringly obvious from any other perspective.</p> <p>*It is also my opinion that I was, at times, condescendingly accused – if only implicitly – of a number of the above, although I should probably mention here that my claim was, eventually, a</p>

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		<p>successfully claim.</p> <p>*Achieving this success occurred, however, after a protracted series of appeals, with multiple tribunal hearings being heard before those concerned found that they were in the position where they were forced to admit, finally, that I do indeed have special needs as a result of the impairments associated with my disabling condition.</p> <p>*So while it was a successful claim, I would like the appropriate authorities to consider that this was through a process that made me feel consistently belittled regarding the difficulties that I encounter – to the extent that it felt as though I was being ridiculed for having presented them for scrutiny.</p> <p>*Rather than being seen as I am – a disadvantaged individual seeking to be enabled in terms of my personal development (and so, potential for social contribution) – I felt like I was being regarded with suspicion in regards my attempts to receive such assistance and support.</p> <p>*I mention the condescending nature of my encounters as this was enacted by an assessment process that, without wanting to be overly critical, or seem ‘hostile’, displays inaccuracies, contradictions and omissions (all of which is demonstrable through examining the relevant material) with the apparent aim of undermining my efforts to access appropriate support.</p> <p>* I also feel that my resultant award, perhaps unsurprisingly, isn’t entirely appropriate, but delving into that further issue here would unlikely be productive.</p> <p>*So it is hopefully understandable that, ultimately, I am left wondering if the entire process was actually worth it, overall, for me, personally – but also, and much more so, who else is being similarly let-down by the system, and how many of such people there are.</p> <p>*I doubt very much indeed that any of this occurred through the malicious intent of any of those involved, and I feel that its reason almost certainly lies in the out-dated assessment process, which is structured around – and places priority according to – the redundant stereotype of the disabled being limited to those with clear physical impairments.</p> <p>*While having a non-means-assessed benefit was undoubtedly established with the best of intentions, the fact is that administering this has shifted focus from regarding lifestyle and personal circumstances – inevitably inextricably linked with ability – onto impairments which are demonstrably evident in terms of an individual’s immediate inabilities in a very specific sense.</p> <p>*In terms of my own disability – as is evidenced if the acknowledged diagnostic procedure is examined – my impairments simply do not manifest under these conditions and so such simplistic scrutiny is plainly inadequate to assess my special needs.</p> <p>*In that sense, the Disability Living Allowance application</p>

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		<p>procedure as it currently exists is prejudiced, as it contains an inherent bias against an unknown quantity of the very group of people who it is intended to target, in-order to make support available for.</p> <p>*I'd also further add that the appeal process does little if anything to address this and in-fact, by focusing primarily upon a 'social' occurrence (the tribunal hearing), again, discriminates against those with impairments relating to social functioning.</p> <p>*As such, in effect, the entire DLA application procedure, rather than offering assistance with the difficulties that such individuals encounter with wider society, actually mirrors these disadvantages very directly and so – in contradiction of the government's stated intentions – the more severe the disabilities of such individuals are, the less likely they are to receive support.</p> <p>*I think that this is, to put it plainly, unfair, and while I didn't necessarily discern any specific mention of addressing such issues outlined in the reform proposal, I sincerely hope that those tasked with undertaking this reform will seriously consider that it offers the potential to remedy this bias, and so give individuals with social impairments (such as those associated with Autism Spectrum Conditions) the fair chance that they necessarily deserve, if we are to live in a society which can truly be deemed equal.</p>
EM770	18/02/2011	<p>Hi I think its a good idea to assess people more in light of their actual needs but without alienating people or making them feel like they won't be believed especially with mentally disabled people. It took 9 months for my boyfriends dla to come through and he was told it can't be backdated. we are fighting this but what are you going to do to make sure that doesn't happen. It says on your website that it will take 4 weeks, making our lives even more difficult. also as he is quite unwell i have to be with him for at least 20 hours of the day ensure his well being. of course some of those i am asleep however i awake at the least movement, but he ha only been given the middle rate of care and lower for mobility. i think this is really unfair and that you should make it mandatory that where there is a carer you speak to them to find out exactly where the needs are. He cannot go to the shops by himself, make food on his own and anxious about being with other people so he has to be accompanied at all times. mobility isn't just physical and that should be reflected in other benefits too like esa. on that form hardly anything was mentioned about mental disability just physical.</p> <p>*you say you will support people to work. but this means you actually have to find them somewhere to work where they will be accepted and actually get them the job that is permanent. my boyfriend has applied for many jobs and always mentioned his disability and the only one to employ him was someone who had done support work and wanted to give someone some help. why don't you give some kind of benefit to people who</p>

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		<p>employ people with disabilities to encourage them.</p> <p>*you say the world has changed but in reality it hasn't that much and the levels of care vary so much. in my own experience we had had some good care and some appalling care and that means he has not always got the help when he needs it. how are you going to ensure that what is supposed to happen does? especially when cutbacks are being made.</p> <p>*he has tried going back to work and was not supported enough and is now back on benefits. people don't want to live on the meagre wage but without the correct help its hard. he would have to get taxis to work because he can't drive to work and that is where it comes in useful or for trips shopping. its important for the money to be allocated to needy people but they must make sure they could actually cope without it. as you are lowering housing benefit as well it ill be even harder to survive.</p> <p>*i am currently off work myself for the last 4 months and i hate it. statutory sick pay is not enough to pay my bills and i am getting further and further in debt. i want to get back to work but all i am being given is ineffective nhs physio treatment and being told i will be permanently in pain and have this issue for the rest f my lie. fortunately my mother has got a new job and is paying for some osteopath treatment. its is already helping and i am already feeling some changes at least in my mood as i have been told that i won't be injured for life. what i have been told by the nhs is it will take another 6 months osteopaths say maybe 3. if you allow people to access all kinds of treatment through the nhs it will lead to less people being off sick. as it is in 10 weeks i will be having to apply for esa myself. it is so important to make sure people get access to treatment asap so it doesn't lead to long term health problems.</p>
EM771	18/02/2011	<p>1. The barriers that disable people within society vary with each person's impairment or impairments. The barriers for a blind person are different to a wheelchair user or to someone with chronic pain or crohn's disease. I think the DLA's separation into 'care' and 'mobility' components is a useful model when determining the barriers that may disable someone.</p> <p>*2. It's vital that disabled people who need DLA don't lose their payments or receive a cut in the amount they receive. DLA has the lowest level of fraud of any benefit, it helps keep disabled people living and working independently and contributing to society. It's important that those in care homes do not lose their mobility allowance, this gives them the independence to allow them to participate in their communities rather than permanently confining them to a home.</p> <p>*If DLA is cut people who are currently able to work with the aid of a PA and transportation costs could find themselves unable to work and ultimately unable to live independently. Taking disabled people out of the workforce will result in the disabled becoming a burden on society, giving them miserable lives and</p>

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		<p>costing the country more than the relatively small costs of DLA. Don't return us to the 1970s and 80s when most disabled people were institutionalised.</p> <p>*3. Mobility aids, assistive technology costs, PAs, transportation costs especially where public transport is inaccessible or impracticable (such as when there is no ability to wait in the street), time off work due to illness, the need for others to perform DIY, maintenance or even basic self care tasks, interpretation, purchasing books in accessible formats etc etc.</p> <p>*5. I think in some cases it's obvious that high level care and mobility will be required. If someone is deaf, blind, deaf-blind, paralysed etc there is no need for an assessment.</p> <p>*6. It's vital that everyone has the right to mobility, to get out and do things and be sociable, even if they're in a home.</p> <p>*People who require 24 hour assistance should have the highest level care component so they are never left with an incontinence pad rather than a carer.</p> <p>*7. If repeat assessments are on the table, permanent impairments such as blindness, deafness, amputation, congenital conditions etc should not need to be reassessed or reapplied for. The process of applying for DLA is highly stressful, upsetting and depressing. For people with impairments like PTSD, re-applying for DLA can be extremely stressful and trigger a relapse.</p> <p>*10. A diagnosis by a medical professional should be enough, especially in cases where illnesses or impairments are permanent or degenerative. If a deaf person has an audiogram that shows deafness there should be nothing more required.</p> <p>*11. As above, I don't think it's necessary to assess people who are blind or severely partially sighted. A diagnosis should be enough in most cases. Face-to-face discussion should be the exception and not the rule.</p> <p>*12. Yes, permanent or congenital conditions should not need to be reassessed. Degenerative conditions should be reassessed through the person's medical specialist or GP. PTSD, anxiety disorders etc should be reassessed by the person's own specialist and in a way that minimises negative impact on the person's health.</p> <p>*13. Encourage GPs or practise nurses to give friendly prompts to report changes of circumstances.</p> <p>*17. As receipt of DLA can be a condition of parents receiving Carers Allowance, it's vital that vulnerable children do not use their support on two fronts.</p> <p>*18. See above, parents and other carers gain access to Carers Allowance through DLA, it's important that no vulnerable people lose their support on two fronts should their entitlement be 'reformed' away. The same applies for blue badge parking etc.</p> <p>*19. Additional stress and time of applying separately for other entitlements. Additional stressful and upsetting assessments. The most vulnerable people will likely lose these services</p>

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		<p>unless they have strong personal advocates, not everyone is lucky enough to have these.</p> <p>*20. As many as possible.</p> <p>*22. Disability Living Allowance has the lowest level of fraud of any benefit, it's a vital aid to keeping disabled people contributing to society and leading independent lives. The costs of cutting the budget for DLA will be greater than any short term budget gains.</p> <p>*I personally recovered from fibromyalgia through graded exercise that was only possible due to mobility component DLA paying for taxis to the swimming pool. Due to my age and lack of NI payments I did not qualify for Incapacity Benefit so DLA was my only support. Without DLA I would have been unable to recover or get back into work. As soon as my pain and fatigue went into remission, I informed the DWP and went off DLA. I have numerous disabled friends who are active, sociable and vibrant members of society, holding jobs, paying taxes and contributing to the economy in part because of the support of DLA to remove barriers and put them on a level playing field with those lucky enough to not have their impairments.</p> <p>*It's vital that the budget pool for DLA payments is not reduced. Disabled people should receive no less benefit. Any cuts and reforms should be to simplify the bureaucracy and clerical errors. No one should lose their support and connected benefits as a result of these reforms. Do not hurt the most vulnerable members of society.</p> <p>*Thank you for taking the time to read this response. [REDACTED]</p> <p>Software Developer and former Disability Living Allowance claimant</p>
EM772	18/02/2011	<p>1. (1)Lack of funds, DLA should not be withdrawn. It is the only benefit that attempts to equalise the circumstances of disabled people.</p> <p>*(2) A tax and benefit system that rewards the rich in hiding their assets and penalises disabled people by calling them scroungers</p> <p>*2. Your response: It should all stay the same.</p> <p>*3. Your response: Transport, Diet, Clothing, Washing, The Cost of advice and support in doing everyday things that non disabled people wouldn't even consider was a problem. A social life. Access to support.</p> <p>*4. Having two rates will double the scope of making mistakes. The idea that having two levels for each component will make things easier is so grossly misleading it looks as though the new benefit is being made almost impossible to negotiate so as to mystify most claimants and cause less take up by the complexity of the form.. It looks like a total put up job.</p> <p>*The DLA forms are already between 30 and 60 pages long and the stress of completing them has affected my health in the past. This looks like a method of making it so hard to complete that a good proportion of disabled people will fall at the first</p>

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		<p>hurdle. Most disabled people have, through bitter experience, learned that the state has no real interest in providing a decent and comprehensible method of providing for their needs. Having multiple levels is simply another way the state has decided to act in a punitive way to disabled people.</p> <p>*5. Individual Assessment appears to be fair but what it actually means is no one can compare their level of benefit with anyone else's. No one is telling me that isn't the underlying intention. It means that arbitrary and unfair criteria will be devised to minimise provision. It is so transparent as to be insulting.</p> <p>*6. This question is so full of undefined terms as to be virtually meaningless. What you are hoping to illicit is a not very comprehensive list of needs that you can then say 'disabled people want these' the unspoken additional phrase is 'and only these'.</p> <p>*You are hoping to reduce the concept of 'essential' to the most basic requirements. Quality of Life and Social Integration are being edited out to produce a very stunted provision that you can then claim is 'what disabled people want'.</p> <p>*7. What you really mean here is how can we justify calling disabled people to round after round of 'Assessments' All of which will have in them booby traps designed to minimise and refuse benefit.</p> <p>*The way you ensure that the system takes into account fluctuating conditions is for you to gain the trust and confidence of disabled people. So they know that they are not going to be forced into catastrophic situations by being expected to perform beyond their ability. Let me say you have a long way to go before you convince a good proportion of us that your intentions are honest.</p> <p>*8. Obviously it is impossible for me to give, with any hope of being comprehensive, a list of aids and adaptations.</p> <p>*The short answer is everything that makes someone's life independent and worthwhile.</p> <p>*The second part looks like a 'deeming' exercise. 'This person has been deemed to possess (a),(b) or(c) because they should have been able to get them from (a),(b) or (c). And so their benefit has been reduced accordingly.'</p> <p>*9. The gruelling and stressful nature of the exercise turns the stomach of anyone I have ever talked to about it.</p> <p>*The problem you have is that any new system does not have advisors that know with any certainty how to give applicants advice as to how to present their symptoms, problems of access, mental confusion or the plethora of factors that will be deemed important in assessment. At least with the present</p> <p>*30 to 60 pages of assessment I can go to an advisor I trust to present my condition in the correct way to accrue the points required to give me the help I need.</p> <p>*Let me say I would not trust anyone from the DWP to advise me on the new system. Through bitter experience I know that</p>

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		<p>officers will lie to trick applicants into booby traps.</p> <p>*You could make the forms easier to filling by making available independent advisors to help applicants. But as The Citizens Advice Bureau funding is being cut and massive shedding of their staff is foreseen, where am I to go for independent advice?</p> <p>*10. The present system has 2 or 3 referees that can substantiate the statements of the applicant. In my case my Psychologist and CPN were referees. Am I to understand that now a range of proofs will be demanded?</p> <p>*Even more hoops to create stumbling blocks to provide booby traps for applicants to be denied benefit. For instance, when I asked for the records, made by my first CPN, to be made available for an assessment at the Maudsley Hospital I was told that none could be found. This was either because they had been lost or were never made in the first place. I could never find out which. I can see this being used by you to deny me benefit in much the same way as if I lose the original DWP notifications and can't provide the originals I will be refused housing benefit.</p> <p>*No one is telling me that the requirement for proof will not be used in the same way to deny this benefit as it is presently used to deny housing benefit..</p> <p>*11. What is your definition of a health care professional? Obviously not a doctor or you would have said 'doctor'.*It all depends on the honesty of the process. Unfortunately many disabled people have had the experience of being put before 'healthcare professionals' who weren't concerned with health and certainly didn't care and were employed solely to reduce uptake of benefit. *If the 'healthcare professional' in question is independent and has no axe to grind then it may be a good way of informing the process.</p> <p>*As in so many other instances with this 'consultation' you have a massive distrust to overcome.</p> <p>*I know for myself that the stress and anxiety of being summoned before a 'healthcare professional' has in the past precipitated deterioration in my mental health. I think at the very least a trusted companion should accompany anyone being grilled.</p> <p>*12. Obviously the criteria and frequency of reviews should not precipitate a catastrophic deterioration in the applicant. This is most important in mental health conditions. It also depends on the age of the person and the resources available to the DWP as to how frequently they can possibly get round all applicants.</p> <p>*It seems to be obvious that different conditions would need different schedules of review but it should not be used to target sections of recipients.</p> <p>*13. Unfortunately, because the benefits system has been so draconian in it's dumping of people off benefits, your organisation has an uphill struggle to convince disabled people of its honesty and good intent.</p>

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		<p>*I know people with mental health conditions summarily deprived of income and made homeless because their mental health condition made it impossible for them to comply with this or that condition.</p> <p>*Somehow I doubt that this government has any other intention than to throw many off benefit without thought or ethical regard.</p> <p>*14. As I said previously, independent and caring advice.. How could the DWP avoid bending the advice it gives to further it's perceived and stated agenda of reducing uptake if it included in house advice as part of the application process?</p> <p>*15. As previously stated an independent advisory service based on a caring and supportive attitude would be best.</p> <p>*You should avoid the historical viciousness of the DWP and its predecessors in treating anyone with the misfortune of having a disability as a scrounger even though it may benefit the politicians to use such calumnies and bullying tactics.</p> <p>*16. So long as it is not simply a tactic to rob Peter to pay Paul.</p> <p>*17. The quality of life of children is founded on play. They need to have provision to meet with and make relationships in peer groups not as 'icing on the cake' but as the cake itself.</p> <p>*18. As DLA has been specifically excluded from consideration for many other advantages a recognition of it as showing a level of need should be recognised.</p> <p>*19. It leads , as in the present situation of ghettoisation.</p> <p>*20. What different assessments for disability benefits or services could be Your response:</p> <p>*This appears to be the thin end of the wedge in privacy issues. Why does the state have to know everything about everybody?</p> <p>*21. Page 28 of what?</p> <p>*22. Why has it taken a posting on Facebook to make me aware that a consultation exercise was happening?</p> <p>*I'm not stupid and I listen to the radio and read the papers. It is the last possible time I can respond and I would have liked to have looked at the consultation in more depth and responded better.</p> <p>*Was it beyond the wit of man to send a letter to all DLA recipients to respond to the consultation?</p> <p>*I have the gravest doubts about what is being planned for the recipients of DLA.</p> <p>*I think you have already made up your minds who you want to target and this 'consultation' is nothing more than box ticking.</p> <p>*Prove me wrong. I would be very glad if you did.</p>
EM773	18/02/2011	<p>I am a 40-year old, single woman living in sheltered accommodation with a Registered Assistance Dog. I have two neurological conditions causing peripheral nerve damage and have been disabled since 1998. Symptom-wise it's like living with MS. Currently I receive Just indefinite DLA awards of Higher Rate Mobility and Higher Rate Care.</p> <p>*1. at the moment one of the biggest problems is public hostility fed by government "cheats and scroungers" rhetoric used to</p>

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		<p>silence criticism of the desired spending cuts. It's difficult to participate in society and lead an independent, full and active life when you're looking over your shoulder constantly worried that people are sizing you up for abuse, threats, violence or simply disdain.</p> <p>*Maria Miller bare-facedly claimed this week that "50% of people receiving DLA have never been required to submit any independent evidence of their need." [Disability Benefit Reforms: Minister undeterred by campaigners anger – The Guardian. 16 February, 2011]. With that kind of 'official' rhetoric, it's difficult to believe that government isn't As deliberately encouraging these attitudes in order to stifle dissent.</p> <p>*2. it seems to be working perfectly well in my experience, I'd have to say everything.</p> <p>*Simplification not abolition –</p> <p>*Removing one level from the care allowance is hardly a major change to DLA's current working. You could achieve the same result simply by abolishing the lowest of the three current rates having seemingly decided that "too many people" now qualify for it.*Keep the name –</p> <p>*Is there any actual purpose in changing the name to Personal Independence Payment? The name Disability Living Allowance is a pretty accurate description of an allowance that pays for the additional costs of living when you have a disability.</p> <p>*Keep the benefit in cash, and untaxed –</p> <p>*We may not all have choice about where the money we live on comes from but we at least deserve the choice to allocate it towards the priorities WE decide are most important. For example, my DLA supports my social life by paying for a broadband connection to connect me to the internet whereas an elderly fellow-resident of my sheltered housing scheme might prefer to attend a luncheon club or pub quiz night.</p> <p>*Keep the 'care' and 'mobility' allowances –</p> <p>*These best describe the two main areas of functional impairment we face as disabled people even though our actual needs can be a complex interaction of the two. (It would be prohibitively expensive to 'personalise' DLA/PIP much further as each disabled person responds uniquely to identical injuries or illnesses).</p> <p>*No conditionality, no means-testing –</p> <p>*DLA is meant to pay towards the additional costs of having a disability and not be based upon engagement with the workforce. I will soon require a powerchair regardless of whether I'm ever able to work again or whether I can afford one and I will certainly benefit from one a long time before the NHS decides I have a 'medical need' for it. Restricting DLA/PIP to those in work (or even just the Mobility component, as happens in Australia) would be a significant barrier to entry to labour market entry – leading to a catch 22 situation where you need</p>

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		<p>an adaptation to apply for a job, but you can't afford the adaptation until you have a job (and it's not like we don't have plenty of those to surmount already).</p> <p>*Continue 'Independent medical assessments' –*For over a decade DLA applicants have potentially faced an 'independent medical assessment' from at least a qualified GP in the pay of the DWP or its subcontractors (I had one in 1998 when I first applied). So far these have proven well suited for purpose, evinced by a recognised fraud rate of less than 0.5% for DLA in the 2008/9 statistics. The original argument for introducing these interviews was that GPs were at risk of being bullied, coerced or otherwise placed under the influence of Patients, which risked undermining the independence of their professional opinion. In Switzerland the response was to 'step up' the doctor's certificate a level to require approval by a Consultant-grade medical specialist, in the UK it was decided that the opinion of a "fresh pair of eyes" at GP level was enough when they were being paid by the DWP. *However the Chancellor announced the introduction of an "objective" medical assessment in the 2010 Emergency Budget:</p> <p>*1.103 The Government will reform the Disability Living Allowance (DLA) to ensure support is targeted on those with the highest medical need. The Government will introduce the use of objective medical assessments for all DLA claimants from 2013-14 to ensure payments are only made for as long as a claimant needs them.</p> <p>*Is an assessment by an ATOS 'health professional' – as likely to be a Bulgarian midwife as a British GP – more objective than the current 'independent' assessment by a Doctor paid by the DWP? If so, how? Or is there an alternative DWP glossary somewhere that will explain what the precise difference in terminology is meant to communicate?</p> <p>*Step up the rate of assessments or make them compulsory if you wish, but you have yet to Having Care and Mobility establish that the current system is 'broken'.</p> <p>*3. needs which we are unable to provide for ourselves, hence the importance of DLA.</p> <p>*One of my biggest complex needs is housekeeping, which I can't do myself because of mobility problems from two neurological conditions, but this is not a 'care' need currently recognized by DLA (or by my local authority Social Care department either). Yet being able to cook is, despite being much simpler to achieve with the wide availability of ready-prepared foods and meals in the shops. Poor cleanliness in a home environment has been associated with ill health for several hundreds of years but it 'falls between the stools' in terms of what does and doesn't qualify as personal care which means I especially need to keep DLA payments in order to afford a cleaner as I don't have a family or partner who could do this for me.*My biggest simple need is mobility and achieving</p>

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		<p>this when I'm not legally permitted to drive, am virtually unable to walk but am not considered to have a 'medical need' for an NHS wheelchair yet. Currently DLA means I have been able to purchase a mobility scooter, and in another couple of years will be No, it won't. You may as well keep DLA as it able to afford a powerchair.</p> <p>*4. currently exists and abolish the lowest rate of care. It would be cheaper than a complete rebranding and more effective.</p> <p>*Having two rates per component is not in itself significant, what matters is what functions the descriptors for those rates include – particularly where the boundaries for eligibility are drawn – and how you aim to distribute qualifying cases. Your aim might be a median 50/50 division of those who qualify, or a 20/80 division into first and second-class eligibility (closer to what happens currently with ESA Yes allocation into Support and Work groups). This should be made clear.</p> <p>*5. there should be automatic entitlement to the benefit otherwise your assessment costs become unreasonable. You can have automatic overall eligibility determined by a table of the most commonly, diagnosed disabilities of a severity likely to require support – this is what happens for the Australian Disability Pension and could be backed up with a variation of the Swiss model requiring medical certification by the claimants NHS By preventing the DLA mobility component being withdrawn from Consultant.</p> <p>*6. people living in Residential Care.</p> <p>*These are neither hospitals nor warehouses, they are residential environments for people with severe personal care needs - by most estimations those “least able to live full and active lives” but most likely to still be trying and being encouraged to do so.</p> <p>*DLA underwrites INDIVIDUAL mobility needs. The argument that this is duplicated by the group-based provision undertaken by local authorities or individual care homes is an utter fallacy. A care home might pay for a wheelchair accessible bus to take residents on group outings once a week, but how do the residents afford the wheelchairs to go in it without DLA?</p> <p>*Even worse was the choice to remove this ONLY from those in publicly-funded care places. Those whose income/assets mean they are MORE able to live full and active lives by offsetting the additional costs of disability would have kept their mobility By having eligibility determined allowance. That's really unfair.</p> <p>*7. automatically by diagnosis but having the level determined by an annual review of status based on a report by that person's GP and signed off by their NHS Consultant. This would simply require a variation on the old IB50 Yes. The forms that were once required for Incapacity Benefit each year.</p> <p>*8. assessment should only take account of aids and adaptations the person currently owns AND that do not involve any moving parts or technology that require maintenance. For</p>

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		<p>example a walking stick or crutch (as these will be provided by the NHS) would be taken into account but not an 'imaginary' wheelchair which might or might not be provided, theoretically available, suitable, affordable or presently in working order. Use of a non-jointed prosthetic could be taken into account but not reliance on a jointed/motorized one that might spend weeks awaiting .? account into take only assessment the Should specialist repair.</p> <p>*• Only aids/adaptations already owned. It is not fair to strand disabled people with unmet needs because some other agency or group "ought" to be providing them with help or equipment but aren't, due to funding or supply issues or eligibility criteria that may vary between local authorities, levels of government or charitable interest. (Maria Miller's suggestion that the Adult Social Care departments of local authorities should to pick up the slack in terms of personal care after the closure of the Independent Living Fund is a case in point. Yes they ought to, Pay specialist social workers to visit the claimant's but will they?)</p> <p>*9. home with forms, announcing that "I'm from the government and I'm here to help you..."</p> <p>*No..?*Alternatively, make it an entirely NHS process with Consultants as benefit 'gatekeepers' in the Swiss manner. Use the existing internationally recognized 'functional scales' for various disorders which are used diagnostically and require a certificate from the specialist confirming that Patient A, has a diagnosis of/may be suffering from Impairment B, at function level C. DWP decision makers would then have 'logarithmic' tables of what benefit this would mean the claimant was eligible for on a condition by condition basis and claimants could have access to an online facility to calculate their own eligibility based on the NHS certificate details prior to lodging a formal claim.</p> <p>*As the plan is to restrict PIP to people who have recognized disabilities or chronic conditions that have lasted for six months or more the vast majority will have already have a consultant and in many longstanding cases, a clear diagnosis. Few patients will see a consultant often enough to be able to 'influence' their professional independence in any meaningful way. The drawback is that a) variability would only be accounted for annually and b) less account would be taken of the cumulative effect of There is no single set of supporting evidence or multiple disorders.</p> <p>*10. even source that will achieve this. Disability is complex and individuals can respond completely differently to identical therapies, adaptations or medications even when superficially experiencing the same disability or illness at a similar level. Both ability and inability may or may not be repeatable depending on the time frame, number of repetitions or variability of the condition/s (as is acknowledged in the ESA</p>

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		<p>rules).</p> <p>*Fifteen-minutes of observation by a complete stranger with mostly irrelevant medical experience and training usually below GP standard as per the Work Capability Test for ESA is probably the least accurate 'evidence' that can provide a clear assessment of ability. This is followed closely by furtive surveillance based on video clips shorter than 20 minutes duration taken on less than 21 consecutive days.*Disabled people themselves are best placed to provide a clear assessment of their own ability. "Supporting Evidence" is better used to prove testable variations of function from medical 'norms' – essentially, disability. For example, with my latest DLA application I was able to provide copies of nerve conduction tests that prove there is nerve damage in my forearms. My actual functional abilities, manual dexterity in particular, depend on how bad the tremor symptom caused by this underlying nerve damage gets. This is one area where it is actually easier to 'prove' a negative.</p> <p>*There is no single "objective" source. A GP is most likely to see a patient regularly enough to make a reasonable approximation of ability but will also have their opinion suspect on the grounds that the patient may be influencing them. Claimants may be financially incentivised to overstate their case, ATOS assessors may be financially incentivised to understate it. Parents may be incentivised to understate a child's disability in order to keep them in a mainstream school, while his or her teachers may be incentivised to overstate the same child's disability in order to obtain Please refer to the Citizen's Advice Bureau report NOT extra funding.</p> <p>*11. WORKING, based on the implementation of the Work Capability Assessment for ESA which is also based on face-to-face "discussions" (a LiMA software quiz) conducted by "healthcare professionals" (seldom even qualified GPs) employed by ATOS who ignore any supporting medical evidence you provide.</p> <p>*As pointed out earlier, DLA has had a perfectly functional system of "independent medical assessments" for over ten years, where actual doctors visit your home and give you a proper medical, having full sight of the medical documentation from your own GP, Consultant and/or NHS specialist staff (eg. occupational therapists etc). Other than making these assessments compulsory there seems little that can be changed for the better.</p> <p>*I also foresee a massive cost issue. The DWP has already announced that it will be putting every single person currently receiving Incapacity Benefit through the WCA as they migrate to its replacement ESA. Currently 1.25 million people receive both Incapacity Benefit AND Disability Living Allowance, which means each of these people face being medically re-assessed TWICE! This can't save more money than it ...?</p>

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		<p>circumstances any there costs, surely?</p> <p>*• Are Where an NHS Consultant confirms the claimant is terminally ill (not necessarily within 6 months of death, just diagnosed terminally ill) or where the claimant is an in-patient in hospital. Or gaol. Or where the individual has a diagnosed and permanent condition that is unlikely to ever improve (nerve damage, tetraplegia, severe genetic/intellectual disabilities etc.) or only likely to worsen and they're already receiving the highest possible award. Otherwise an actual doctor, not necessarily your own, should visit your own home as was historically done for DLA (I understand that more centralized ATOS testing centres are used Everyone should be asked to complete an annual "change of now).</p> <p>*12. circumstances" form similar to the old IB50 but certified by their NHS Consultant, even if that means a certain number of "yes I AM still paralysed from the neck down, thank you for asking" replies. Actual reviews involving medical assessments could be automatically triggered by consecutive changes over two years (in one direction – getting either better or worse) or above two function levels in a single year as well as a sample set chosen entirely Only that the functions tested at random for quality control purposes.</p> <p>*• I seriously doubt that it will be be those relevant to the diagnosis.</p> <p>*13. easier to understand, but as previously suggested, people can be encouraged to report changes in circumstances by sending out an annual "change of circumstances" reminder (like the old IB50) to be signed off by their NHS Based on the experience of those who've been applying for Consultant.</p> <p>*14. ESA, the phone numbers of a) the Samaritans and/or Dignitas b) a welfare rights advisor and c) local solicitors who offer pro bono work in the Administrative Law area now that Legal Aid funding has been withdrawn from No. There should be no benefits matters would all be of practical use.</p> <p>*15. Disabled people conditionality attached to the benefit at any stage.</p> <p>*16. currently fund their aids and adaptations through a mixture of NHS/local authority provision (where choice is extremely limited and budgets even more so), personal savings and more normally, Disability Living Allowance. PIP should be kept as an entirely cash-based benefit that the disabled person can allocate entirely as they see fit, whether that's financing a large one-off cost or regular living expenses. The only people for whom this would not be the case would be those incapable of handling their own financial affairs who would have a financial guardian appointed through the usual legal channels. It might be worth the government considering whether addiction-based substance abusers should be similarly considered 'financially incapable' but Their needs change a lot faster that is a wider issue than PIP policy.</p>

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		<p>*17. DLA has been extremely useful at providing access than those of adults.</p> <p>*18. to other services. It is a useful shorthand to establish levels of need when applying for Social Care support from local authorities and means the DWP doesn't have to reproduce the cost of medical re-testing for every single disability-related benefit or pass, every time your condition changes slightly. Somehow it seems more fair for eligibility to be determined 'top-down' in this manner than 'bottom-up' as seems to be happening with the use of WCA results (often contested and under appeal) being used to They would be stuck in an endless immediately withdraw DLA awards.</p> <p>*19. circuit of testing and retesting which would benefit no-one but the private firms awarded the government contracts and most likely collapse the entire The DWP DWP (a bit like student loans) and a good chunk of the NHS.</p> <p>*20. seems to already be 'sharing' information about disabled people – between the Disability & Carers service and wider DWP (with contested WCA findings used to cancel existing DLA awards), even apparently between ATOS and the Tribunals service for 'pre-appeal' case reviews (which is technically illegal). Bureaucracy can only be 'minimised' at the cost of my privacy, so I'm willing to live with a little red tape and duplication in order to Please consider preserve my private medical information, thanks.</p> <p>*21. functional needs as well as medical ones. In the next couple of years when my mobility scooter wears out I will use my DLA to purchase my first powerchair. It will be an indoor/outdoor model most suitable to fit inside my home, retain independent ability to access shops, the new ability to access public transport (which my mobility scooter is too large for) and exercise myself at the local swimming pool and my Assistance Dog at the local park. I'm hoping I can eventually return to full-time degree study and eventually work, regardless of whether that's actually being realistic.</p> <p>*The NHS would only provide an indoor/outdoor powerchair after they'd issued an indoor-only one for twelve months. Not surprisingly, I'd rather not spend an extra year needlessly housebound or take a year off mid-degree while I wait for my "medical" need to catch up to my need to actually have a life.</p> <p>*George Osborne may have meant "highest medical need" as an empty rhetorical device (a bit like IDS's "protecting THE MOST vulnerable", ordinary vulnerability no longer being sufficient presumably) but it has a very specific meaning.</p> <p>*So please ALSO define your terms clearly in order to reduce the opportunity for misunderstanding and accusations of 'spin'.</p> <p>*For example, how does an existing 'independent' medical assessment differ from the proposed 'objective' medical assessment precisely?</p> <p>*Is the proposed name change an indication that plans already</p>

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		<p>exist to restrict the uses to which this benefit can be put so that only a Motability wheelchair useable by the individual can be purchased for example, rather than a Motability car which might benefit the entire family of which the disabled person is a member?</p> <p>*When Maria Miller claimed in The Guardian that half of those on DLA haven't supplied "any independent evidence of their need" was she actually stating that that 50% of us provided no medical evidence from our NHS GPs/Consultants AT ALL, or that she simply doesn't consider evidence 'independent' unless it comes from an employee or They're unwise, unnecessary and prohibitively subcontractor of the DWP?</p> <p>*22. expensive, as well as being based on some pretty shoddy research.</p> <p>*For example, receiving DLA may well be associated with lower rates of employment, but that may have a lot more to do with it being 100% untaxed rather than having any mystic power to prevent people working. For those whose health conditions limit them to part-time hours at minimum wage there's little point working, especially as there are effective marginal tax-rates of up to 295.5% on other means-tested benefits payable at the same time as DLA, which is not effected by employment status at all. Thank you for your time. Regards, [REDACTED].</p>
EM774	18/02/2011	<p>1. Your response: Despite the wide spread changes since the DDA there are still many physical barriers to leading as independent a life as possible. These may be as simple as cars parking on pavements and refuse bins being left in the middle of pavements preventing safe passage for wheelchair users to a lack of accessible toilets that include a changing bench and hoist.</p> <p>*2. Your response:</p> <p>*3. Your response: From a financial point of view there is an added financial burden in respect of extra heating, washing of clothes and bedding, purchase of extra clothes (needing a number of changes a day), trips to the chemist to collect medicines, wheelchair adapted vehicle, specialist equipment, wheelchair (one provided by NHS too basic). In respect of children – one parent not being able to work.</p> <p>*4. Your response:</p> <p>*5. Your response: There is a danger that some unusual conditions or conditions that remain undiagnosed will be sidelined. If all claims are based on the needs of the individual a level playing field will be created</p> <p>*6. Your response: This is a very difficult question to answer as everyday life means different things to someone with PMLD and severe physical disabilities than it does to someone who is able bodied. Mobility is essential as is access to equipment and therapies to ensure physical health. For someone who needs 24 hour care, carers being available is vital.</p> <p>*7. Your response:</p>

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		<p>*8. Your response: Firstly, here is an assumption that aids and adaptations are easily available – this is not the case. Secondly, the use of a wheelchair does not equate with being able to walk, particularly of the person's disability means they cannot control it themselves and need a carer. A hoist does make a person's life 'normal'. The idea of taking into account aids and adaptations is fundamentally flawed and implies that these aids normalise a person's life. The result of such a change will be a two tiered system where those with physical disabilities will be seriously disadvantaged.</p> <p>*9. Your response: The current forms are difficult and depressing to fill in. They rely upon certain key phrases that not everyone is au fait with. In every section is it necessary to repeat information as it appears that the information is assessed by people who have no understanding of disability. There are some conditions that will either only get worse or will never get any better if there not a way that people could claim for life supported by the medical profession?</p> <p>*10. Your response: Medical professional</p> <p>*11. Your response: It is vital that any healthcare professional has a real understanding of disability and the effect thereof. Some conditions are rare or undiagnosed and they will need someone with an open mind to understand the implications of the condition on their everyday life</p> <p>*12. Your response:13. Your response:14. Your response:15. Your response:</p> <p>*16. Your response: If this isn't an increased payment, people with a physical disability will be seriously disadvantaged. Aids and adaptations do not take the place of being able to do something e.g. walk</p> <p>*17. Your response: Stop asking if the child will recover from conditions such as Down's Syndrome</p> <p>*18. Your response: It hasn't been useful, but could be if other agencies used it as a criteria</p> <p>*19. Your response:20. Your response:21. Your response:</p> <p>*22. Your response: People with PMLD, severe physical disabilities, complex medical needs and no communication are a very small group. For obvious reasons they don't have a large lobbying voice and there is the real chance of them getting forgotten. Their lives are completely different from most others, having a wheelchair and a hoist in no way equates to be able to walk, having a special bath and bath chair again does not equate to being able to have a bath independently. As a Society we cannot allow our most vulnerable people to be disadvantaged however much cuts are needed. I am deeply concerned about the affect of any changes relating to aids and adaptations on people with both physical and learning disabilities.</p>
EM775	18/02/2011	Hello There, Just a note to say that these are my personal observations and not a generic response from this Local

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		<p>Authority.</p> <p>*I had to finish in something of a hurry and have omitted some of the latter questions but I have completed those on which I have specific knowledge or opinions. Regards [REDACTED]</p> <p>*1. Many disabled people are unable to use standard public transport. They may need specialist vehicles and escorts to help them. Some disabled people also lack mental capacity and cannot manage any daily living tasks nor any financial arrangements.</p> <p>*2. No</p> <p>*3. Transport Cleaning Gardening Money Handling Shopping services Cooking Laundry Fuel</p> <p>*4. I think there should be two components for DLA (care) @ Severely Disabled And @ Exceptionally Severely Disabled</p> <p>*I think there should only be one rate of Mobility Allowance based upon whether a person can / cannot use public transport.</p> <p>*It is highly likely that a person so disabled would be able to use public transport and therefore I would make it an automatic payment to people on the highest rate of DLA (care) but assessed for those on the Lower rate.</p> <p>*I think that the benefit premiums that are aligned to DLA should also be reviewed.</p> <p>*Eg. Disability Premium for those in the Lower Group (currently £28)</p> <p>* Severe Disability Premium for those in the Higher Group (currently £53.65)</p> <p>* The enhanced disability rate of £13.65 should either be removed or simply added to the current higher rate.</p> <p>*At present, a person in receipt of the highest DLA care rate of £71.40</p> <p>*Is also entitled to all 3 disability premiums = + £28.00</p> <p>* + £53.65</p> <p>* + £13.65</p> <p>*Making a total additional weekly income of £166.70 compared to people who are not disabled and if they were also entitled to high mobility at £49.85 pw, their additional disability income would total £216.55. This, in addition to basic benefits of £65.45 per week plus Housing Benefit and Council Tax Benefit can make a disabled person considerably better off than many other people.</p> <p>*In terms of equity with older people there are also a number of issues:</p> <p>*1. Older people have a much higher basic income through MIG @ £132.60 rather than £65.45 for working age people.</p> <p>*2. Older people cannot claim DLA mobility once they have reached pension age but can claim Attendance Allowance at one of 2 rates which match the two higher DLA care rates.</p> <p>*3. However, people already in receipt of DLA care and DLA mobility do not lose it once they have reached pension age and so they can have both the enhanced MIG payments and SDP</p>

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		<p>and DLA care and mobility. *4. A non-disabled older person would receive MIG at £132.60</p> <p>*A disabled older person (previously disabled prior to 65) could possibly receive:</p> <p>*£132.60</p> <p>*£53.65</p> <p>* £71.40</p> <p>* £49.85</p> <p>*A total of £307.50 per week. I think this should be reviewed as an additional £174.90 for disability seems exceptionally generous.</p> <p>*5. I don't think eligibility should be automatic but I am very much in favour of having a simplified eligibility criteria that does not depend upon the discretion of local GP's. I think this is a very difficult thing to achieve. If the costs involved in the medicals outweigh the savings made in ensuring eligibility then maybe it would be better to have some automatic entitlements based upon certain pre-diagnosed medical conditions?</p> <p>*It may be appropriate to use specific doctors who deal with medicals for ESA etc. Joining up the two benefits would make for efficiencies with regard to the medical evidence?</p> <p>*6. Given that ASC departments within LA's are generally responsible for providing personal care, I would say that the most essential element of life is being able to get up, and out and about. Aside from walking aids and wheelchairs etc. people generally need appropriate transport. The motability scheme is good in this respect. Joining up needs assessments carried out by ASC professionals with potential benefit claims would seem an efficient option.</p> <p>*7. Again this is difficult to get right but in the main, I would advocate the simplest of systems eg. qualification for the benefit applies to a bad day scenario but reviews of benefit are more frequent (say annually) for fluctuating conditions. Another option, which is, I think, too complex, would be to have a "half-time" rate at half the value of the normal rate OR lower rate as opposed to higher rate.</p> <p>*8. Evidence for this could be administratively cumbersome. Given that payment will not generally be made until the person has had the condition for 6 months it is almost certain that they will have any relevant daily living equipment and minor adaptations by then. Equipment may have been provided by Health or social care and checking this could be inefficient?</p> <p>*9. It seems to me that the DWP need to know the medical status of the person in order to provide appropriate disability benefits. Adult social care financial assessment officers already work jointly with DWP in most areas to assist in maximising appropriate benefits and to apply the correct charges for any ASC services. Therefore if ASC staff assisted ALL applicants to claim they could verify the provision of equipment in the person's home whilst visiting and could have</p>

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		<p>shared data access with DWP to medical conditions and so could co-ordinate the full completion of the relevant forms on behalf of the claimant. Anything that joins up and saves the claimant having to go from pillar to post must be a good thing?</p> <p>*10. As above for question 9.</p> <p>*11. Where a person has already been able to go through medical assessments for other benefits, the same information should be used to determine any and all benefits that relate to disabilities. Where it is not possible for a person to go to the medical professional then a face-to-face meeting at their home will be inevitable.</p> <p>*12. Some lifetime conditions should have a longterm review date : say 10 years *Most other conditions should have a medium term review date: say 2 years</p> <p>*A few fluctuating conditions should have a short term review date: say 6 months</p> <p>*13. This is extremely difficult, especially for people who are ill or mentally incapacitated. I think you can only deal with this through review but you could pick up on other benefit reviews and make it a condition for any benefit that PIP details must be included on the review form simultaneously.</p> <p>*14. Your response:</p> <p>*15. Your response:</p> <p>*16. Many people receive all aids and adaptations under £1000 from the local authority or health authority free of charge (as is the law). Some people make their own arrangements for various reasons of choice but they are not required to. I don't see how the PIP would be relevant to this.. it is best left as it is.</p> <p>*17. Your response:</p> <p>*18. DLA is useful for passporting to other entitlements eg. Blue Badge and there maybe more useful applications for passporting.</p> <p>*19. More inefficient administration in determining eligibility another way, medical evidence etc. (which incurs a cost as GPs like to charge for this).</p> <p>*20. As above*21. Your response:*22. Your response:</p>
EM776	18/02/2011	<p>Please find attached my Disability Living Allowance reform consultation questions answered. As you will gather, I was very disappointed in the questions.</p> <p>*1. : Their disability, of course, and in the case of mental disability the inability of others to see any manifestly obvious disability.</p> <p>*2. : Should stay the same as what? Who compiled this questionnaire? I thought DLA was going. Did a committee agree that as the second question? On we go with little encouragement ...</p> <p>*3. : Additional expense relating to their situation and carers, whether family or professional.</p> <p>*4. : It is impossible to assess physical disability with the same criteria as mental disability. Levels of suffering and caring</p>

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		<p>requirement vary over a period, but there must be recognition and provision for the worst case scenario which occurs from time to time, often quite regularly.</p> <p>*5. : It would be impossible to assess every physically and mentally disabled person individually.</p> <p>*6. : It depends what you mean by everyday life. Someone who has recently become disabled after a very active life will have a different view of everyday life to someone who has known nothing but a wheelchair or daily epileptic fits.</p> <p>*7. : Employ the worst-case scenario.</p> <p>*8. : That question makes disabled people sound helpless. Won't most people be trying to come to terms with their disability as well as possible already?</p> <p>*9. : Keep everything simple and use worst-case scenarios as criteria.</p> <p>*10. : Supporting evidence firstly comes from a clinical diagnosis and secondly from the sufferer themselves.</p> <p>*11. : Given Government cutbacks, this is likely to be a rushed tickbox procedure by ill-equipped assessors, which will make it much harder for people who find it difficult to express themselves, particularly the mentally disabled, to convey the correct impression.</p> <p>*12. : Supporting evidence firstly comes from a clinical diagnosis and secondly from the sufferer themselves.</p> <p>*13. : Adapt the reporting procedure to whatever remaining ability they may have – or hope that a carer will oblige.</p> <p>*14. Your response: The assessing criteria should be transparent and national so that there are no postcode lottery type situations where one set of assessors has different criteria to others, depending on the facilities available or not in a certain postcode.</p> <p>*15. : At the clinical diagnosis stage the need for assessment should be flagged to all concerned.</p> <p>*16. : This wholly depends on the individual disability. A general answer is impossible.</p> <p>*17. : That their parents are likely to be involved in alleviating their disability and that just more time, TLC, has a value, a priceless, immeasurable value, which comes as a cost to not just the parent but other non-disabled children in the same family.</p> <p>*18. : 'Personal Independence' doesn't remotely have the same accurate descriptive signposting as 'Disability'. Why pretend the disabled are not disabled. Most of these questions start on that presumption. Everyone on earth would like "personal independence". It is a description that in no way indicates disability. *19. : Suffering would not be alleviated. That was really a dumb question!</p> <p>*20. : A one-stop-shop assessment of requirements as opposed to disability. One disabled person in a wheelchair might want to gaze at the stars through a telescope and find huge comfort</p>

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		<p>and reflection in that. An identically disabled person may want to participate in a wheelchair marathon. No two people are the same.</p> <p>*21. : There is a HUGE range of disabilities, mental and physical, and an equally huge range of requirements by the sufferers. No two people are the same.</p> <p>*22. : The questions in this survey are very discouraging. I would be astonished if a disabled person set them. There are so many questions that haven't been asked. What does it feel like to be disabled? Physical disability is generally recognisable, especially if the sufferer was able-bodied previously. Mental disability is a totally different ballgame, especially for those with mental conditions, whose very condition makes them think they haven't got a condition. I hope this funding is being met from a separate budget and not taken from the DLA pot. These questions don't begin to scratch the surface of the situation. Most disabled people, however much they or others may pretend it's a challenge or God's way of making them special, would rather NOT be disabled. They would rather have normal lives. Don't ever let the tickbox assessment deny that.</p>
EM777	18/02/2011	<p>1. Your response: The physical or mental disability, the ability to care for oneself and the financial resources support the disability. Also I note in all of your document you make no mention the mental effects of disability. many people who have a disability suffer from clinical depression and often the two go hand in hand, quite clearly this admission shows your lack of understanding of many disabled conditions! *2. Your response: Yes most of it you should just tidy it up and access those conditions from which people could recover and maybe access them more thoroughly initially.</p> <p>*3. Your response: Transport cost of specialised treatment that cannot be obtained on the NHS such as hydrotherapy, cost of care.</p> <p>*4. Your response: No. There are hundreds of different types of disability and levels thereof, two rates per component is far too inflexible and crude.</p> <p>*5. Your response: Absolutely please see my comments below. It is ridiculous that people who suffer an immediate disability or illness that is permanent would not get automatic qualification. And to postpone it 12 months in my opinion is scandalous!</p> <p>*6. Your response: First of all the basics food, heat, basic care and as much independence as possible. Then the ability to get out and meet people and participate in 'normal' life.</p> <p>*7. Your response: Separate the disability conditions that are not permanent from those that are and access the former properly and at regular stages.</p> <p>*8. Your response: No see my response below.</p> <p>*9. Your response: It was clear enough for me, but by using more experienced as well as disabled people to rewrite the forms would help. Also the use of real life examples as guides</p>

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		<p>to filling the forms would also help.</p> <p>*10. Your response: Your doctor or NHS consultants report.</p> <p>*11. Your response:</p> <p>*12. Your response:</p> <p>*13. Your response:</p> <p>*14. Your response:</p> <p>*15. Your response:</p> <p>*16. Your response:</p> <p>*17. Your response:</p> <p>*18. Your response: Yes make it clear what services are available in one source document and or website rather than it being fragmented.</p> <p>*19. Your response: Catastrophic, why would you want to do that apart from being deliberately obstructive. It is a again inefficient. One assessment should be enough to gauge what benefits someone qualifies for!</p> <p>*20. Your response: Obvious, all relevant information held by social services should be held together</p> <p>*21. Your response: Please spare me from the PC world. It should have none.</p> <p>*22. Your response: Firstly I would question you are genuine in actually wanting a response to your consultation, as I only found out about this by accident. If you really wanted disabled people's opinions why did you not post this out to all recipients of DLA? It seems to me you have publicised this process as little as possible.</p> <p>*In my opinion you reform of the DLA is simply nothing other than a thinly disguised move to think of any way to reduce the expenditure of the DWP. And is based on the endemic distrust of the conservative party to anybody who receives any benefit at all.</p> <p>*It is nothing to do with improving the protection of the vulnerable, because whatever the faults of DLA it achieves that now. All you have to do is weed out the ones who do not deserve it, which could be done with the existing DLA.</p> <p>*You say 'However, we need to ensure that the benefit reflects the needs of disabled people today, rather than in the 1990s'. Well please tell how fundamentally the needs for disabled people have changed from 1990 to 2011? They are basically the need for help in getting around and caring for oneself and the costs incurred from both. This statement clearly displays to me the views of someone who does not understand disability, and is no more than waffle!</p> <p>*Again you say 'Personal Independence Payment will also be a more dynamic benefit – it will take account of changes in individual circumstances and the impact of disabilities, as well as wider changes in society, such as social attitudes and equality legislation.' Again this is just more cuff! Pray tell me how social attitudes and equality legislation effects the amount I should receive in DLA or PIP? Frankly they have no effect on</p>

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		<p>my day to day problems or costs!</p> <p>*More twaddle 'we know that work is the best form of welfare for those who are able to do so. That's why I want as many disabled people as possible to benefit from employment – it is not acceptable for anyone to be trapped in a cycle of dependency. By giving people the right level of support through Personal Independence Payment, I hope that many more disabled people will be able to work and enjoy the advantages that an active working life can bring.' Now you have the nerve to patronise and lecture the disabled (I wonder if you are disabled yourself, so far from your opinions I find it hard to believe that you are?). Effectively when you say it is not acceptable to trapped in a life of dependency you are saying to most disabled people that their disability is not acceptable! Frankly the arrogance and ignorance of this statement beggars belief!</p> <p>*This consultation document seeks your views to inform our policy for reforming DLA and introducing a new objective assessment. No process that involves people judging others is ever objective, and how objective it is depends on the quality and relevant experience those people have in understanding disability, something I doubt you will be able to find enough off.</p> <p>*Executive Summary:</p> <p>*Disability Living Allowance (DLA) has become confusing and complex. The rising caseload and expenditure is unsustainable, the benefit is not well understood and there is no process to check that awards remain correct. Well it is not complex to me. and even if it is this may have something to do with the fact that disability is very complex and comes in a myriad of forms, something which you do not seem to have realised. I do partially agree with the last statement, but only in the cases of people who's condition it is possible will change. To reassess someone who has say lost their legs is frankly ludicrous since quite clearly their condition is not going to improve, are they going to start growing new legs! Take my condition I have nerve damage (caused by medical negligence when given radiotherapy) to my legs which has caused muscle wasting and which has been gradually been getting worse for the last 14 years. All experts have consistently said that there is no treatment and it will only get worse or stay as is. If I had to go for benefit assessments every few years I would not only see this as an insult and an imposition but it would also be a waste of time and therefore inefficient something you say you are trying to stop?</p> <p>*4. This is exactly the same as before so why change?</p> <p>*5. To ensure that support goes to those who face the greatest challenges, the benefit will only be available to people with a long-term health condition or impairment. Individuals will have to qualify for the benefit for a period of six months and be expected to continue to qualify for a further six months before</p>

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		<p>an award can be made.</p> <p>*This is frankly ridiculous. If you happen to have lost a limb or have any condition that your doctor has said is permanent and will only get worse why would you be expected to wait 12 months to get PIP. In very serious conditions you will most likely have lost your job and will faced immediately with extra costs and may have lost your income, in which case how can you in any sane world expect people to wait a year to qualify!?</p> <p>*6. Currently individuals on DLA with certain health conditions or impairments are automatically entitled to specific rates of the benefit without a full assessment. We propose that for Personal Independence Payment there are no automatic entitlements, other than the special rules for people who are terminally ill. Instead, each case will be looked at individually, considering the impact of the impairment or health condition, rather than basing the decision on the health condition or impairment. Again as with point 5 this is total rubbish and just shows again you have no understanding of the worst disabilities! How can you not give automatic qualification to a soldier who has had his or her limbs blown off in Afghanistan! Frankly I do not know what planet your are on but quite clearly it is not earth! Quite incredulous! Do I need to say more!</p> <p>*7.Key to the benefit will be an objective assessment of individual need, which we are developing in collaboration with a group of independent specialists in health, social care and disability, including disabled people. The new assessment will focus on an individual's ability to carry out a range of key activities necessary to everyday life. We will gather information from the individual, as well as healthcare and other professionals who work with and support them. We also believe that advice from an independent healthcare professional should be an important part of the new process. In most cases, we envisage that this will involve a face-to-face meeting with an independent healthcare professional, allowing an in-depth analysis of an individual's circumstances. As I have already when people are involved in judging others there is no objective process. As regards independent specialists I suspect they will be under qualified lacking in experience and not as well placed as your own healthcare professionals to judge whether you qualify for DLA or PIP. The opinion of your doctor should be the most important of all.</p> <p>*8. Successful use of aids and adaptations can increase an individual's ability to lead a full, active and independent life. We believe that Personal Independence Payment should take greater account of aids and adaptations. We are considering how best to take account of aids and adaptations in the assessment in a way that reflects how they are used and paid for. Well I do not agree. I use two 'foot off' carbon fibre leg braces which do help me. But they are freezing cold in winter so my feet are like a block of ice they are very tight in summer</p>

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		<p>because my legs swell, the velcro fasteners fall off in very hot weather because the glue melts making them effectively useless, and they are prone to breaking while you are wearing them again making them useless. Therefore you should not access somebody with an aid as you are assessing them in the very best scenario you must access them without it because that is their natural condition and how they are in the worst case.</p> <p>*9. To ensure that everyone continues to receive the correct amount of benefit, we plan to periodically review all awards. This is totally unnecessary for disabled who's condition is not going to improve, what you are effectively saying is we do not trust doctors opinions!</p> <p>*10. We want to make Personal Independence Payment a more active and enabling benefit and we are exploring ways to help individuals manage their health condition or impairment. For example, as part of the administration of the benefit we could signpost individuals to other support, or ensure they have the opportunity to discuss their health condition or impairment with an appropriate professional. Again unnecessary as you get this support as a normal course of events from your medical specialists. What you could do is stop the closure of hospital hydrotherapy pools and open many more across the country as this the one the best ways of helping people with many disabling conditions such as MS, strokes, most hip and leg disabilities, and many many more. The only one I can access is private it is the only treatment that helps me and it costs me approximately £4500 per year to use it. I have run out time.</p> <p>Kind Regards [REDACTED]</p>
EM778	18/02/2011	<p>1. Barriers include: Prejudice, Strong Medication that makes you drowsy and sleepy and unable to function correctly, Inability to complete given tasks in daily life and or work, less accepted than others in society an the work place, general lack of understanding of certain chronic diseases and illness's.</p> <p>*My previous place of work was a fast paced recruitment organisation and although they took me on knowing I had MS once started to have problems with work I face dall types of prejudice from line managers, work colleagues and other staff in general.</p> <p>*The reasonable adjustments required to my working schedule were not met in any means by my previous employer and even though they claimed to have researched my condition they still did not really seem to understand what effects relapsing with my condition had, had upon my life and my daily routine and what I could actually do on a daily basis.</p> <p>*Even when I worked in Recruitment I was told to not bother with those that had disabilities as its very hard to place anyone with "problems" as they called it. So what place do I or anyone with MS have on the cog of the wheel that is industry? None as they have no time for those that can not run as fast as the rest</p>

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		<p>of the pack.</p> <p>*2. I believe the "tier" system should stay the same reflective of that persons capability.</p> <p>*3. carers equipment housing modifications activities to help exercise with that particular illness or disease that is more specialist than every day activities or just even to use your local pool diet requirements transport clothing (increased amount due to excess bodily fluid problems) the list is endless.....*1. *2. *3. **4. This all depends on the qualifying terms of the components as long as they are clear this should pose no problem, but this is hardly likely to be the case.</p> <p>*5. I have MS and not one two days are the same for me, why is it so hard to make people see that my disease is so un-regimented, MS is a chronic disease of which the severity is already classed by medical professionals, why can the Government not adhere to that scale of things too???</p> <p>*6. Essential every day activities that are essential for everyday life for someone suffering from a chronic disease or illness are as follows:</p> <ul style="list-style-type: none"> *Getting up *Washing *dressing *feeding yourself *going to the toilet and wiping after the toilet *basic tidying <p>*so if that said person can not complete or needs help to complete these basic tasks ON A DAILY basis then that person should need to take priority but then again when you have MS some days you need more help than others this is the variations of MS which makes it very hard to manage.</p> <p>*7. Easy enough!!! you go by the medical recommendations that the medical profession have spent years and lifetimes putting together about our particular diseases. If you are told by the leading medical professional in the world that MS fluctuates and the sufferer can not plan any two days as the same then you have to accept that this is the case, even if that person has 2 good days a week that may also be met with 4 bad days a week, that is just how it is! Take it from the medical professionals that deal with our diseases and illnesses as to how you asses our fluctuating conditions.</p> <p>*8. no the assessment shouldn't as I do not need my aids on a daily basis so it does not give you a clear indication of my daily capabilities if you just go on what aids i use and do not use. It is not viable that I answer the sub sections of this question as i don't think this is a good way of assessing things.</p> <p>*9. The claim form repeated a lot of questions in different ways?? why not just have one question to cover that area of question save people writing or typing out the same thing over and over.</p> <p>*have a guideline of people of people who will definitely not be</p>

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		<p>included to save anyone having to fill out all of the paperwork in the first place</p> <p>*have them complete a small point scoring questionnaire before they do the whole thing and that questionnaire will decipher if they will qualify or not.</p> <p>*10. The supporting evidence will be the daily limitations, daily capabilities, drugs prescribed, medical records and physical problems for that individual as well as supporting evidence as clear evidence from their medical professionals that deal with them on a regular basis and those providing care to that individual also.</p> <p>*11. the benefits is that you are speaking to a human being and not a piece of paper! the difficulties is that medical professional will not be impartial and not have the specialist knowledge of your particular illness or disease. They will judge circumstances on that day only when for someone with MS you maybe having a reasonably good day compared to the next day or the next week.</p> <p>*A face to face meeting is not appropriate when the individual is too ill to attend a meeting or currently going through a very bad time with the given disease or illness. Could the board just not wait until that person is feeling better or having a better time dealing with having the disease or illness.</p> <p>*12. the evidence put together by our medical professionals should be used to ascertain the frequency that reviews should be made.*all that i would suggest is that the medical professional assessing us is a specialist within the field of the given disease. Seeing as MS faces a lot of differing opinions throughout the medical profession it is only fair that the given individual is met by someone totally understanding of the given or that persons given disease or illness.</p> <p>*13. This is not something i am going to proceed with answering as I have MS and typing all these responses is playing havoc with my hands, fingers and eyes !!! sorry</p> <p>*14. To have all the contact details for all of your medical professionals that deal with you at hand and any letters and any notes to back up their claims copied and ready to include.</p> <p>*15. This is not something i am going to proceed with answering as I have MS and typing all these responses is playing havoc with my hands, fingers and eyes !!! sorry</p> <p>*16. Family, Friends and Charitable organisations fund any additional aids and adaptations we may need.</p> <p>*17. This is not something i am going to proceed with answering as I have MS and typing all these responses is playing havoc with my hands, fingers and eyes !!! sorry</p> <p>*18. Yes you could tell us all about them when we first apply for things as I was unaware I was entitled to anything until I had been diagnosed for over 4 years, even then I had to struggle to find out everything for myself and look to</p> <p>*19. without that passport to other services that you qualify for</p>

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		<p>the implications could lead up to a 40 to 50% loss of other services and monies available to that person! Is each disabled person to live i poverty! Money worries and general stress have a terrible effect on most people with MS*it is very hard not to be emotive when writing the responses and details of these answers when i myself have MS and all of this will directly effect me in some way.</p> <p>*20. if you qualify for one area that is assessed and granted through the level of illness or disease that you suffer from then why would you not qualify for other areas too??? all the lack of communication between areas of benefits is so annoying and useless.....share it all for goodness sake there is no closed books when it comes to suffering from a chronic disease or illness!</p> <p>*21. The only impact I can see if those with MS are refused the new payment scheme that they will be left to struggle in the work place making themselves worse than when they were first diagnosed causing to relapse and life long disablement that may or may not recover and heal thus leading to a DLA style payment of the higher rate anyway.</p> <p>*22. I would just like the consultation process to keep clearly in its minds eye that MS is not a disease that is easily managed and manifests itself differently in every person that is diagnosed. To be blind to those facts should be illegal and a crime against everyone that has MS!</p>
EM779	18/02/2011	<p>Dear Sir / Madam, Please accept the attached document in response to the DLA consultation. Thank you for your time and consideration. Yours Sincerely,</p> <p>**1. Unfortunately, I feel that is a very involved question and would be necessary to perform a consultation on that issue alone. The scope of this consultation should be kept specific.</p> <p>*2. The current arrangements rely on report from a claimant's General Practitioner and any medical specialists. The option is open to the claimant to supplement this information with statements from other relevant people, for example carers. Common sense tells us that those with close involvement with a claimant will have a far better understanding than an independent medical professional who will not have a longitudinal exposure to the claimant, and hence will not have a historical experience on which to rely.</p> <p>*In light of this, it would seem prudent to ostensibly retain the current arrangements with any independent medical opinion being held secondary:</p> <p>*i. the DWP should seek a statement from the claimant's General Practitioner and any specialists treating the claimant;</p> <p>*the DWP may supplement this information with an independent medical assessment;*any information sought in ii. should not be used as a primary determinant of the claimant's condition as their exposure to the claimant will be inferior to that of the claimant's regular physicians;</p>

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		<p>*the information sought in ii. should be used to bridge the information obtained from the claimant's regular physicians into the context a decision maker can more readily utilise.</p> <p>*3. A. The existing provisions focus on two metrics as an estimate of additional costs incurred as compared to a person without a relevant disability: mobility costs and care costs.</p> <p>*The former – mobility costs – I would imagine still remains relevant. However, in my view the current arrangements are too restrictive. The current assessment focuses on the claimant's (in)ability to walk a set distance and whether the claimant would be able to walk or travel to a new area unaided.</p> <p>*These considerations are somewhat artificial and narrow. While it is obvious that someone who cannot walk themselves unaided should be provided support to ameliorate that problem, it does not however provide for other problems. The following examples illustrate the deficiency of the current arrangements:</p> <p>*i. a person with a visual impairment may be able to walk without hindrance, and be able to go into new areas themselves however find themselves unable to read the numbers on buses and so cannot use public transport effectively with the concomitant increases in travel costs;</p> <p>*a person suffering from Obsessive Compulsive Disorder may have severe problems leaving the house and using transport in general, which is a scenario not really addressed in the current mobility needs.</p> <p>*B. Moving on to “care needs”. The current provisions work on determining whether the claimant would require assistance to undertake a variety of personal care tasks. This is artificial at best, as the DLA awards would be highly unlikely to be enough for paying a carer to actually do what is assessed as required.</p> <p>*A disabled person will incur extra costs from not being able to do many daily tasks, or only being able to do them at a slower rate. There are also many more subtle causes arising here that would increase costs. For example, if someone is hypomanic their shopping patterns may change to start “stock-piling” large numbers of one type of item; this can be as simple as buying several loafs of bread at once, which then go off. It is not an inability per se but it is an increased cost that flows from the disability. The other side to that example is if someone is suffering from major depression, they will often find making a choice of food excruciatingly difficult and end up picking something that does not require effort to prepare before eating. This also incurs increased costs.</p> <p>*4. Having only two rates per component promises to cause a number of very serious problems and is a move in the wrong direction:</p> <p>*i. a large number of people with borderline cases but in obvious need of support will be denied that support;</p> <p>*having only two discrete levels of support implies claimants with vastly different support needs will receive the same benefit</p>

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		<p>awards;</p> <p>*it entirely undermines the government's assertion in the consultation paper that the new PIP will be focused on the individual, by reducing a population with vastly different support needs into two small categories it cannot possibly focus on the individual;</p> <p>*there may be a saving in first line administrative costs but the vast number of borderline cases will invite a massive increase in Tribunal appeals, which will overwhelm any savings and I would expect cost significantly more in the long term.</p> <p>*To be fair, easy to administer, immediately comprehensible and reduce Tribunal appeals, a points system on a sliding scale would be more appropriate. It would be perfectly feasible to build an assessment that allocates points for each daily activity the claimant has a problem with, and potentially the level of severity with respect to that activity.</p> <p>*The data can then be normalised and matched against a sliding scale with say one hundred increments, which is easily interpreted as a "requires x percent support" metric.</p> <p>*In the current provisions, it is common for borderline claimants on first assessment to be awarded the care level below that which they actually need. These decisions are commonly overturned on appeal, which must be a significant cost to the tax payer. If a claimant were assessed on a sliding scale then it is far more likely that a claimant will receive support that more closely matches their requirements on first assessment, hence saving the tax payer money and also saving the claimant an immense amount of stress.</p> <p>*5. The assertion made in section 19, page 15, of the consultation paper, "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." is not substantiated and I would imagine not based in evidence. The support needs that are incurred by a patient on renal dialysis, as used as an example given in section 19. will not substantially change between claimants. The extra costs of individually assessing many thousands of claims would not be offset by any cost saving. Furthermore, for conditions of this nature where the baseline impact is well known, any cost savings made would be automatically incorrect. If the claimant has additional support needs, or the person's illness is worse than a baseline then the claimant should be able to have their additional needs assessed.</p> <p>*The question states, "...based on the needs and the circumstances of the individual applying". This sentence is potentially problematic and misleading in-and-of-itself: the DLA and proposed PIP arrangements are focused around using day-to-day needs as a proxy for measuring increased living costs as a result of disability. Using a claimant's circumstances potentially invites an assessment of their family, financial, living</p>

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		<p>or other live circumstances and thus going against the spirit of the arrangements – the assessment is based on need, not circumstances.</p> <p>*6. A. From my own experience, and from talking with others, one of the primary deficiencies of the current assessment scheme is that it does not take into account combinatorial factors. While it may be perfectly feasible for a disabled person to undertake maybe one or two tasks without difficulty, that will invariably have a knock-on effect against other activities or tasks later (or earlier) in that day or week.</p> <p>*Using myself as an example, I have Bipolar Affective Disorder II. Much of the time, I can complete tasks and undertake activities with as much efficiency and competency as people without the disorder. However, arranging more than a small number of activities or tasks in one day will often cause a rapid instability of mood, decrease in ability to concentrate and memory, and will usually cause a range of problems for several days/weeks afterwards.</p> <p>*Any assessment should and must be able to take account of this problem: it is not just individual activities or tasks that are a problem, more often it is the combination of them.</p> <p>*B. Section 22. of the consultation paper stated that, “The process is based on unclear criteria and often does not make the best use of available evidence. As a result, awards can be subjective, inconsistent and do not always focus support on those who need it most. Disabled people also tell us that the DLA claim forms are too long and can be difficult to understand.”</p> <p>*which is not entirely true. The form is indeed very long. It is indeed extremely arduous to complete and due to the focus on incapability can have an incredibly detrimental impact on the claimant's state of mind. The criteria are unclear because they are not published along with the forms. However, my own complaint is that the assessment process is itself subjective: in my own experience, decision makers have not related the evidence provided to the law and hence have made subjective decisions. When questioned on the reasoning, the rationale behind the decision is not elucidated. The framework as it stands allows for objective assessment, albeit on undesirable criteria – the problem is with a flawed and unaccountable assessment process.</p> <p>*Focus should be directed towards ensuring decision makers actually use the evidence provided by the claimant, their General Practitioner and specialists and not to substitute their own opinion. Decision makers should also be able to justify their decisions by reference to specific sections of the evidence. That would immediately remove much of the subjectivity currently plaguing the current system, and improve user confidence. If a claimant has confidence that their details will be treated with respect and fairness then the difficulties with the</p>

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		<p>form are not as much of an issue.</p> <p>*7. By explicitly stating to claimants to take an approximation of the disability over a suitably long time period, e.g a year. The current arrangements instil a certain amount of anxiety, which is entirely unreasonable and unnecessary.</p> <p>*8. Only if the aid or adaptation in question is voluntarily used by the claimant. There is an inherent risk that uniformly taking into account adaptations or aids will have what the IT industry calls “function creep”. A specific individual may find an aid or adaptation that is useful to others will actually hinder their own condition or abilities. By making it mandatory to assess a claimant with reference to an aid or adaptation that is commonly used in association with a disability, the state risks interfering in a person's medical treatment decisions.</p> <p>*This measure can lead very quickly to undesirable situations. For example, it would not be inconceivable for the situation to arise whereby a person with a mental health disability finds prescription psychotropic medication actually worsens their condition but the assessment of the claim is done with reference to them taking the standard first line medication.</p> <p>*9. Some of the suggestions in the consultation paper of moving to assessing daily activities rather than purely care needs is a positive step, and will allow people to provide evidence more easily related to their own lives and conditions.</p> <p>*The current length of the form may be long but it is not long enough to easily provide the evidence sought. The only way to reduce the length of the form is to reduce the amount of evidence sought and the required thresholds.</p> <p>*Filling in the form is indeed arduous, difficult and stressful. I doubt there is a method to gather the evidence required to make the decision otherwise. What would improve matters is an assurance that the assessment process is fair, transparent, accurate, rational and based on the evidence. The feeling I get from others and hold myself is that some of a person's most intimate details go onto that form, yet the decision makers are able to blithely ignore most of it. If the data on that form is treated with the respect it deserves, the experience will be more positive.</p> <p>*The form will be easier to fill in if there were a clear explanation as to the purpose of the question, how that specific answer will be used and the rationale behind each step in the decision process.</p> <p>*The bottom line is it requires the DWP to be as transparent, open and accountable as it expects claimants to be.</p> <p>*10. Curious phrasing of this question: is the whole purpose of the assessment not to determine problems, i.e. “inability” not “ability”?*The current evidence provided by the person, GP, specialist, carers and family should be more than sufficient, one would have thought.</p> <p>*11. There is little benefit to be had. Surely, the individual's</p>

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		<p>own GP and specialist will be able to provide enough evidence to confirm the primary account the claimant has submitted... unless the DWP are so paranoid that they do not accept the submissions of two medical professionals, the claimant, and usually at least one carer/family member? The fraud rate with DWP is, by the DWP's own statistics, less than 0.5%; I am not sure how the DWP intends to reduce expenditure by introducing blanket medical assessments at significant cost when the potential savings are so small.</p> <p>*Yes, I would imagine there are situations in which this is inappropriate:</p> <p>*i. it is infeasible to imagine the independent healthcare professional will be a specialist doctor in the relevant area and they will not have had a longitudinal exposure to the patient, two factors which suggest their assessment will always be inferior to the patient's own doctors;</p> <p>*to be anything more than a box-ticking exercise, the healthcare professional must be suitably qualified and any assessment will likely span over at least a day, which is also infeasible from a resource consideration.</p> <p>**In fact, the only situation where an independent assessment would help is if there is strongly conflicting evidence. In those situations, it may be of utility to resolve any inconsistencies or differences of opinion.</p> <p>*12. The current provisions already allow for time limited awards. If the initial assessment is performed correctly, a decision maker will be able to suggest a reasonable time limit on any award with a potential maximum of, say, 12 years. Performing reviews too frequently will only result in increased workload for decision makers, medical professionals and increased stress for the claimant. I would imagine the current provisions do not need much alteration in this respect.</p> <p>*13. It is perhaps somewhat naïve to suggest the new "Personal Independence Payment" will be easier to understand. There is a minimum necessary complexity in any system required to undertake a given task, I do not think the current system can be simplified without reducing the granularity of the solution. This principle was stated quite succinctly by Albert Einstein, "Make everything as simple as possible, but not simpler".</p> <p>*In most cases, people will still not know what changes are likely to affect the decision. They will be very reticent to notify changes on something that frequently changes, aside from anything else the DWP would be snowed under with the increased workload. There is also the issue of fluctuating conditions: most people are able to reasonably take an average.</p> <p>*If someone permanently ceases to have the same requirements for support, yes, they obviously should notify the DWP of such. However, with a disability, that scenario rarely</p>

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		<p>happens and the progression is usually in the opposite direction.</p> <p>*You can encourage people to notify changes by making the tiering of benefit awards more continuous rather than the current discrete three levels. The suggestion of moving to only two levels will make this situation worse.</p> <p>*14. Offering more information on available support can only be a good thing. People may already be making use of everything available but many will not be aware of what is out there.</p> <p>*Creating a repository of not only general resources but also of what is available in a person's local area could really help. Also references to advice agencies on related issues may help, as disabilities usually have wide ranging effects on a person and their families lives. So for example, local support groups, counselling services, advocacy or rights advice.</p> <p>*15. No. It is not appropriate for the government or state to force an individual's decision on whether to use support services available. Ancillary support services are often a "hit-or-miss" affair, and it is immensely prejudicial to mandate a requirement that someone uses a service they find detrimental.</p> <p>*The purpose of DLA or PIP is to provide support, not to dictate how a person should lead their life or their best options for treatment.</p> <p>*16. As an option, yes. But as an option.</p> <p>*What would be useful is for the government to give tax relief to the relevant manufacturers when bought through DLA / PIP channels.</p> <p>*For example, "light boxes" are often advised and very efficacious for those with affective disorders. There is good research to support the efficacy and safety but these devices are not available on prescription and are fairly expensive to buy. If the government were to offer the relevant companies tax relief, there are obvious benefits to both the government, tax payer and individual.</p> <p>*17. Unanswered.</p> <p>*18. It is very useful. For example, the Housing Benefit and Working Tax Credit arrangements both have differing criteria but accept DLA as a "short-cut" evidence.*I'm not sure whether it makes sense to consolidate in all cases. It is the situation again where these entitlements were created to address specific need, and whether those needs can be met as accurately when consolidated remains to be seen. Care also needs to be taken to ensure that any consolidation is not seen as an excuse to cut benefit entitlement.</p> <p>*19. Well, obviously, multiple assessment. This is a wasteful cost to the tax payer and also more stressful for any applicant.</p> <p>*The DLA assessment is very thorough, there is little point in duplicating that work in what would be a less thorough manner and at significant cost.</p> <p>*20. I thought it already was the situation that another benefit,</p>

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		<p>for example Housing Benefit or Incapacity Benefit, and even Tax Credits, could contact the DWP and determine DLA status of the claimant?*It is unclear whether any change or improvement can be made here, as it is already the de facto situation.</p> <p>*21. I would imagine the only equality group affected in that table is "Disabled" and that is already discussed.</p> <p>*22. It is not clear why the government is implementing what is in essence a cosmetic re-branding of DLA. At best the changes are incremental, and could be introduced as a amendment to existing legislation.</p> <p>**Section 14. and 15. make the point that the caseload and expenditure are increasing beyond original expectations and that the application is wider than originally intended. What is not discussed is whether this increased caseload is actually meeting the needs of the population: there is no evidence to say that the current number of claimants do not need support. The fraud rate on DWP is quoted as less than 0.5%, which strongly suggests that DLA is fit for purpose and that the expenditure is what is necessary to ameliorate the problem.*Any real reduction in awards will not happen by elimination of fraud, more frequent reviews or compelling claimants to more readily notify changes. The cost savings can only come from improved administration or barring people in real need from being able to claim.</p> <p>*So in conclusion: the processes that need improvement to better serve the population will likely come at increased cost, not reduced cost. The government can either be committed to improving the lives of disabled people, or it can be committed to reducing expenditure and consequentially detrimenting the lives of many hundreds of thousands of people. The choice is mutually exclusive.</p>
EM780	18/02/2011	<p>The answers below are all connected with my son, [REDACTED]. He will be [REDACTED] next May, and has suffered from Cerebral Palsy since birth. He lives in a local Residential home, will never be able to work and will always be dependent on the correct decisions made by others for his well being.</p> <p>*On some questions below, I have written 'Don't Know', where I have no real answer to give, so please don't take this as meaning that I think any of the questions are not necessary – they all are relevant.</p> <p>*1. The costs to the public purse, particularly if Local Authorities are having to look for cheaper options.</p> <p>*Sadly the occasional lack of understanding from the older generation of the needs of disabled, young people seem to be much better in this regard.</p> <p>*2. Don't know.</p> <p>*3. Everyday life – Care, Mobility, Transport.</p> <p>*4. Don't know</p> <p>*5. Based on needs</p>

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		<p>*6. In my Son's case – Day Centre [or similar] provision, transport for this. He and others do need the incentive and stimulus from this for their lives. They just vegetate if confined to 4 walls.</p> <p>*Physical activities – swimming, gym, horse riding.</p> <p>*7. It will need correctly trained people to administer this.</p> <p>*8. Again my response at 7, but I agree with the second statement.</p> <p>*9. Needs understandable language, whether written or verbal.</p> <p>*10. In my son's case – the manager at his home.</p> <p>*11. I don't see difficulties provided the Healthcare professional has the relevant training and understands the subject.</p> <p>*12. Frequency of reviews will depend on an Individual's needs and agreed in advance.</p> <p>*13. A difficult one, but regular contacts with professional staff as outlined previously, hopefully might help.</p> <p>*14. As with any new system, proper initial assessment will be vital.</p> <p>*15. Don't Know.</p> <p>*16. Yes</p> <p>*17. Their needs may change and vary more rapidly.</p> <p>*18. Ensuring that people know the procedures and their entitlements.</p> <p>*19. Re. no 1 on this consultation, many, many barriers.</p> <p>*20. Don't Know</p> <p>*21. Don't know</p> <p>*22. Sadly I suspect in the foreseeable future, funds available will not match needs. Regular communication will be vital.</p>
EM781	18/02/2011	<p>Introduction.*I have multiple sclerosis, diagnosed in my mid 40s. The principle effects at present are on my mobility (I cannot walk more than about 4-500 metres) , my balance (I fall regularly, especially when turning) and fatigue (even performing routine tasks tires me very quickly). As it is a progressive condition, I can expect all these effects to worsen and others to present themselves.</p> <p>*Response to questionnaire.</p> <p>*1. Fatigue is probably my principle issue. Carrying out routine tasks around the home exhausts me, leaving limited or no energy for a "full and active life". I have two choices: either to pay for assistance or not to leave my home.</p> <p>*2. It should remain accessible to those that need it.</p> <p>*3.</p> <p>*1. Transportation is important; having a car is not a luxury but a necessity.</p> <p>*2. Care in the home is essential, although the extent varies from person to person.</p> <p>*3. Being less mobile means that utility bills are higher – gas, electricity, water – as I am at home more of the time than would be normal.</p> <p>*4. Many aids and adaptations are not funded. I am presently</p>

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		<p>facing a bill in excess of £1,000 for functional electrical stimulation to be supplied along with the hand controls to be fitted to my car that will be necessary for me to use it.</p> <p>*4. Any benefit can be as complex or as simple as it is defined. Whether it provided appropriate support depends on the wording and how open it is to interpretation (or, more likely, misinterpretation).</p> <p>*5. Some conditions should trigger automatic entitlement, and only the level of benefit should need assessment of circumstances.</p> <p>*6. Making the questions asked less likely to lead to the wrong answers. If I am asked "can you dress yourself", the answer is "yes". If I am asked "can you dress yourself, then go out to work, come home and cook a meal, take a shower and get yourself to bed", the answer is different. It is all a case of prioritising demands on energy reserves; if I do all the things I listed in the previous sentence, I would have no energy for any leisure activities at all.</p> <p>*7. Either the assessment has to be performed with full knowledge, understanding and account taken of likely variables, or regular assessments need to be carried out, or the advice of healthcare professionals with full knowledge of the person needs to be taken into account.</p> <p>*8. Yes, if the aids and adaptations are free and freely available, but the assessor also needs to understand that the use of an aid or adaptation might not reduce the additional costs of living with disability.</p> <p>*9. The claim form is presently a mammoth task to fill in. Having applied twice for the care component of DLA, I have twice been refused, despite my local authority having assessed me as requiring care (for which I am required to make a contribution on the assumption that I will receive DLA). *The process can be dehumanising and frustrating.</p> <p>*10. Any supporting evidence provided by professionals with direct knowledge of the individual would improve and inform the assessment process.</p> <p>*11. A face-to-face meeting in the home is a more appropriate and realistic environment.</p> <p>*12. The frequency of reviews should depend on the type of disability.</p> <p>*13. If it is simple to report changes, people are more likely to do so.</p> <p>*14. There are a multiplicity of types of information, many from different sources. A 'one-stop-shop' would be a great help to people making a claim so that they are aware of all assistance that might be appropriate. Joining up local and central government services would help enormously, and minimise duplicated effort.</p> <p>*15. Making advice and information easily accessible would help. Any compulsion to seek such advice should be avoided</p>

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		<p>where possible.</p> <p>*16. At present most are funded from personal resources or charitable funds. Enabling these to be funded centrally would be beneficial – provided that it does not result in a person being financially disadvantaged.</p> <p>*17. No comment.</p> <p>*18. It has been of very limited assistance, other than as a proof of disability. Eliminating the need for repeated assessments for different purposes would be beneficial and cost effective. But then the assessment requirement for other purposes may be different.</p> <p>*19. Overcoming the oft-used excuse of data protection – which would only require a limited release by the individual.</p> <p>*20. Assessments could be more comprehensive to cover a number of purposes. At present it seems duplication is rife and assessments are misused.</p> <p>*21. No comment.</p> <p>*22. No comment.</p>
EM782	18/02/2011	<p>1. Mainly their disablement.</p> <p>*2. Your response:</p> <p>*3. Costs of moving around, going to shops, unable to go shopping for bargains.</p> <p>*Having to pay for small jobs around the house as cannot do things themselves.*Having to buy ready prepared meals. Extra costs of heating.</p> <p>*4. I do not think it makes any difference.</p> <p>*5. Some conditions will mean that the claimant will automatically have certain needs. It would be a waste of money to assess these.</p> <p>*6. The danger here is that people with a small need will be unable to live a full and active life for want of a little help. These people also need to be able to get about for education, training, shopping, socialising etc. For want of a little support now, these people are going to deteriorate and need more help later on. Prevention is better/cheaper than cure.</p> <p>*7. This should be based on the proportion of time it would be reasonable for a person to have time off work. If it is considered reasonable for a person to have 2% of time of work, then you should consider what they are able to do 98% of the time.</p> <p>*8. Any aids that are (or can definitely be provided) should be taken into account.</p> <p>*9. The assessor should not have any targets for proportion of claims allowed.</p> <p>*10. GP's report, Carer's report, Person's report. The benefit should aim to give a person as normal a life as possible.</p> <p>*11. This will obviously be very stressful for people. I think a doctor would be better than a health care professional as a doctor would have a greater understanding of the way conditions can affect people and how multiple conditions can</p>

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		<p>interact. This person should not have targets(or rewards etc) of the proportion of claims allowed.</p> <p>*12. The frequency should be based on the likelihood of a person improving.</p> <p>*13.</p> <p>*14. Blue badge; help with cooking, cleaning etc</p> <p>*15.</p> <p>*16. It is very hard to get a wheelchair.</p> <p>*17. Your response:</p> <p>*18. Higher mobility DLA enables people to get a blue badge, but some councils insist on another report from the GP and/or a medical form to be filled in.</p> <p>*This is a waste of taxpayers money.</p> <p>*19. More stress at filling in more forms. It is hard to think about your disability and these things take a bigger proportion of available effort when you are having trouble coping with everyday needs.</p> <p>*20. *21. Your response:*22. Your response:</p>
EM783	18/02/2011	<p>We are the parents of a 27 year old man with Down's Syndrome who has severe learning difficulties.We have only very recently accessed the questions on DLA reform, therefore our response is brief and only pertinent to the questions we feel are relevent to our family and we have some experience of.</p> <p>*1. Access to public places (now improving), appropriate facilities for leisure activities, suitable accommodation, lengthy and complicated form filling, peoples attitudes and reaction to people with special needs.</p> <p>*3. Heating, transport, respite with all associated expenses.</p> <p>*5. Severe learning difficulties, related to a condition which will last a lifetime, should mean automatic entitlement.</p> <p>*6. Full support of social work and relevant stimulating continuing education.</p> <p>*9. A nominated person to fully explain questions.</p> <p>*10. Carer, G.P. social worker.</p> <p>*12. * Reviews at the request of disabled person/carers.*</p> <p>* if no change in condition/disability/ health ,then no revue needed.*</p> <p>* permanent mental handicap should be reviewed by G.P.</p> <p>*18. Extremely important. Ensure Social Workers are well trained and keeping abreast of passport procedures to advise what is available to people with special needs.</p> <p>*19. Would make life much more difficult.</p> <p>*20. Not sure what assessments could be done, but it would be so much better if bureaucracy could be cut down.</p> <p>*22.* Form filling, meetings, assessments, reviews, medicals are really difficult and often demoralising for elderly carers especially knowing that the person with special needs has a lifetime condition so that often the the process is unnecessary. Anything that makes our life more settled and less complicated would be welcome.*</p>

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		* Can we say that the Flexible Respite and Direct Payment system that we have in East Renfrewshire has improved our lives as carers and particularly our son's life.* Also good support from the Local Area Co-ordinaters and Social Work Department.
EM784	18/02/2011	I believe this to be a bad mistake. It is not about helping the sick but about penalizing innocent people who are an easy target.*
EM785	18/02/2011	<p>1. I am working full time and find that I get so tired as soon as I am home I have to rest on the sofa and usually fall asleep for about an hour. I do not want to go out socially as I am too tired. I find it difficult to motivate myself after being at work all day and often I will not cook and will eat cereal.</p> <p>*2. Knowing that I will have a set amount extra to spare means that I am in a position to be able to have food delivered, and pay someone to help with my cleaning and ironing etc. I am also unable to groom my dog myself which I have had training for and now need to pay someone to do that for me.</p> <p>*3. I find that the extra expenses I have are: I use my car more often as I cannot walk to the shops, I am unable to groom my dog, it helps with having someone do my ironing, cleaning etc and being able to have take-aways delivered when I am too tired to cook.</p> <p>*4. I am unsure on this one. I have multiple sclerosis which is an incurable condition and has fluctuating and progressive symptoms. Who knows what I will be able to do in the months/years ahead.</p> <p>*5. If you have a proven medically recognised, incurable, progressive or fatal illness this should be automatic. This also applies to people who are amputees, or with visual / hearing problems. I have heard that people receive DVLA for "conditions" such as "night terrors", obesity, drug / alcohol abuse, depression and stress. Some of these are bought on by the individuals themselves, and are not medical conditions they have been diagnosed with that occur without any control of the individual.</p> <p>*6.</p> <p>*7. Listen / read be aware of the medically proven evidence on a "diagnosed" person.</p> <p>*8. This is difficult as there are many different types of adaptations and aids that can be used. Personally I have a defined progressive condition that could leave me permanently in a wheelchair or paralysed. My condition is incurable and progressive, who knows when or if adaptations/aids may be needed.:</p> <p>*9. How could we improve the process of applying for the benefit for When I applied for DLA the form was very daunting. It was very depressing when you actually have to put in writing how your condition affects you personally and how much of an impact it has had on you and your family.</p>

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		<p>*10. If evidence is provided for a “real” condition then surely once the person has been diagnosed and there are medical books, literature etc that describe the condition then this must be the best way to look at that individuals case.</p> <p>*11. Is the “healthcare professional” a medical person or someone in the medical field. Are there to be “specialists” involved or are decisions based by a layperson who has no medical background?</p> <p>*12. *13. *14. This would depend on mental capacity etc as some people will need more help and support than others.</p> <p>*15. This needs to be available and provided in a supportive way.</p> <p>*16. One off costs should be provided for larger more expensive things ie stairlifts, hoists, electric wheelchairs/scooters etc,</p> <p>*17. They are children, and also just because someone is an “adult” it does not mean they have the mental capacity to deal with an assessment.</p> <p>*18. As I am working I am not entitled to claim. Having DLA has enabled me to keep working. I have worked since I was 16 and am now 43. I have never claimed anything prior to my illness and receiving extra support financially has enabled me to continue working.</p> <p>*19. This would be different for the individuals concerned.</p> <p>*20. If it is a medically recognised condition then this should be confirmed.*21. *22. Your response:</p>
EM786	18/02/2011	<p>Response to the consultation on the reform of DLA, [REDACTED], [REDACTED] BASE (Blind Activities Support Events Charity SCO37538), [REDACTED] Charity Inclusion Scotland, [REDACTED] National Federation of the Blind of UK, Scottish Central Branch.</p> <p>*Parts of my response come from a draft of the committee of Dundee Visually Impaired Ladies Club.</p> <p>**Question 1 Eyesight is the brains main source of information, estimated by the Royal National Institute of the Blind (RNIB) to provide 90-95% of the brains information on the world around us.</p> <p>*Left with only c. 5% of the normal information everyone else takes for granted the barriers and problems Visually Impaired and totally blind people face every day are: physical-getting around safely, and dealing with day to day problems when you cannot access the information that is thrown at everyone everyday-bills, newspapers, medical appointments, etc you cannot read, eating (shopping-finding the beans, etc and cooking finding the right ingredients and amounts), cleaning your body and house when you cannot see the dirt, or even colour of your clothes, or see the face in the mirror, in the face of all these problems maintaining your health physical, (and especially severe in sight loss-mental health (see 2 below: Scottish Rehabilitation Group Independence and well-being In Sight-Developing the Vision: February 2007) is very</p>

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		<p>challenging. Attitudinal problems-most ordinary people, officialdom, and businesses have little idea of the effects of sight loss, and generally care little. If your eyes do not function, you have to find another way or sense to cope.</p> <p>*DLA helps buy the extra resources needed to deal, to some degree, with the many barriers and problems visually impaired people (VIP) have to cope with.</p> <p>*Question 2: DLA is administered nationally and is therefore applied uniformly over the country. Other forms of social care which are administered by local authorities and are thus often subject to wide variation in interpretation and implementation – the dreaded “post-code lottery.” Were DLA devolved to local authority control this vital source of support to many with disabilities may be potentially subject to a regulation by those not well informed or qualified to assess particular needs of those with disabilities.</p> <p>*A number of local authorities in Scotland administer their duties to VIP through local charities introducing another variant in the application of legislation and resources. My personal experience is that some of these charities have poor internal governance and inadequate external regulation by funders e.g. local authorities. Often this means charities are not necessarily an efficient means of delivery of duties delegated to Local Authorities (LA) who then delegate these duties to e.g. a charity for VIP. In such circumstances a LA is dutybound to carefully monitor such charities to ensure they implement the duties thus delegated. Such charities need to know and enforce Employment Law, Charity Law, Company Law, Disability Discrimination Law, Equality Law, etc, and too often supervising Boards do not have the knowledge and or experience-the capacity to ensure the charity is carrying out all the duties it should, and acting lawfully.</p> <p>* This can result in some inappropriate use of resources, or apply duties and responsibilities outwith the spirit of the legislation e.g. the Disability Equality Duty (DED see below). One local charity I know had a contract with the LA to provide counselling for VIP, but when challenged in a local paper denied this, but was later proven to have this responsibility but was not fulfilling it. A report by Guide Dogs for the Blind, on behalf of the Scottish Rehabilitation Group (Independence and well-being In Sight-Developing the Vision: February 2007), stated that “the impact of sight loss on mental health cannot be over emphasised” and that rehabilitation for visually impaired people including counselling was identified as the key necessary initial process-i.e. this an important omission.</p> <p>*If the DED is not enforced, the voice of people with disabilities is not heard, and this often results inappropriate policies, and decision making as above, resulting in waste of public resources.</p> <p>*Question 3: These vary with the disability, the extent of the</p>

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		<p>disability and the personal Support networks of the individual concerned. Extra expense may be incurred for all or some of the following:</p> <ul style="list-style-type: none"> *• Transport* *• Ready cooked meals when the affected individual cannot cook* *• House cleaning *• Extra heating costs, due to reduced mobility *• Laundry* *• Shopping* *• Paying bills and managing finance *• Correspondence, official and social *• Mending clothes and domestic appliances *• Personal care such as chiropody, exercise *• Social interaction, sport, culture, entertainment, civic interests *• Accessing exercise to maintain health <p>**Question 4 Reducing the number of levels for the daily living component, and mobility component. reduces the ability to match the resoures provided to the requied needs and will increase the difficulties in judging support awarded to borderline cases.</p> <p>*Question 5: It very likely would save on assessment time if some severe irreversible disabilities were recognised for automatic awards.</p> <p>*Question 6: All the activities listed under Question 3 are important. The priority given by individuals may differ. For many visually impaired people the biggest barriers to full participation in all aspects of life are: Mobility getting out and about safely- this directly affects physical and mental health, personal care-feeding and personal cleaniliness-directly linked to good health. Visually Impaired People's (VIP's) inability to read and write this severely affectd independent communication and expression of needs and opinions. The technology exists to provide a literacy and commication work station via a PC and voice operated software for £1000 to £2000. But there is no recognition of the vital importance of this to VIP by many care provides or even major charities for the Blind.</p> <p>*It is very important to visually Impaired people (VIP) to achieve a reasonable level of independence and dignity. These are severely limited if you have to get a family member or neighbour to read and write your personal letters. For many visually impaired people this is a major gap in present provision, especially as "buddies" or personal helpers are hardly ever provided, and are hard to find yourself.</p> <p>*Question 7: Some expenses which are helped by DLA cannot be switched on and off easily: direct debit utility bills, for example. It must be recognised that for many people with disabilities money is very tight (see response to Q22) and that the loss of what may seem small suns brings real hardship – less food, less heating, great worry and distress.</p> <p>* If changes are to be made, they must be implemented swiftly and accurately. The record of Government agencies in that respect is lamentable. The fear is that failure to provide adequate administrative resources will lead to unacceptable</p>

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		<p>delays, and erroneous assessments of need.</p> <p>*Question 8: Absolutely no question yes, (See response to Question 6 and Question 16). To ask this question of visually impaired people (VIP) betrays an ignorance of the effects of sight loss. As an example, Dundee Social Work Department only funds the provision of a suitable white stick and a liquid level indicator (audible signal when cup is full). This goes nowhere near the list of potential needs under question 3, but regrettably is typical of present provision. The range of assistive technology for VIP is considerable (check the catalogue for RNIB on-line shop) but every item, from a talking watch to a reading system, has to be purchased by VIP and the cost is often prohibitive. An additional expense is caused by the limitations of the Low Vision Clinics, which supply only hand held or spectacle mounted reading aids. Reading is possible for many visually impaired people only with more expensive aids costing up to £2000, and finding money for this basic need is beyond the means of many VIP.</p> <p>*Question9: Disability takes many forms and each has variations; human life is complex and people vary. If the system is to take this into account, it cannot be simple. It cannot be made user-friendly. The repetitive nature of current forms needs reducing. Any changes to forms must be in consultation with people with disabilities-under Disability legislation-the Disability Equality Duty (DED) now I believe incorporated into the Equalities Act 2010, and independent medical advice.</p> <p>*Question 10: For the visually impaired a qualified and experienced visual rehabilitation officer, a GP who knows the individual concerned well and all the difficulties they have faced, or perhaps a senior officer in a disability led organisation who knows the individual may be suitable. A holistic approach is required looking sensitively at how well an individual copes.</p> <p>*Question 11: This would be totally inappropriate for most visually impaired people, most of whom are otherwise as healthy as the rest of the population. It would only be of service where there is another disability, such as diabetes. The aftercare of those registered as blind or partially sighted is a matter for Social Services and although opthalmic specialists can indicate the precise type of eye problem they have no knowledge of how this affects their patients' lives.</p> <p>*As a general comment this use of health professionals does not sit well with the acceptance of the social model of disability.</p> <p>*Holding an interview in the applicant's home will be very informative about their ability to cope in various ways and could put the applicant at ease. The choice of location for interviews should be in consultation with the person with the disability.</p> <p>*However the proposed changes to welfare benefits are solely driven by cost cutting. Before this consultation, or the taking of evidence, a Government heavily populated by those from privileged backgrounds, who have personally never</p>

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		<p>experienced financial hardship decided to cut DLA by 20% come what may. This was made necessary chiefly by the disastrous incompetence and negligence of bankers and their regulators who seem likely not to suffer greatly.</p> <p>*In these circumstances it is deeply antagonistic, unjust, and offensive, to try to impose the consequential savings on genuinely vulnerable and disabled people(see 22.1 below), and make them to feel guilty about what support they receive, particularly in view of the low level of support given (see evidence at 22 below). Home visits will thus probably be perceived as prying, intrusive, and an affront to those with disabilities when the purpose is to cut their support.</p> <p>*Question 12: This is a technical administrative decision, balancing the cost of the review process with the savings if PIP could be reduced and the extra cost if PIP needs to be increased. People with disabilities need stability and security in their lives more than most-not continual harassments and potential cuts, and if the condition they suffer from is age related-which most are, the condition will almost certainly only worsen requiring more support.</p> <p>*Question 13: If this question assumes that people are not reporting improvements in their condition it is offensive.</p> <p>*The general tendency is for disabilities, which are often age related, especially eye conditions, is for them to worsen or become more oppressive with time and age.</p> <p>*Question 14: As always, for visually impaired people, printed information should be available in a range of formats, and also audio format for the entirely blind. Access to good rehabilitation services would be even more effective.</p> <p>*Good quality national standards and training for rehabilitation workers for VIP, and what they do for VIP, which do not exist at present would be a big step forward, as would national standards of training for Guides for VIP.</p> <p>*Question 15: This also implies that recipients are remiss. Advice is often so general as to be useless. The most effective advice would come from care providers, such as rehabs and occupational therapists, but they often lack the resources to be effective, and some lack the necessary skills and experience to understand the needs of VIP.</p> <p>*Question 16: This is an extremely sore point amongst any visually impaired person who realises the present situation. Although every local authority, in partnership with the NHS has an Aids and adaptations scheme, the visually impaired are virtually excluded from it.</p> <p>*Since by tradition the care and services to the visually impaired have been the responsibility of local Authorities rather than hospital departments, it would seem appropriate for them to provide suitable funding streams for essential equipment VIP need to survive in this world. As detailed earlier this does not happen. *Substantive systemic improvements in the provision</p>

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		<p>of modern equipment for VIP and the training in the use of such equipment, and support services, not cuts, is essential to promote the independence of VIP, and improve on the appallingly low rate of employment of VIP of working age in the UK-only 25% are in employment.</p> <p>*I believe this low rate of VIP employment is directly related to: virtual non existent equipment provision, absence of standards for, and numbers of rehab workers, poor implementation of disability legislation, poor regulation and governance of some organisations FOR VIP, lack of resources, and poor general understanding of the effects of sight loss (see general comments below).</p> <p>*Question 17: Visually impaired children get special needs support in term time, but lack support during holidays. A member was distressed because her child was progressing at school, but could not make progress like a sighted child because of lack of access to technology. This could be a case for variation and increase in resources for children during school holidays to redress the balance, and make it more likely they can get into employment later, rather than become dependent on benefits.</p> <p>*A nationwide support system like that described below (see 22) in Sweden or the CVISTA is essential.</p> <p>*Question 18: This saves expense in a second assessment. It should be noted that DLA can be a bar to other benefits when Local Authorities take it into account for means-tested benefits. There needs to be absolute clarity over these issues.</p> <p>*Question 19: It means that service providers will have to introduce their own assessment procedures. These may not be uniform across the country which will introduce anomalies and uncertainties for disabled people. It will increase the workload of service providers and will subject disabled people to a series of stressful assessments.</p> <p>*Question 20: As service users, we do not have the information to answer this question, but hope that any investigation will include a wide range of disability groups as required under equality and disability legislation.</p> <p>*Question 21: Ageism is a feature of the treatment of visually impaired people. A member was told that it was not worth retraining at the age of 50 as he would not get a job anyway, which was realistic, if somewhat cruel, and probably unlawful depending on the source of such advice. But visual impairment tends to come late in life and the belief that the visually impaired should resign themselves to a quiet life, accepting services and listening to Talking Books is all too prevalent. It is also expensive for the state as it is usually cheaper to give people equipment and training to do things for themselves than it is to supply services longterm.</p> <p>*Question 22: General comments on the documents approach</p> <p>*1: This Reform seems to imply there is a massive amount of</p>

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		<p>fraud and overpayment. My background is in science and latterly law. In both those areas, opinions, decisions, and policies are based on facts and evidence. To have any credibility, a reform of policies affecting people with disabilities must be evidence based.</p> <p>*The response to Q11 above detailed why the cuts in DLA were being imposed-heavy losses by the financial sector, then rescued by the taxpayer leading to a Government drawn from a well off background deciding before evidence was taken that the support to people with disabilities was to be cut by 20%. Now in February 2011 Barclays bankers are to get £3.5 billion in bonuses,*Research by the Joseph Roundtree Foundation showed that 30% of disabled adults of working age are living in poverty in Britain – a higher proportion than a decade ago and approx. double the rate among non-disabled adults.</p> <p>*At a recent conference in Glasgow “Welfare Reform-Who Benefits?” 4th February 2011 hosted by Inclusion Scotland and Glasgow Disability Alliance, Professor Adrian Sinfield of Edinburgh University stated that in the early eighties recession under Thatcher welfare benefits were at 20% of average incomes, and now they are at 10% of average incomes, the second lowest proportion in Europe. He also stated that benefit fraud was at less than 1%. Evidence does not support any further cuts.</p> <p>*The almost Dickensian injustice revealed above may lead to trouble as happened when PM Thatcher tried to introduce the poll tax.</p> <p>*2: Revamping the whole system will be expensive to do properly and cause great hardship if it is carried out with limited resources leading to errors. It is too ambitious a change.</p> <p>*3: The consultation document shows little knowledge of the realities of disability, of its different forms and the variety of problems still needing addressed to achieve decent support for VIP and other groups of people with disabilities.</p> <p>*Comments from the visually impaired angle,</p> <p>*1: There is a shortage of people competent to assess daily living needs, as rehabilitation officers are few (44 full time equivalent in 2006 in Scotland) and they will usually also be employees of service providers and possibly biased by local considerations.</p> <p>*2: Many of the assumptions in this document do not apply to the visually impaired; in particular there is effectively no provision of assistive technology for this group. In Scotland (and presumably in the rest of the UK) the autonomy assigned to the 32 Local Authorities allows them to ignore the policy recommendations in statutory instruments issued by central government, as instanced by the Guidelines on Equipment and Adaptations issued by the Scottish Government in 2007. This implies that people with sensory impairments are eligible for suitable equipment, yet Perth and Kinross, as policy, supply</p>

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		<p>nothing. and Dundee only a white stick and a liquid level indicator.</p> <p>*3: Provision of care and services from Local authorities is variable in the extreme. This is especially true if the LA has delegated their responsibility to e.g. VIP (often for historic reasons) to a local charity which as described earlier sometimes has virtual “carte blanche” to do what it feels depending upon the diligence of the LA’s regulation. I saw a situation where the CEO of a charity funded by an LA providing services for a vulnerable group of VIP behaved almost like a local warlord-provided by the charity with a CEO’s BMW by the charity while it ran a £80K deficit, and asking VIP to pay more for services, removing directors who disagreed with his policies, and removing services from a VIP who disagreed. While this individual has now I beleive been sorted out, the system that allowed this to happen has not.</p> <p>*There are no standards of any description for the range, extent or content of service provision. Service charges may be applied at short notice. Eligibility criteria vary and there are none specific to sensory impairment; additionally eligibility criteria may be used as a means of rationing services. The situation in Scotland has not improved since the paper by Skellington Orr and Leven, 2006.</p> <p>*4: The majority of visually impaired would seem ideally suited to the Enablement Model of Rehabilitation. Registration triggers a process which is similar to Enablement Rehabilitation, but incomplete due to economies of resource. This is entirely counter-productive, since unless people are equipped, trained and supported in independent living they will require palliative services on a long term basis – a lifelong basis. The deficiencies, lack of standards and the variations in the service provided by Local Authorities were signalled in 2006 in the Scottish Government Research Paper by Skellington Orr and Leven, as noted above. The situation has not changed and many local authorities have reduced their allocation of resources to visual impairment units. Where care is delivered in-house this cannot be monitored and the heads of such units are in no position to protest publicly, but where local charities have a contract to deliver care, two have withdrawn because they considered the amount offered inadequate (Angus, Grampian for Aberdeenshire) and others have had to cut services (Perth & Kinross, Dundee). In such conditions, a stable source of support is essential.</p> <p>*5. When resourcrs are scarce it is vital to ensure that support systems for VIP and others use the available resources as efficiently as possible. An essential part of that is to listen carefully to the views of those inside the system-the end users VIP I.e. to have robust feedback mechanisms from VIP to determine what works for them best.</p> <p>*This is actually set out in legislation as a duty:</p>

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		<p>*Under the Disability Discrimination Act 2005 the Disability Equality Duty (DED), placed a duty, from December 2006, on public authorities to promote equality and DEMONSTRATE involvement of disabled people.</p> <p>*Reinforcing this: the Guidance from Scottish Health Department, Directorate of Primary Care and Community Care, Adult Care and Support directed to: Directors of Social Work/Chief Social Workers*Local Authority Chief Executives, CHP and SSA leads</p> <p>*Voluntary Sector Organisations; about: COMMUNITY CARE SERVICES FOR PEOPLE WITH A SENSORY IMPAIRMENT: POLICY AND PRACTICE GUIDANCE 20 April 2007 by MS JEAN MACLELLAN wrote:</p> <p>*Under actions recommended:</p> <p>*4 Ensure the involvement of deaf, visually impaired. and dual sensory impaired people in planning services</p> <p>* This begs a question: what provisions are in place to ensure VIPs involvement in deciding policy before decisions are actually taken?</p> <p>*Our experience is this does not happen. In general, Local Authorities pay little if any attention to the views of those with disabilities, including VIP.</p> <p>*The evidence of only 25% of VIP of working age being in employment clearly demonstrates that the present system for supporting VIP in Scotland, or more accurately the absence of a decent support system, as detailed in this document is failing VIP, and it is not the case that VIP are in some way letting society down. Ex PM Blair talked about removing barriers and creating opportunities for disabled people. For VIP this has not happened, successive Governments have, usually for short term financial reasons, failed to put in place the necessary legislative adjustments to ensure that existing legislation and guidance is fully implemented. In such circumstances it is patently unfair to penalise VIP.</p> <p>*6. The built environment. There have been significant changes made to streets to accommodate the needs of those in wheelchairs. Such people are given wheelchairs, electric buggies, free cars funded through DLA, and parking spots, indeed the general symbol for disability is a wheelchair symbol.</p> <p>*Little has been done for VIP. As alluded to elsewhere very little equipment is provided to VIP by LA. Only recently were those with severe sight loss given the higher rate of the mobility component of DLA to help them get around. There has been a trend in recent years towards "shared spaces" in some town centres. e.g. Dundee, Kirkcaldy and Dunfermline, all tactile and audible clues are removed and a person with sight loss is left to navigate in open space where there is the additional hazard of occasional access by vehicles. Guide dogs for VIP are trained to follow kerbs, and stop at the edge of pavements. Shared surfaces would in part destroy a guide dogs usefulness to VIP.</p>

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		<p>In one London borough Guide Dogs for the Blind were so concerned about this they instigated a judicial review of “shared spaces” to challenge this policy. Guide Dogs for the Blind have an excellent document on accessible streets: “Inclusive Streets: Design principles for blind and partially sighted people.”</p> <p>*This has a Position Statement: “Good streets are inclusive streets, and streets that are not inclusive are simply not good enough”</p> <p>*For VIP there is a considerable way to go before all or even the majority of streets are good streets. Ex-PM Blair’s barriers have not been removed.</p> <p>*7. Equipment for VIP: Improving Quality and Reducing Costs</p> <p>*There is equipment around to help VIP read, write and communicate, thus promoting independence. If VIP need such an adapted workstation to communicate costing c £1-2K (see responses to Q6, 8, and 16) generally they must pay for it themselves and often pay for any training themselves, neither DLA or often local authorities provide this.</p> <p>*These are generally of two types-firstly magnifiers which are either purely optical, or electronic/optical via a digital camera. Magnification programs also exist to assist when using computers.</p> <p>*The second type uses OCR technology-Optical Character Recognition. In OCR devices digital images of text from digital cameras, or scanners are scanned and alphabetical letters are recognised and converted into a word processor format-e.g. Word, and can be read out by text to speech technology, manipulated, and stored.</p> <p>*The first type-magnifiers are only useful for those with some sight. The electronic magnifiers can vary in price from £65 to over £2,000, and programs for computers can cost c, £500-900. OCR devices can be used by those with some sight, and those who are totally blind, and generally are more expensive, sometimes over £2,000.</p> <p>*Many devices of both types are foreign products imported under license and often UK distribution is controlled by one company with a monopoly who can push prices up.</p> <p>*My experience is that there is equipment that is good for VIP and that is bad equipment for VIP. *GOOD equipment is:</p> <p>*1. What does it Do?: well described in a clear, easy to understand manner by a lay person and also accessible to a VIP.</p> <p>*2. How to use: the instructions are easy to follow, and accessible to a lay person AND VIP, and the device is easy to use by a VIP.</p> <p>*3. The device is affordable to VIP. As mentioned elsewhere for a variety of reasons given in this document most VIP are presently unable to work and can simply not afford expensive equipment needed to help them read, write, and communicate,</p>

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		<p>which would make them more employable. There is something of a "Catch 22" situation here.</p> <p>*BAD equipment for VIP is:</p> <ul style="list-style-type: none"> *1. Poorly described, it is not clear what the device does, *2. the instructions are difficult to follow, or are inaccessible, or both. The device is difficult to use, and/or inaccessible by a VIP, *3. The device is expensive-sometimes many times that of an equivalent device for an ordinary person. <p>*I have had both types recently. The Geddes Reader at £65 is cheap, easy to use, and well described, see geddesreader.com, and sold I was told at cost price. The only improvements I could suggest would be to add a facility to reverse the colour-white text on black background, and suggest several cheap digital TVs to use with the magnifier as a permanent setup.</p> <p>*I got a mobile phone, that talked to you about what button you pressed, various options available, and was able to take photos of documents and through OCR technology read the document to you, advertised as: "Print Accessibility Software for the Blind, Vision impaired and those with reading difficulties." This was of American origin and supplied by a specialist UK firm. For me this was bad equipment. It cost c £1,000, the "Quick start" description that came on a card and several CDs was not for the model of phone I was supplied with-the Nokia C5. The "talks" set-up talked far too fast to follow, and as a program it is complex, and will take a lot of work to get familiar with especially in the absence of accessible instructions. The only description of the C5 phone that came with what I got was a c 50 page booklet in 6-8 point, and the only diagram of the phone provided was c 1cm x 2.3cm identifying 12 functions in c 6 point, none of which my fully sighted friend could access. Products for VIP should help them not create further barriers as I found this phone did,</p> <p>*Companies that sell to minority use groups such as VIP, sometimes make the claim that the price is high because the numbers they supply are limited. However RNIB figures state there are nearly 2 million VIP in the UK. To justify high cost, the technology should actually really help and be fully accessible to VIP, and not be an extra burden on VIP. Having worked in the Citizen's Advice Bureaux and with a diploma in law two thoughts occur:</p> <p>*Under the Sale of Goods Act 1979 goods must be fit for the purpose they are meant for, and of a quality one would expect from such products.</p> <p>*Under the Disability Discrimination Act 1995 and 2005 service providers must make reasonable adjustments to accommodate the needs of people with disabilities.</p> <p>*If the price is high, and the device is not accessible for VIP, but claims to be, companies selling such items, may be subject to the aforementioned legislation.</p>

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		<p>*Charities, Social Work Departments, Colleges, etc that interact with VIP, and advise on suitable supportive equipment for VIP could do a good service for VIP by assessing the suitability of such equipment judging by previous VIP's experience, and the criteria described above. Such organisations could even set up a "purchasing cartel" for equipment for VIP, to up the quality and accessibility of such equipment, and with a centralised buying power, and recommendation lower the costs to VIP (something like "Which" does. and cut the need for DLA/PIP support.</p> <p>*8. A centrally administered, uniformly applied system of support for VIP of good quality is essential to eliminate variations, bad practice as described elsewhere, and ensure laws designed to improve VIPs life chances are actually implemented.</p> <p>*While many charities, for VIP in Scotland try their best for VIP but do not have the necessary resources, or internal capacity to provide a decent service. The visually impaired get no equipment, or support on how to use equipment and local; authority services are uneven. All transparency and accountability are lost- see 22-2 above and Q2 (report Scottish Rehabilitation Group (Independence and well-being In Sight- Developing the Vision: February 2007),</p> <p>*The alternative would be to provide consistency, transparency and accountability at local level would require setting up well defined and enforceable standards for local authority care, and is currently politically impossible. Either as DLA or PIP, a centrally administered scheme is the only protection available against chaotic variations in practice. Resources available to people with disabilities are already unacceptably low (see evidence cited at 1 above) and for VIP are inadequately implemented due to a legislative framework that so lacks definition and teeth as to be not fit for purpose.</p> <p>Recommendations and Guidance from central government should become mandatory duties, and statutory requirements.</p> <p>*Further cuts will lead to further ill health, putting more pressure on now "ring fenced NHS resources."</p> <p>*In short there is no decently defined, enforced, or resourced support system in place for VIP across Scotland, and this directly relates to high VIP unemployment. Cuts to DLA for VIP is the last thing needed.</p> <p>*9. At a housing conference in Glasgow several years ago hosted by Inclusion Scotland I met a Swedish Professor working in the area of support for people with disabilities. He stated there were no charities in Sweden, and VIP and others with disabilities had a hearing before a multidisiplinary panel of medical people. care workers, educationalists, psychologists, lawyers, etc and individuals needs, abilities, problems-family, education, housing, health, income, employment were assessed, and a care, and support plan was drawn up for each</p>

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		<p>individual, with ongoing lifelong reviews.</p> <p>*At another conference hosted by the Scottish National Federation for the Welfare of the Blind (SNFWB) a similar long term multidisciplinary, multiagency support system for visually impaired children was described by Dr. M Campbell, Tayside University Hospital, called CVISTA. (See below).</p> <p>*For me a support system for VIP similar</p>
EM787	18/02/2011	<p>1. Your response: 2. Your response: 3. Your response: 4. Your response:</p> <p>*5. There should be no automatic entitlement in the legislation : however the law should make provision for 'automatic condition-based entitlement' based on which illnesses are likely to meet the functional criteria for certain rates. These conditions and their rates would be kept under review by the DWP.</p> <p>*The objective is to begin paying PIP to claimants who fall into certain categories without filling in a form or undergoing a medical – for example, if both a GP and Consultant say you have 'Severe ME/CFS,' PIP would be paid at given rates based on this evidence alone.</p> <p>* A proportion of these claims would then be 'spot checked' at random intervals to check both the honesty of the claimant and that the 'automatic condition-based entitlement' medical conditions and their allocated rates reflect accurately the needs of the vast majority of people who fall into those categories. The 'spot check' would comprise the standard application process of the form and the DWP medical assessment.</p> <p>*A few people will get more than they would have done via filling in a form (unless/until their award is 'spot-checked'.) A few others may get less, and may elect to fill in the claim form to apply for higher rates. This 'inaccuracy' is the 'price' for an applications process which will be accessible to more genuine claimants. This 'unfair' system would actually be fairer overall because it would enable more genuine claimants to successfully navigate the claims process. The money saved on the initial assessment would be spent on 'spot checks'.</p> <p>*Currently, a similar system to 'automatic condition-based entitlement' is already unofficially in operation via the DWP Decision Makers' Handbook. The Handbook advises Decision Makers that a claimant with 'Severe ME/CFS' is likely to qualify for certain DLA rates, that those with 'Moderate ME/CFS' are likely to qualify for other rates, and so on. This is obviously intended to influence decisions, or it would not be issued to Decision Makers. ME/CFS sufferers currently have DLA claims rejected because the Handbook underestimates how disabling ME/CFS is. What these claimants put on the form seems to be completely ignored in favour of the Handbook entry. Therefore the DLA system already effectively entitles claimants to pre-set DLA rates according to their medical condition.</p> <p>*Some may seek to claim fraudulently or misrepresent the severity of their condition to the medical professionals looking</p>

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		<p>after them. However, deliberate exaggeration is unlikely in someone who has recently acquired a genuine disabling condition and is 'naive' about disability benefits. They will be looking to health professionals for help in their distressing new situation. Outright fraud is different and should be more readily detectable.</p> <p>*6. Your response:</p> <p>*7. Your response: Rely more on evidence from professionals giving the claimant continuing medical care. A DWP medical should only be given by someone specially trained in the particular fluctuating condition – this would mean giving extra training to a particular DWP examiners on ME/CFS, for example. We need specialist assessors for different conditions in the same way as patients would have medical care from different specialists.</p> <p>*8. Your response:</p> <p>*9. Your response:</p> <p>*10. Your response: Where a person has a confirmed diagnosis and has seen a consultant, this should be evidence of 'genuineness', rather than evidence of a particular level of ability.</p> <p>*The DWP needs to recognise that there is unmet demand for ongoing specialist care in certain illnesses, including ME/CFS, and not assume that a claimant who is not seeing a consultant or attending a specialist clinic does not have a genuine continuing health condition.</p> <p>*I have been refused DLA despite a letter from my regular GP, who has known me throughout my illness for 13 years, and was only awarded DLA on appeal when I had a letter from a consultant, who knows far less about my day-to-day function.</p> <p>*11. Your response: The benefits of this extra evidence must be balanced with the impact on the claimant of undergoing the examination. For example, it is highly likely that, if a GP and Consultant say someone has 'Severe ME/CFS', they will qualify for a predictable level of benefit. It is also highly likely that the effort of an assessment (even in the home) will make their illness worse for a time. This is not trivial for someone with ME/CFS who has to do many other things that increase their illness/disability for a time, including - assessments for other benefits, seeing a doctor for medical care, seeing the dentist, etc. Medicals should be avoided wherever possible if undergoing one is likely to worsen the individual's disability.</p> <p>*12. Your response:</p> <p>*13. Send out a yearly declaration for the claimant to sign to officially declare that the claimant continues to qualify. Stop the benefit if this is not returned. Include a box for 'yes, I declare I continue to qualify' and another for, 'no, I stopped qualifying for the benefit at the rates I am paid, on....' and then a box to insert the date that the claimant stopped being entitled. Make it clear upfront that all overpayments will be repaid in full, but do not</p>

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		<p>charge a penalty unless a claimant falsely ticks, 'yes, I declare I continue to qualify.' The incentive to inform the DWP when the change occurs is therefore that the claimant knows that overpayments will be reclaimed.</p> <p>*14. Your response: 15. Your response: 16. Your response: 17. Your response:</p> <p>*18. Your response: 19. Your response: 20. Your response: 21. Your response:</p> <p>*22. Your response: The emphasis needs to be changed from DWP medical examinations to relying on evidence from the patient's own doctor, OT, etc. Many long-term conditions could be managed far better than at present within the NHS or by Social Services' OT's, because there is a shortage of medical care in these areas. It is far better to spend money on an OT who can advise the patient of an aid, or on a yearly GP home visit, or on other appropriate continuing care that will actually benefit the individual and lessen their disability, than to spend the same amount on a DWP examination, which does not benefit the individual. There will then be more good quality, relevant evidence from the patient's own continuing care to use in assessing for benefits. I appreciate that these two things currently come out of two different budgets. However, the fact that it is proposed to refer claimants for attention from OT's and other health professionals shows that the two are linked : it is just that these proposals have got it the wrong way round.</p> <p>*The DWP needs to assess not only how effective the claims process is at combating both outright fraud and exaggeration of disability ; it needs also to assess how many genuinely entitled people are not able to claim or appeal successfully because their disability prevents them from doing so. For example, many people with ME/CFS find that the claims and appeals process is too arduous. They either miss out on money, or claim successfully at real and lasting cost to their health. I pursued a DLA appeal and ended up with worsened ME/CFS - for which I then received higher Social Services Direct Payments. The claims process itself increased my disability, then the council met this extra cost. (Not to mention my own increased suffering.)</p> <p>*The claims process should be accessible to all by being as simple as possible. At present, DLA is so complicated that it is impossible for an advisor who does not know you well to help you fill in the claim form. It is also too complicated for a family member who does know you well to take on. There is a danger that the new, 'simpler' PIP criteria will become just as complicated as the current DLA ones, because they will still be based on individual function. This is why the DWP should take as many people as possible out of the detailed functional assessment (form plus medical), and instead use the 'automatic condition-based entitlement' system proposed above.</p> <p>*The more accurate the PIP assessment is at the claims stage,</p>

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		<p>the fewer genuine cases will miss out. It can be too difficult for a genuinely disabled or ill person to pursue an appeal, ironically due to the disability which is the reason for their claim. The appeals process weeds out those who are too ill to appeal, rather than those who do not qualify for the benefit.*In order to discourage fraud or exaggeration of disability, the claimant should be aware of the possibility of a 'spot check' to make sure the award remains correct, which would involve another disabled person employed by the DWP (like the current tribunal system uses.). I understand that disabled people are used as assessors in the US welfare system to discourage fraudulent claims.</p>
EM788	18/02/2011	<p>1. There are practical/physical barriers, such as access to buildings, transport etc. Even with access legislation there are still many non accessible areas. And even when access arrangements are in force there are barriers. For example, in a manual wheelchair getting up a ramp alone can be impossible (when I went to vote last time, the ramp was too steep for me and I had to wait for someone to go by who could help push me!). There is an expectation that if access complies with legislation the problem is solved, which then creates an even bigger barrier.</p> <p>*This relates to the crucial role of attitudes and expectations of society more generally and the problems these cause. The impact of government and media expressed attitudes about fraudulent claimants, which has become even more prevalent with the "cuts" agenda, is fostering a very negative perception of people with disabilities. There becomes a sense of needing to justify one's existence constantly and one's entitlement to any consideration. This creates an enormous stress and a sense of being "other" than the rest of "normal" society. When the emphasis is on the value of "hard working people" as compared to those who don't work who are a drain on society, people whose disability prevents them working are inevitably seen as invaluable too. I am very conscious of being seen as a less valuable member of society now that I have a disability which prevents me working and interferes with my ability to engaging fully in life.</p> <p>*2. A recognition that while mobility aids can help, they do not necessarily mean a person no longer has mobility problems that impact on their lives and ability to engage in and with society.</p> <p>*3. Mobility Aids - They are expensive. My Severe mobility problems require me to have a walking stick and wheelchair in order to maximise my ability to get anywhere at all. Walking sticks wear out; wheelchairs wear out, need maintenance and insurance.</p> <p>*The NHS does provide some mobility aids, but these are of a very basic type for most people. For example the manual wheelchair I was provided with was too heavy for me and</p>

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		<p>injured my shoulders. But as I am not a full-time wheelchair user (I do not use it in the home) I am entitled to neither a really light manual chair nor a powerchair.</p> <p>*An extra light wheelchair costs upwards of £1500, of which the NHS will pay approximately £250. A powerchair with supportive seating for someone with spinal problems will cost a minimum of £3000. In order to have powerchair I would also need ramps and hoist to get the chair into the house for charging and into the car. These will not be funded by the NHS (nor will the hoist they recommend I have for getting my manual chair into my car).</p> <p>*All mobility related equipment is very expensive (even without V.A.T.), as is specialist clothing which wheelchair users need - protective clothing for rain etc, gloves to use manual chairs etc.</p> <p>*Transport costs - I need a car to go anywhere and if I can't park sufficiently closely I must get a taxi. This means my transport costs are far higher than the average person. Without transport I can't get out at all. Because of my disability I need an automatic car, with a high seating position and room in the boot for my wheelchair. This means an expensive car and consequently is not cheap to run.</p> <p>*If the above are taken as offsetting my mobility problem, how am I supposed to fund them? (As I will mention in another section, these do not, in any event, stop me having mobility problems)</p> <p>*Other aids: There are many aids that I have bought in order to help me manage around the house – tools to pick things up/reach when I can't stretch; lighter (and therefore more expensive often) household items, such as cleaning tools; supportive cushions/chairs, heating pads; adjustable mattress, to mention just some.</p> <p>*There are many things around the house that I am no longer able to do - cleaning, looking after the garden, general basic maintenance. All these things I used to do in pre-disability days. I have to pay to have these essentials done by someone else (even allowing for help of family/friends). These are activities that are not considered by current DLA assessment, which I consider an essential part of living an independent life, particularly if, like me, you live alone.</p> <p>*Utility bills: Due to my disability I move very slowly and therefore feel the cold even more. I also have to spend large amounts of time at home (I spend about 95% of my life at home). I therefore have large heating bills - far larger than before my disability. I have more/longer showers and baths (help with disability symptoms) and therefore use significantly more water/power for this.</p> <p>*There are adaptations to the home that are needed. Whilst these are generally one-off costs, they are high. E.g. grab rails for bathroom/bedroom, extra rails for staircases.</p> <p>*Shopping: most of my shopping has to be done on the internet</p>

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		<p>(thank god for the internet!) and therefore I often have to pay delivery charges, sometimes return postage costs. Some things are cheaper on the internet, but grocery shopping loses out because you can't buy cheap food at or near its sell-by date. I buy more "convenience" foods than pre-disability as I often can't prepare a meal myself and this is more expensive. I also buy labour saving cleaning aids that I would not have previously considered, as they are expensive.</p> <p>*Technology – a computer is an essential part of my life, rather than a luxury or merely a useful thing to have. It enables me to keep in touch with the world, given most of my life is in the house. As I can't go around most shops, it is the only way of independently shopping. I can't access computers in library due to my mobility and other problems.</p> <p>*Prescription charges – although many people require long-term medication whether or not they have a disability, for me this is an additional cost I didn't have previously. Even with annual prepayment this is a big expense. There are additional non-prescription medications etc that can ease symptoms and are an on-going expense.</p> <p>*Holidays cost more - can't go for cheap deals because of need to ensure wheelchair accessibility. Always have to get a taxi to the airport or station. In a wheelchair I can't manage a suitcase etc. Need to stay somewhere central because of access.</p> <p>*The loss of my salary now I am no longer able to work (really!) also constitutes an extra cost in the form of less income. While this is not an "extra cost" for everyone with disability, it is for me.</p> <p>*4. I think there was a clear rationale why mobility had two rates and care had three when DLA was devised. Delineating mobility problems as two discrete levels makes sense and provides a fair encompassment.</p> <p>*However care needs are not so simply divisible and I believe that many people will be unfairly assessed if there are only two levels.</p> <p>*I am in the middle rate care. There is no way that I would (or should) qualify for higher rate care and yet my care needs are significantly higher/more than the lower rate. Even stretching the cut-offs to incorporate the middle rate into the higher and lower rates will inevitably leave many people wrongly assessed - most likely in the lower category.</p> <p>*I do not believe that having 2 rates for the care component will make the benefit simpler to understand - the distinction between the current 3 categories is very clear and there is a huge gap between the needs of higher and lower rate recipients.</p> <p>*There is no reason to think a two category care rate will be simpler to administer. Rather, it will be harder I think to fairly assign people to an accurately reflecting category.</p> <p>*5. Don't feel sufficiently knowledgeable to comment</p>

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		<p>*6. In addition to the activities mentioned in the consultation document, I believe that the ability to carry out domestic tasks (such as cleaning etc) must be taken into account, particularly for individuals who live on their own. Domestic tasks are essential for everyday life and if someone chooses to live alone/personal circumstances dictate them living alone, the inability to do such tasks means either someone must be paid to do them or else they will eventually be unable to live independently.</p> <p>*When assessing people's ability to carry out specific tasks, it is important to take into account real life situations, rather than theoretical. For example, transport doesn't run on time, traffic jams are a daily feature of life in a city. Therefore when assessing the length of time an individual might be able to sit in a vehicle/transport such factors must be considered. Very little in life runs smoothly in terms of the reality of getting somewhere, cooking, personal care, domestic tasks.</p> <p>*When assessing people's mobility this needs to be in the outside world, as well as indoors. Assessing capacity to do things and mobilise etc. in optimal conditions is rarely an accurate reflection of life. Flat pavements have cambers, bumps and obstacles that mean considering an ability to walk/use a wheelchair on a flat surface is not real life.</p> <p>*7. This is a real problem.....and requires careful analysis. Obviously a formula considering the proportion of time at the lowest level of functioning must be considered. But such an objective assessment will likely miss the cumulative effect fluctuating conditions have on overall quality of life.</p> <p>*Further, fluctuating conditions tend to be unpredictable. For example, I know that I deteriorate if I do too much – e.g. a hospital appointment or a meal out. It may take me anything between three days and two weeks to return to my optimal level of functioning, but I cannot predict how long it will be. Therefore a realistic assessment of how much of the time I am fully housebound is always a best, an inaccurate, guess.</p> <p>*A compassionate system that does not want people to fall through the safety net has to weight lowest level of functioning more highly than highest level of functioning and, indeed, average level of functioning.</p> <p>*8. This is an incredible important issue that has the potential to have a highly negative impact on a disabled person's life if the wrong decisions are taken.</p> <p>*Obviously if aids/adaptations truly mean an individual's mobility problems no longer have any impact on their life, then of course they should be taken into account.</p> <p>*BUT the reality is rarely this.</p> <p>*As such, starting with an a priori assumption that having a wheelchair means that a person is mobile is a complete misunderstanding of the reality for many people with mobility problems.</p>

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		<p>*To illustrate:</p> <p>*I have severe mobility problems. I can walk perhaps up to 10 small steps (on a good day) before I must stop and have a break. Each step I take is very slow and causes significant pain. However, sitting aggravates my condition and so even a wheelchair cannot overcome my disability (so identifying me as mobile because I have a wheelchair is unhelpful and inaccurate). I need to regularly get out of the wheelchair and move about, causing yet more pain, and slowing any progress in getting anywhere.</p> <p>*Before I received my wheelchair, I had thought it would overcome many of my mobility problems. Even without the above restriction the reality is very different. Using a wheelchair is incredibly difficult (anyone who assumes having a wheelchair solves mobility problems really needs to spend a couple of days in one trying to get on with their usual life). The world is not flat and smooth, so assessing an ability to use a wheelchair inside on a flat, smooth surface is meaningless. Pavements have cambers, bumps, obstacles and kerbs. The world is full of slopes (up and down cause problems), ramps are steep, often too steep to use if alone. If you have a wheelchair you need a car that accommodates it, you need accessible public transport etc. Not everywhere is accessible in a wheelchair yet.</p> <p>*Then there is the wheelchair itself. The local wheelchair service provided me with a wheelchair that was too heavy for me and aggravated my back and caused injuries to my shoulders from the efforts of propelling it (classic wheelchair athlete injuries I was told!), meaning it is even more problematic to self-propel. I self-funded a lightweight chair (having to pay 80% of the costs). As I am not a full-time user, I am not entitled to a lightweight chair on the NHS. Nor am I entitled to have a hoist provided for my car, which they recommended I need. Nor am I entitled to a powerchair, again because I am not a f/t user.</p> <p>*If regulations assume that an aid solves a problem fully, rather than recognising that it may merely ameliorate some aspects of the problem, people will be discouraged from getting that aid.</p> <p>*This is particularly the case when the optimum aid has to be self-funded - the NHS rarely provides the optimum aid for an individual, because it is generally significantly more expensive than a standard aid. Aids don't last forever. Disability benefit helps fund the costs of these. I am looking into the possibilities of self-funding a powerchair at some stage so that I could do a bit more. But it won't solve my mobility problems. Rather it will help a bit some of the time. If its effect is overrated by a future assessment, it may well be detrimental to my overall situation to get it.</p> <p>*Taking into account aids "the person might be eligible for and can easily obtain" is very problematic. Just because the</p>

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		<p>benefits agency assessor believes this, doesn't mean another agency's assessment will concur.</p> <p>*9. I think it is unavoidable that an assessment such as this makes claimants focus on the "negatives" of their impairment/condition/situation. If there weren't such negatives, there would be no reason to be applying for the benefit. Recognition of this is important. This is also why over frequent assessments can have a deleterious impact. I find that in order to psychologically/ emotionally survive (and more) my situation I need to focus as little as possible on what I can't do. However, if I am going to be accurately assessed I cannot but focus on the negatives – even if an assessment focuses on what I can do, rather than what I can't, by omission of "normal" activities I become acutely aware of what I can't do (I realise this is a somewhat circuitous statement, but I hope conveys my point. See also question 10). The fact that I have mobility problems has no positive aspect! The fact that I can take a few steps emphasises, for me, that I can't walk normally and that it is painful and curtails my life enormously.</p> <p>*In a job interview emphasising and focusing on what someone can do is essential. In an assessment of the impact of someone's disability/condition on life merely emphasising what can be done will always give an inaccurate picture.</p> <p>*10. Undergoing a detailed assessment with a new professional is a very stressful experience for many people with long standing disabilities. This is particularly the case given the purpose of this assessment. Any assessment will be much more comprehensive and accurate from someone with a long-standing knowledge/relationship with a patient (e.g. GP, Consultant Specialist, Physio, O.T., S.W. etc.)</p> <p>*If you have a long-standing disability that has a negative impact on your life, one of the most helpful ways of managing is to downplay and minimise the effects of your problems. This helpful way of surviving life with a disability is not a helpful strategy when being assessed by a benefits assessor. A professional who knows the true nature of your problems and its impact on your life is far better placed to make a valid and reliable assessment.</p> <p>*Considering information from healthcare and other professionals who work and know the individual (as is suggested in the consultation document) is very different from taking advice from them.*In general if the "independent healthcare professional" is employed by a private agency their independence will always be in question. Given a clearly stated aim of the change to PIP is to reduce the number of people who qualify for the benefit, any private company employed for the assessments will be under pressure to reduce the numbers who qualify for the benefit. This inevitably questions the independence of an assessment done by professionals they employ.</p>

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		<p>*Currently information is also sought from a private individual who knows the claimant in a personal capacity on a day to day level. Of course the objectivity of such information is always open to question, but they may often provide crucial information that no one else will ever have access to.</p> <p>*It also needs to be recognised that for many people with long-standing conditions/disability that the notion of the expert patient is encouraged and encourages self-management as far as possible. As such, on-going contact with professionals may not happen on a regular basis. Yet the professional they have previously had may still be best placed to undertake a meaningful current assessment as they will have knowledge of the history and a relationship with the patient to build upon.</p> <p>*11. As previously mentioned, it is unavoidable that there will be a focus on the less positive features of someone's life, which is stressful. In addition physically demonstrating what one is able to do can aggravate physical problems. At my first assessment for Incapacity Benefit my levels of pain and incapacity were increased by complying with the assessment.</p> <p>*Personally I do not see this as having a benefit for me and I wouldn't expect it to.</p> <p>*12. Prognosis provided by individual's consultant/GP should have a major role in determining both frequency and type of review. From initial assessments it should be clear if certain impairments are an inevitable part of a particular condition or whether deterioration is a clearly anticipated outcome. So, for example, if there is little likelihood of improvement predicted there is little to be achieved by face to face re-assessments or, indeed, long self-completion forms.</p> <p>*I suggest (see below) that simple forms are sent to claimants on an annual basis asking them to respond to a single question asking if there has been a change in their circumstances. This should be sufficient as review data for people with no/little likelihood of improvement. Perhaps every 10 years would be reasonable to ask this group of people to complete a more detailed self-assessment.*If an individual's prognosis is less certain or significant improvement may be anticipated/expected, then a review date should be established from this at the initial assessment stage.</p> <p>*13. Enable information regarding changes to be submitted on-line. Perhaps have phone help-line for people to check whether a specific change needs to be reported.</p> <p>*An annual letter/email could be sent to PIP recipients asking simply if there has been any improvement in their circumstances (asking for information about deterioration seems unnecessary). This would require a simple "no" response if there is no change or ask for details if there is a change. This would serve as a clearer reminder to people than the prompt at the end of the letter informing them of annual changes to payment, as happens now.</p>

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		<p>*Do not have such an emphasis on fraud, as there is in the consultation document. It will be far more effective in getting people to comply if they are asked about change in a non-punitive framework, rather than an assumption that people will try to claim fraudulently.</p> <p>*14. Information as to where they can receive independent help in completing applications if necessary. Information about the criteria used to make assessments, so people know what is relevant to provide information about in detail.*While I think it sounds very sensible to view PIP as an active and enabling benefit, I do not think it is helpful to confuse this with other active and enabling help that may be needed by someone and available elsewhere. If there is a need for such advice it should be made available elsewhere, e.g. with GP as gatekeeper, not DWP. Certainly information about what options are available will always be welcome. But there needs to be a realistic knowledge of accessing these services. *I think there will be an unhelpful blurring of boundaries that will be confusing for all concerned if DWP tries to take on a more active role than this.</p> <p>*15. There is a somewhat punitive tinge to the way this is suggested in the consultation document. I think a clear distinction needs to be between providing information and beating people with a stick.</p> <p>*Similarly, I think compelling someone to access advice and support is rarely going to be helpful. Who is going to decide when the “expert” patient knows what they need and when a Benefits Assessor knows best? If it becomes a condition of receiving PIP, all that will be achieved is a superficial compliance at best.*Ensuring that there are adequate resources in health and social care for people who need and want advice and support would probably be more useful.</p> <p>*16. I use my DLA to partially fund these. I have also used savings and taken out HP agreements to fund such things. So, my car was bought direct from a dealer on a finance agreement, as this was cheaper for me than buying through Motability. I use my DLA mobility component to partly cover the repayments.</p> <p>*17. I am not in a position to comment on this.</p> <p>*18. DLA has been extremely useful for me in gaining automatic entitlements for a range of helpful things, as detailed, as well as other services. It has also served as a passport in the private sector. For example, reduced travel costs, reduced costs for a “carer” to accompany me when necessary. All these services/entitlements have been incredibly important in helping make my life more manageable – practically and financially. Without them my access to society etc would be even further undermined by my disability.</p> <p>*DLA is incredibly useful shorthand for organisations to determine whether or not someone merits such services, without engaging in their own assessment.</p>

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		<p>*I think it may be useful to enable people to have access to the “passport” aspect of DLA, even if they do not wish/need to have the more important financial aspect of it.</p> <p>*19. It would mean multiple and lengthy applications for other services, such as those mentioned above. I suspect some people would no longer receive services/helpful concessions as organisations may well drop them, if they otherwise need more administrative input (particularly given the cuts). Also, the process of multiple applications will be too onerous for some people. Even with the best spin in the world, applying for something/needing something because of my disability forces me to focus on its limiting effects.*If there is a concern that some people only apply for DLA in order to access its passport aspect, see my recommendation above.</p> <p>*20. While undergoing multiple assessments for benefits/services is stressful and burdensome (and potentially aggravates some conditions), confidentiality of information must be paramount. Computer-held information is always open to fraudulent/hacking attacks. The more organisations/people that have legitimate access to data, the greater is the likelihood of confidentiality being breached. Of course, with permission, information can, and is, shared. But individuals must be able to refuse to permit one assessment to be passed to another provider, particularly when it crosses agencies, which compounds the risk to the confidentiality of information.</p> <p>*I am certainly not happy at the thought of difference agencies sharing information they have obtained in their assessment of me with another agency, without prior consultation and permission given.</p> <p>*There is a big difference in the rationale of different benefits/services that a person with disability may receive and I believe these may be compromised and important boundaries blurred if assessment information is shared. There would also, then, be a greater risk of mistakes being made.</p> <p>*However, merely telling another organisation that an individual is in receipt of PIP is less problematic. It makes it far easier, for example, that car tax exemption can be electronically confirmed.</p> <p>*21. Don’t have specific comments to make.</p> <p>*22. I have no problem with the idea of reforming this benefit per se and some of the motivation cited is laudable. However, the fact that the reform is linked absolutely with cutting the amount spent on DLA and reducing the number of people entitled to it suggests the underlying motivation is less praise-worthy. It also adds to the continuous attacks on people with disabilities being a drain on society, “scrounging” benefit etc. I think the manner in which this reform is being talked about has an impact on the attitudes of society at large to disabled people, which is becoming increasingly negative. There is also the cumulative effect because of the simultaneous critique of</p>

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		<p>people on incapacity benefit/ESA.</p> <p>*Changing the criteria by which people are deemed entitled to a benefit that acknowledges the additional costs their disability entails does not change the impact of an individual's disability. So, creating a higher threshold can reduce an individual's eligibility and the amount paid out, but it doesn't change a person's impairment and, hence, needs.</p>
EM789	18/02/2011	<p>Good afternoon I wish to make the following contribution to the consultation.</p> <p>* At a briefing on changes to welfare the issue of replacing DLA and the assessment for the replacement was raised.</p> <p>* During the briefing it was considered that those in work who receive the mobility element of DLA could lose it under the new system. This loss could result in them not being able to work. The point made was that the mobility element is the specific contributory payment that allows them to access the workplace.</p> <p>* It was also considered that if the assessment was medically based that the specific relationship between an impairment and the transport that the mobility element facilitates would be lost.</p> <p>* There will be cases where someone in receipt of the mobility element of DLA will be paying more in income tax and national insurance than the benefit received. In these cases it could be that loss of the mobility element in the new system may remove a disabled person from the working population with the resulting reduction in revenue to the treasury.</p>
EM790	18/02/2011	<p>Question 1:- The issues that prevent disabled people participating in society and leading full and active lives are predominantly because of attitudes within the wider society which discriminate against them. There may be issues associated with their disability but most of these will not disappear with the help of aids and adaptations. Many disabled people will experience fluctuations in their health. Many employers find these issues difficult to deal with in the workplace, this may be due to the type of work or sheer embarrassment regarding the disabled person. It is a well researched fact that in times of recession disabled people find it increasingly difficult to find employment and to remain in employment if their disability is fluctuating. Many employers do not have accessible workplaces.</p> <p>*Question 2:- The problems that have arisen with DLA are in my view due to the application form and the lack of understanding by the DOH Assessors of disability. I think that there is a lack of real understanding that most people do not want to sponge off the state and that the DLA has made a real improvement to the lives of disabled people and their carers. The different levels are useful in that disabled people can make an assessment of their needs against the different levels and can assess whether or not they should apply for the benefit. It is clear what the different levels are and it is useful to be able to</p>

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		<p>apply for the correct level.</p> <p>*Question 3:- The main extra costs are help with personal care, housework, and getting out of the house to do their shopping or attend a variety of personal events, such as attending hospital, going to their GP, attending family events and taking part in other activities.</p> <p>*Question 4:- This is very much like the existing benefit but only two rates will not take into account the existing spectrum of disability. There is a great deal of difference when a disability increases and the existing benefit takes this into account. It will not be sensitive enough to support disabled people properly.</p> <p>*Question 5:- Yes some health conditions should give an automatic entitlement to the benefit. I think that paragraph 19 shows some prejudice against some disabled people. How can anyone know how exhausting kidney dialysis is unless one undergoes it or has expert knowledge of kidney disease.</p> <p>*Question 6:- It is very important that disabled people have full and active lives even when they are living in a care home. The mobility component of DLA enables such people to go out and about in their local area, it might be that all the residents of a care home put some of their mobility component into a fund which is spent on maintaining or buying a communal form of transportation. To take the mobility component away from such people will make them prisoners in the care home. I think the activities that are most essential for everyday life are personal care, help with house and garden, getting out of the house to do some sort of activity even if it is just going to the local shops, being able to visit local special events and being able to take responsibilities within the family and wider community.</p> <p>*Question 7:- The new assessment needs to be sensitive to how the individual experiences their condition. The assessment needs to ask how people are on their worst day and how their condition affects what they can do.</p> <p>*Question 8:- The usefulness of aids and adaptations is not a good indicator of the assessment of a disabled person. They may aid the disabled person up to a point but only if the disabled person uses them and the aids are in good working order. Someone who has an environmental control can do lots of things within one or two rooms but the control does not take them to the toilet, make a meal or help them dress. It may open the door, switch on the television or radio or activate intercom systems but too much reliance on such things can be detrimental as they can break down without warning. They only help in as much as they can do very simple tasks.</p> <p>*I do not think that aids and adaptations should be heavily relied on in the assessment, in fact such aids and adaptations are very expensive and cannot always be easily obtained. I think this question really shows a lack of understanding about aids and adaptations, how much they cost etc.. Too much reliance on such things is detrimental, often it is very difficult</p>

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		<p>and costly to have them maintained unless this is done by Social Services Departments.</p> <p>*Question 9:- It is never a positive experience applying for a benefit of this nature as one has to focus on the things one cannot do. The questions should be clear as should the information about what it is for and who is likely to qualify. I would suggest that the Department undertakes focus groups with disabled people and their carers when the form is in a draft so that changes to it can be easily made.</p> <p>*Question 10:- The best supporting evidence is from the individual concerned, their carer, their GP, Consultant or District Nurse.</p> <p>*Question 11:- The Health Care Professional should not be a stranger to the individual, I would find the whole process intimidating. I don't think this would have many benefits as these assessments have become inappropriate and intolerable to the individuals undergoing them. It is inappropriate to ask someone with a very severe disability that they have had since childhood to go through such a process, to be asked whether one can walk when one is sat in an electric wheelchair is very painful when one has used a wheelchair since being a child.</p> <p>*Question 12:- Reviews are necessary but they should only be done in certain cases, they should not be done when the level of disability is never going to get better. This sort of evidence is available from lots of sources. A review should not be done too frequently as they are often upsetting for the individuals concerned. Information can be obtained from their GP, District Nurse or Consultant. Of course there should be different types of review depending on the needs of the individual and their disability.</p> <p>*Question 13:- This issue is one of trust, honesty and responsibility, if you know that people do not currently keep the Department informed about changes in their circumstances, then the Department should give people more of a carrot rather than a stick in these circumstances. The Department also needs to understand that if an individual is going through a change with their condition this can be a very negative experience because for the most part people in receipt of such a benefit are more likely to get worse rather than better. After all a disabling condition is not like having the common cold.</p> <p>*Question 14:- They need clear information in plain English.</p> <p>*Question 15:- The Government and the Department needs to fund disability organisations to do this. There are very good examples of this already.</p> <p>*Question 16:- Social Services Departments usually supply aids and adaptations. Some individuals get adaptations carried out through the Disabled Facilities Grant. There should not be an option to use personal independence payment to meet a one off cost. If one is considering buying an aid or having an adaptation it is essential that an Occupational Therapist or</p>

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		<p>some other professional advises the individual.</p> <p>*Question 17:- I have no views on this.</p> <p>*Question 18:- Yes it is useful for some people but I have no knowledge of whether it has been beneficial in my case.</p> <p>*Question 19:- I do not know.</p> <p>*Question 20:- Whilst the sharing of information about an individual may be useful to bureaucracies, it is an intrusion of privacy. I would be content about the matter if the agency wishing to share information got the individual's permission every time they wanted to share something with another organisation. The reasons for sharing the information should be crystal clear to the individual concerned. Yours sincerely,</p>
EM791	18/02/2011	<p>I have been in receipt of the highest care & mobility benefit for some years now. I had to stop working due to worsening Multiple Sclerosis and Severe Intestinal Dysmotility - I did not do this lightly, I liked my job and have worked since my children were of an age I could leave them. The money I receive goes toward paying for heating, washing, clothing, special foods, hospital visits and fuel for my car etc., without which I could not get out. It also allows my husband, who is my carer, to work at a much lower paid job than he is trained to do so that he can be near our home (2 minutes drive away) in case I need him - he also comes home in the middle of the day to see that I have everything I need. This of course, saves money on carers allowance etc. My size fluctuates on a daily basis due to the Pseudo Obstruction and I need to buy extra clothing to facilitate this, I also have an appliance that wears clothing out quickly. I had a medical before I received DLA and cannot understand why I would need another as both my illnesses are incurable and worsen with time - they will never improve. This is causing a lot of worry, which in turn causes stress - not good for sick people. The reality is that the money from DLA helps, but it is not enough to make us "comfortable due to me not working etc." and we still need to penny pinch". We had to relocate to a cheaper part of the country as we had a mortgage that we would not have been able to pay, this has meant that we are no longer near to our families and need the car to visit them. I am also very concerned that the benefit will be time linked to working age only. I had a company pension with my job, but since giving up work I have not been able to contribute. My husband is now working at a hotel and there is no pension there either. He had to draw his work pension when he went to work at the hotel so that we could make ends meet, so his is reduced as well. I receive DLA for an "Indefinite" period, which I assumed was to allow for the fact that we could not bring our pensions up to a reasonable level.</p> <p>**Please seriously reconsider the moves you want to take. It is very, very difficult coping with disabilities. Depression is only kept at bay by getting by. If you can't do that, what is life about?</p>

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EM792	18/02/2011	<p>Sir/Madam I am writing to explain the importance of DLA for my 2 year old daughter who is diagnosed with autism. 100% of [REDACTED]'s DLA is spent on supplying [REDACTED] with ABA (Applied Behaviour Analysis) therapy. Despite being the therapy with the most empirical evidence supporting its capacity to promote the acquisition of new skills and future mainstream integration in the educational system, our Local Authority has refused to fund it. DLA is therefore essential to us.</p> <p>*I would urge you to consider the importance of DLA for children with hidden disabilities such as autism - it is not just children with mobility issues who rely on it! Thank-you</p>
EM793	18/02/2011	<p>Disability Living Allowance reform – consultation questions</p> <p>*You can respond to the consultation questions in this document and send it to us at consultation.dlareform@dwp.gsi.gov.uk</p> <p>*1. Money. People with learning disabilities are amongst the most impoverished in our society. Transport. Particularly in rural areas it is not possible to get where they want to go. For example, for our trainees to get to work they have to get 2 buses and it takes them 5 hours a day. We have to use volunteer drivers (which technically we do not have access to, but the council have bent the rules for the duration of our funded project) or taxis. Taxis would cost £60 per day. Attitudes. low expectations and intolerance. Work demands. increasingly the job market demands high flexibility, good communication skills, ability to manage a wide range of demands simultaneously. Manual jobs which are easy to learn and do independently are disappearing. With support people can do more imaginative things lack of appropriate and dignified toileting facilities. People with profound disabilities in wheelchairs need hoists as they cannot manage the transit from chair to toilet. they are limited to 3 hour visits out, because of the need to change.</p> <p>*2. It is imperative that people in care homes retain their mobility allowance. Without this, they will lose the small amount of control they have over their own lives</p> <p>*3. transport costs - need for taxis see above</p> <p>*heating –</p> <p>*equipment - hoists and adapted facilities</p> <p>*support people - in order to access education and work, many people need a support person to be there, if not to supervise then to touch base with.</p> <p>*4. there is not enough information provided in the consultation to allow me to comment on this. It depends what the rates are and how they are calculated.</p> <p>*5. some health conditions should mean automatic entitlement</p> <p>*6. as well as the obvious (health. housing, safety), mobility and personal relationships MUST be prioritised</p> <p>*7. flexible and responsive administration. passport access</p>

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		<p>to ensure people do not have to make a new claim each time condition worsens.</p> <p>*8. Your response: the latter aids and adaptations should be included using FACS criteria and should be tapered rather than having an absolute threshold (eg no support for moderate impact on activities and mobility). this is because some people at moderate may well lapse to substantial or critical need if there is not adequate support</p> <p>*9. Your response:</p> <ul style="list-style-type: none"> *use all accessible media *use consultants who have learning disabilities to create and road test the forms. *co-operate with the voluntary sector and advocacy groups so that they feel ownership of the new benefit. <p>*Note: if you persist in cutting mobility allowance for people in care homes, you are going to alienate the very people who you should be relying on to support the implementation of this reform.</p> <p>*10. 1. the person themselves</p> <p>*2. accessible evidence eg Multimedia profiling which uses photos and films created by/with the person to provide evidence of activities and mobility 3. carers</p> <p>*4, social workers who know the person well</p> <p>*11. It depends entirely on how well people are trained. Experience with the capability assessment has shown that regardless of how sensitively the descriptors are drawn up, if the assessors are not properly trained, are seen as prioritising cuts and saving money, and do not have a full understanding of the lives of disabled people, the process will be experienced as humiliating and degrading, fear inducing and will lead to a huge number of cases going to review (i believe that current estimates are that around 40-50% of appeals are being accepted in the case of some benefit claimants -see the Harrington Review and there is a steep upward curve of appeals. this is a huge waste of taxpayers money and totally needless). An advocate should be present to support anyone who wishes.</p> <p>*12. should be determined through a process of negotiation by the individual in consultation with professionals. Health and social care professionals should advise on the possible time range for different conditions</p> <p>*13. by making them feel confident that the process is about their needs not about saving money. This would all be much easier if you were not simultaneously operating a slash and burn approach to community resources. For example, if you can train and encourage people to visit their local libraries to find out information, they will not be so dependent on support. However, if there is no library or the hours are so limited and the librarians so stressed and untrained that they cannot help, this will increase dependence.</p>

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		<p>*14. see above. There needs to be a community mapping service, and this could be run by people with disabilities themselves. I think it would be better to separate the roles, but it would certainly help to have some simultaneous signposting</p> <p>*15. Requirement, eh? Well the first thing is that there is so much muddle and confusion that it is really difficult to get good advice. We have been trying to get advice for our trainees and running into the sand. *as councils cut support and charities go to the wall, the access and support becomes even more limited and superficial. If the requirement means you have to talk to yet more ill informed and stressed people who have nothing to offer then it will be seen, quite rightly as a fig leaf for coercion. I</p> <p>*16. My main experience is in the field of communication aids. After a short period with CAP where it was possible to get state funding to allow people the tools they need to fulfil the basic human right to communicate. At present i know that one young man, leaving school, is required to leave his aid behind with the education system and apply for funding himself to get the aid he has been recommended.</p> <p>*I know of another lady who spent months on her back before she died because she was unable to get her wheelchair mended. her death was undoubtedly the result of pneumonia incurred because of the failure of services to meet her needs.</p> <p>*of course PIP should be flexible enough to do this.</p> <p>*17 Your response: Train your assessors properly and use play based materials.</p> <p>*18. I don't have the relevant information to answer this</p> <p>*19. I don't have the relevant information to answer thi</p> <p>*20. I don't have the relevant information to answer thi</p> <p>*21.</p> <p>*22. The proposal to take away mobility allowance from people living in care homes is iniquitous, inconsistent and retrogressive. The analogy with hospital is completely misplaced. These people are not ill, where they live is their home.</p> <p>*Since regulations require you to take account of the need for access to health and to interacting with others, removing personal mobility allowance will mean you are in breach of your own terms and conditions. I quote:. "Proposals to replace DLA with a new benefit that is better focused on helping disabled people to lead independent lives provide an opportunity to promote equality of opportunity to those least likely to live full and active lives".</p> <p>*Removing mobility allowance from people in care homes will do exactly the opposite. This is because mobility is quintessentially to do with individual choice and autonomy in a way that health and care are not. Whereas with health and care it is evident that a basic set of requirements MUST be put in place to maintain life, mobility is about quality of life. People do not die because they cannot go out. So it must be within the</p>

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		<p>governance of the individual where and when they want to travel.</p> <p>*When an individuals care package is negotiated, this is on the basis of an averaging of the amount of basic care and support they need. Individuals have almost no input to this process. Mobility allowance is different. You cannot negotiate a package on the basis that Jane will want 10 cinema trips, one holiday and 14 visits to friends per year - or if you do, you are institutionalising her. What Jane needs, what she has at the moment, is a small sum that allows her to change, learn and grow and make her own decisions about where she will go tomorrow, next week. It is the one thing that people with more severe disabilities can really understand. If you take this away, we will be going back to the situation where it is institutions who decide where people go and when, on the basis of the good of the greatest number. BAck to the Sunshine bus, with large groups going to Butlins. Is this really what you want? The only way of avoiding this is ring fencing (which is clearly not going to happen). If you are ring fencing, you might as well give it to the individual. Are you really saying that personal budgets and individual decision making is barred to people because they live in a care home? The cut is going to mean that people I know will not see their families, will not gain the experiences they need to grow and change. It runs counter to ALL governemnt policy - Valuing People- which has been moving towards independence, full and active lives.</p> <p>*in a situation of severe cuts, going out and trips are what will be slashed. Already in my area people are sitting around in portokabins being warehoused with low paid undertrained staff (the price per head being cut from £51.25 to £30, which means only the most basic care) After 30 years of gradual improvement in adult services I am now seeing services back to how they were in the 1970s when I first started working as an SLT.</p> <p>*This is one of the most vindictive measures I can imagine. How a prime minister whose own son was disabled can countenance it I cannot think. I would urge those civil servants and the minister concerned to spend a week shadowing tenants in care homes. They might then gain a tiny insight into what this allowance means to people who are living on the margins of our "big" society.</p>
EM794	18/02/2011	<p>1. I have very reduced mobility as a consequence of my condition Multiple Sclerosis. Up until 2 years ago, when I was diagnosed, I used to be very active but now trying to keep on working takes all my energy. I have had to cut down my hours quite radically to try and reduce the number of relapses I was experiencing during the year and therefore my part-time hours have had a serious impact on my income. *DLA helps me bridge that loss of income but more importantly, is essential to my continuing to work. Access to transport is a great barrier to</p>

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		<p>being able to carry on working. I live in Belfast County Antrim but work in Holywood, County Down and therefore cannot avail of the Door 2 Door transport scheme to drive me to and from work. There are many days in a month when due to extreme fatigue and pain I cannot drive myself to work. My only option is to take a taxi from my house to the train station (less than a mile which I can't walk), take a train to Holywood and then call a taxi to take me to my work. This commute sucks up a lot of my energy and is extremely costly. DLA allows me to spend money on private transport without which I would most certainly be obliged to take sickness absence on my bad days. Staying in employment is essential to me, for my lifestyle but most importantly for my state of mind. It is my lifeline in remaining independent and not relying on income support benefits.</p> <p>**The biggest problem I face living with MS everyday for the rest of my life is staying independent to go to work, to shop, to enjoy cultural events, attend sport events, to meet with friends, participate in sporting activities, ...because access is the first thing that comes to my mind. Everything must be planned and thought out carefully, the most insignificant trip to a shop, a pub, an airport...can turn into an enormous mountain. My condition is unpredictable and changes in the levels of pain, spasticity, fatigue vary from day to day, hour from hour. Without DLA, I will no longer be able to assess my current needs and find the best strategy to meet those needs.</p> <p>*Staying in employment takes most of my energy out. Most days, I come home and go to bed. Looking after my house is difficult for me. Cooking, even though I enjoy it is a huge task. It is painful to vacuum and mop as it requires walking...and I walk with two sticks! I spend all my free time at home, rarely going out; therefore I want to be able to enjoy a clean and pleasant environment. Without DLA, I will no longer be able to pay for a cleaner to come once in a while to give me some help with housework. I will no longer get my groceries and vegetables delivered and in the long run, my diet will suffer and so will my health.</p> <p>*Any adaptations or equipment to help me live in my house have had to be bought as I am still waiting on an occupational therapist to come and assess my requirements, more than 16 months after requesting it.</p> <p>*Another great problem is a direct consequence of the lack of access to physiotherapy and holistic therapies on the NHS. Living in constant pain and having reduced mobility means that I can either manage with a lot of medications, which are added to the heavy treatment I am under or use holistic therapies to help me manage pain and keep my muscles and joints moving. I attend a chiropractor once a month and once in a while attend reflexology and massage therapy. Each treatment costs between £30 and £45. Without DLA, I will not be able to take responsibility for the care of my health by being proactive and</p>

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		<p>seeking non chemical means to manage pain and fatigue.</p> <p>*Wanting to be active when you are disabled requires a will of iron and determination. Accessible leisure centres, shops, bars and restaurants, further education colleges...are few and far between. Having to phone in advance to plan a trip or visit means that often I decide to stay at home instead. To go out to buy a loaf of bread is a big deal, because the logistics of it require a lot of energy. I can't afford to get a motorbility scooter now with DLA, how will I ever be able to buy one to keep up with my increasing disability without DLA?</p> <p>*2. See above. To meet with the changing needs of living with a condition like MS and try to stay in employment and live independently.</p> <p>*3. Suffering from MS myself, I can only strongly suggest that conditions for life such as MS attract automatically entitlement to the benefit. Imposing an assessment suggests that there is a consistency in symptoms and disability, everyday is the same and therefore assessment can be validated. It is near impossible to measure fatigue and the impact fatigue has on the cognitive side of things as well as the physical side. On my bad days, I can't wash and dress on my own. But on good days, I will do it on my own.</p> <p>*How can someone assess the needs and circumstances of a disabled person they don't know, unless assessments can be made by living with a disabled person for at least a week? With a condition like MS, there is no standard. No two sufferers are the same. You can't fit it into a well defined box.</p> <p>*The non visible impact MS has on my health can't be measured: fatigue, managing my bladder by self-catherisation, managing my bowel with peristeen, the constant pain and its impact on mood and motivation, slurred speech during relapses...etc. My condition will not improve, ever. It will stay as it is in the best case scenario. I can only hope that it does not worsen too quickly, as I am only 37.</p> <p>*My needs are not critical as I still manage to live independently and work for my income. Does it mean that I will not be supported anymore? If that's the case, I will no longer be able to look after my health the way I can with DLA. I will no longer be able to get private transport to go to and from work, work part-time...and very quickly I will be back in the vicious circle of getting multiple relapses a year, therefore developing critical needs which will require more expensive support from the state at increasing costs.*The reform of DLA is very short-sighted and will have a great impact on increasing costs in the long term.</p> <p>*4.</p> <p>*§ Being able to live as full a life as a partner, parent, friend by enabling disabled people to be as independent as possible</p> <p>*§ Keeping clean and living in clean home</p> <p>*§ Keeping healthy by having access to healthy food and</p>

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		<p>holistic therapies</p> <p>*§ Working- having support in getting to and from work</p> <p>*§ Keeping fit by having access to leisure and sport</p> <p>*§ Continuous personal development by having access to learning and CPD and by getting access to specialised career coaching to manage change in health and its impact on employment</p> <p>*§ Access to transport for social activities which does not require a 48 hour booking</p> <p>*Everyone is entitled to enjoying spontaneity in their lives, like deciding to meet up with friends or going to the cinema.</p> <p>*5. With fluctuating conditions like MS, the only way to assess accurately the needs of individuals is to take into account all the healthcare professionals who are involved in a disabled person's life and care. They are the people who can give a realistic picture. To be assessed by a general practitioner without any specialist training in MS is just insulting. In my case, assessment for eligibility should take into account what my MS nurse has to say, my neurologist, my continence nurse, my chiropractor, my psychotherapist...etc</p> <p>*Filling in the DLA application form has enough of a humiliating experience for me; an interview would be very stressful. The assessment should be made during relapses and thorough the year to take into account the many changes I face regularly. That type of assessment would be impossible to administer and would be a great cost.</p> <p>*6. I can walk short distances with two sticks! Wow! Should I be encouraged to use a wheelchair now so I can travel longer distances? Therefore reducing my needs in mobility support? That would ensure that my walking worsen quicker, my bowel and bladder problems too.</p> <p>*With regard aids and adaptations that can easily be accessed, I am laughing out loud as support services are not flexible and responsive. I had to buy my own walking sticks, otherwise I would have had to try and get an appointment with a neurophysio (4 months minimum waiting time for referrals) or go and sit in Casualty department of local hospital for hours on end to waste critical time of emergency service healthcare professionals. If I want to stay in employment and carry on with my life, I can't rely on support services meeting my needs in my time frame. DLA helps me do that.</p> <p>*7. All the healthcare professionals involve with the individual</p> <p>*8. Assessment should take into account the worst of my symptoms and the limitations they have on my life. However, during a bad relapse, I am unable to speak, think, get up and wash, eat. An interview would increase the level of stress I would be under already (thinking about whether I will be able to work again, will the new symptoms go away, will the pain stop, how long will the relapse last...etc)</p> <p>*9. I experience new symptoms very frequently...new burning</p>

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		sensations in part of the body, headaches, changes in my vision, loss of feeling in face, spasms in new parts of the body, weakness in hands, incontinence, constipation...it is difficult enough to keep a diary to discuss changes in my condition with my neurologist every 3 to 4 months...it would be impossible to keep the Department informed of every single change. How would it be administered?
EM795	18/02/2011	Hi changes would be a disaster as some people who qualified before would miss out. People are struggling enough without being cut of altogether and the disabled are an easy target to focus on as a lot arnt able to fight back themselves.
EM796	18/02/2011	<p>For info, I am the parent of a 5 year old boy with Duchenne Muscular Dystrophy.</p> <p>* 1) The barriers to prevent independant life are that society is not fully accessible. Not every place is accessible or suitable for my child. Public transport for those that can't drive is often not suitable or accessible. There are not enough disabled parking spaces. Society is not very accepting of disability and with all the recent publicity about the costs of publicity and the suggestion that costs should be saved on DLA only fire that. My son will never be able to go out on his own, I am not able to do enough for him due to time constraints and other children. Many disabled people, my son included, are simply too tired to get out and about enough, it is part of many medical conditions and is unavoidable.</p> <p>* 2) I think it should stay entirely separate from Council funded care otherwise they will simply be swallowed up and the Council will end up spending the DLA equivalent allowance, and not provide any council funded care. There should be some automatic entitlement for some conditions. For instance Duchenne Muscular Dystrophy is progressive. They need a huge amount of extra care than any other child of their age and always will. As adults they will all be totally dependant on a carer, the only variable being how long they spend in hospital and how old they will be when they die. Families and sufferers are under a huge amount of stress already, why add more, which will also involve extra costs to the government.</p> <p>* 3) Extra costs. For physically disabled children: lack of access to standard childcare which means parents are unlikely to be able to work. The cost of equipment is horrendous, everything is dearer, starting from a toilet seat that costs £45 for my 5 year old and is not eligible for funding, to his £1800 wheelchair which we had to buy ourselves because the NHS was unsuitable for his needs. We have to run a large car, we can not walk very far with him (I can not push him and my baby daughter). The nearest suitable school is a drive away so I have to pay for petrol or he has to have transport. We have to have an extension. The Occupation Therapists, grant officers from the council, specialist architect were all in agreement that the only way to provide my son the space he needs (under DDA) and to</p>

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		<p>lead a normal family life will cost £100,000. There is no way cheaper but we can only claim £30,000 DFG, thus leaving a £70000 deficit. Beds cost £4000k plus. He will need equipment just to lift his hands, specialist laptops etc, very little of which is funded. He needs specialist swimming lessons and horse riding lessons for his muscles and core strength plus self esteem (he is a child!), which I have to pay for. I can not access many regular activities for him, most places as he gets older will require an escort, when healthy children could do things on their own, that includes cubs, scouts etc as well as all the other activities young children like to do these days. My local wheelchair services do not provide power wheelchairs for his condition, as the expectation is that charities will pay. However, as we both work we are not eligible for much charity help therefore we will have to buy his, no doubt he will need more than one over the years at a cost of £30,000+. I am going to have to give up work in the near future due to lack of childcare, he will even need an escort for his holiday club at a school with a resource base specialising in disabled children. There is little funding for that. I will therefore have to live off Carers Allowance with is a pittance, and therefore in reality DLA just goes towards the cost of equipment and for the fact that someone has to stay at home to care. When they are over 18, it is something to try and bring them out of poverty a fraction.</p> <p>*4) Two rates for each component is a blanket approach and does not take individual circumstances into account.</p> <p>*5) Automatic entitlement. Yes, see above. Duchenne Muscular Dystrophy being an example, and Motor Neurone Disease for another. Being totally blind, being totally deaf for instance. There are many more. Specialist advice from working neurologist and other consultants should be sought. No one with Duchenne Muscular Dystrophy improves, they gradually deteriorate until they die, and there are charities and specialists that could document that perfectly.</p> <p>* 6) Prioritise support. For starters actually listen to the feedback you receive. Do not judge your idea of disabled living by that of David Cameron's son. The vast majority of disabled people do not have his resources. It is essential for people to have personal care, and preferably to take into account who provides that. For instance, if it is family, provide a decent carers allowance so they can afford to give up work or work part time or do what is necessary to care. It is essential all personal care is met with dignity, and when they need it. It is essential to lead a full family life, be able to go out and socialise and see people, and not be a recluse in your own house like most seriously disabled people. Children should have the right to have escorts to allow them to take part in activities for a healthy normal life or just so their parents can work work, (to fund the expenses as above).</p> <p>* 7) variable conditions. Take advice from those people's</p>

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		<p>consultants.</p> <p>* 8) Take into account aids? No, absolutely not. Having a wheelchair does not make you mobile. A wheelchair is a difficult thing to use, it does not make the person in one have the same life as a person not in one. Having a laptop to speak to your friends doesn't mean your communication is the same as a healthy person. Did David Cameron consider his son as fully mobile as his siblings because he had a wheelchair. It is a disgrace to take this into account and is actually a disincentive to improving your life. In fact, needing this equipment usually means you have to buy it or contribute it, taking into account the state of the wheelchair service, the cutbacks in Councils etc etc. People that need this equipment actually need more money. Wheelchairs often don't go on buses, there is no way a person in a wheelchair can safely use busy city centre buses for example, they just can't. It would be a disgrace to include this.</p> <p>* 9)</p> <p>* 10) Feedback and reports from the consultant dealing with the person, and also physiotherapists, psychologists etc. In reality most people send in evidence from these people anyway, so why not take advantage of it and actually read it. These people know the persons life so much better than a general expert who studied the persons condition for a brief period at medical college. In fact, most GP,s for example deal with one case of muscular dystrophy in their careers. surely you need to listen to the individual experts involved?</p> <p>* 11) Face to face situations would be very distressing for seriously disabled people and what can they tell in a brief meeting anyway? Children would find it distressing having to justify their condition for a stranger when they may be unaware of the facts themselves. My son knows he uses a wheelchair, he doesn't need to know how seriously ill he is yet. That would apply to many others too. How can a brief meeting show the assessor that after walking into a supermarket my child's behaviour would become terrible, he would have to go home to bed to rest all because he did something that a person who didn't fully appreciate his condition asked him to do. He can do PE at school for instance in a limited way, but they he has to stay in his wheelchair for the rest of the day. Just the evidence of one activity for instance does not show how it affects a persons life. Only the experts who know him intimately knowthat.</p> <p>* 12) Review? In conditions that can improve, than perhaps yes. However a paraplegic is unlikely to change much, or only worsen, why go to the expense of doing this. Yes, different reviews are necessary according to the condition.</p> <p>* 13)</p> <p>* 14) Advice needed. All people should have the right to have an independant person to help them fill in the forms. Many</p>

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		<p>people actually underestimate how their conditions affect them because they have learned to live with it.</p> <p>* 15)</p> <p>* 16) Many seriously disabled people have to rely on fundraising by friends and family such as running marathons etc. Fit for purpose equipment should be provided as a matter of course by wheelchair services, OT services etc and certainly not via their Independence Fund. That again, is penalising the most seriously affected people and it will end up basically that social care & equipment will totally swallow up any payments for things that should be paid for by the state, and is eventually worthless.</p> <p>*Most able bodied people would assume that things like wheelchairs etc are provided anyway, if they knew what really happened, and what could happen in the future they would be against it, they simply just do not know.</p> <p>* 17) Children. They need to develop like other children, they need to develop social skills and lead as normal a life as possible or how will they cope when older? Consideration should be given to the parents and families that give free care, and struggle day to day as David Cameron claims to understand. These conditions are so complex that advice should definitely sought from their consultants. Children have a right to a childhood, as do their siblings.</p> <p>* 18) DLA is essential to accessing other services, this should continue, in particular motability cars (even when in residential schools and homes, as presumably they still need to go out, even if just for being taken to medical appointments, let alone having a real social life). Lack of access to suitable cars will only make a condition worse through depression etc.</p> <p>* 19) Without this facility even more disabled people would spend their lives justifying themselves to others (they spend enough time doing that anyway). Repeatedly being assessed for services etc is a waste of tax payers money. Once should be enough.</p> <p>* 20) I think the proposals discriminate against disabled people. They would not be able to lead lives that we all consider our right, ie to eat well, heat our houses, go out, be educated, have a social life etc. I believe depriving people of these rights, which is what will happen when financial pressure on these people is increased even more, is actually against Human Rights legislation (as per the Muscular Dystrophy Campaign). .</p> <p>* 21) I would like to add that it is morally wrong and unethical that disabled people are being targeted in this way. Many disabled people simply can not work, and even if they could perform minor tasks, most employers can't or won't take them on. Why should work always make a person better off if you are seriously disabled. Why should my son be penalised for his condition. There are benefits such as fuel allowance being paid by wealthy 60 year old, some of whom live in Spain, why are</p>

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		<p>they allowed to continue when the Gov is looking at cutting every little thing that helps seriously disabled people live the limited life they already do. My son did not get us in this situation,. it could happen to anyone. We have always worked and not claimed anything, yet our family feels persecuted, starting with cutting our child benefit (when people earning twice us will keep it) to cutting all my sons services and ultimately his living allowance. We all appreciate cuts need to be made, but why target DLA on top of everything else, when your own figures state that less than 1% of claims are fraudulent. The aim is to cut DLA by 20% +, by definition, this will affect 19% of innocent disabled people. How does this fit in with the Big Society and the promises that David Cameron made in honour of his son. It really feels like the Conservative voters are being taken care of, but even conservative voters can become disabled. I think the cost of these changes could be better spent elsewhere, maintaining essential services for vulnerable people. Regards</p>
EM797	18/02/2011	<p>1. There are so many barriers, for so many different types of impairment, that it is almost impossible to say. I will describe my own experience as a young, physically disabled woman with a progressive degenerative condition.</p> <p>*The barriers I have faced in preventing me from participating in society and leading an independent, full and active life:</p> <ul style="list-style-type: none"> *- Impacts of life-long discrimination due to inability to participate fully in school *- Psychological impacts of coming to term with chronic disability *- Physical barriers of accessing transport, including the pedestrian environment *- Not having access to appropriate equipment at the right time *- Being trapped in inaccessible housing *- Lack of fully wheelchair accessible housing *- Not having access to appropriate care services and, when care services were available, the difficulty of accepting the need for this *- Lack of coordination between services including employment, health, social care *- Being trapped in a local authority area due to social care funding/ social housing allocation criteria *- Capital limits on social care meaning that it is not in my interest to save, for instance, for a deposit on a house. *- Lack of knowledge of GPs, local authority social care and health staff *- Lack of information about access <p>*The things that have enabled me to have a full and active life, including working full time, acting as tenant representative, being a trustee of two charities, and being involved in "normal" activities of cooking, shopping, socialising....:</p> <ul style="list-style-type: none"> *- Having time to come to terms - this has taken many years

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		<p>which included periods of great psychological distress</p> <ul style="list-style-type: none"> *- A car at age 17 paid for through DLA *- Support from an Occupational Therapist from the Muscular Dystrophy Campaign to access care and appropriate equipment *- 24 hour care, funded through social services, ILF and DLA *- Being able to claim HB for an extra room for my live-in PA *- Being able to choose and buy the right equipment for me, without the interference of the local authority <p>*2. DLA should remain as a non contributory, non means tested benefit, not linked to whether or not a person works</p> <p>*3. Some examples: Care costs: My live-in care is extremely expensive and I am very lucky that my social services provides me the funds to purchase it.</p> <p>*Care expenses: I use 24 hour live-in care. That means as well as the normal everyday costs I have, I also must pay the expenses of my PA: her accommodation, food, travel expenses, tickets. At one point these were not covered by my care package, and though that package already took account of half of my DLA (care) I used the other half to pay for these.</p> <p>*Transport: Living in London where buses are accessible I am lucky, but when I go outside the city I am reminded how difficult and costly accessible transport can be. I often have to drive and then, despite having a blue badge, may have to pay expensive parking costs, or I pay for an accessible taxi. Two years ago I went on holiday and had to pay to park my car in the expensive short stay car park at the airport, because the transport from the cheaper long stay car park was not fully accessible.</p> <p>*Equipment: My powerchair costs £20,000. The lightweight manual wheelchair I use costs £2,500. Access to Work and NHS wheelchair services pay towards these, but services are different around the country, and criteria of what can and can not be provided differ. I have three different manual chairs for different purposes. Two have been purchased privately. I have also purchased lifting equipment costing £900 because my social services is unwilling to provide the equipment that meets my needs. I use DLA and savings to pay for these.</p> <p>*Physiotherapy/ exercise equipment/ hydrotherapy: There is no treatment for my condition but exercise can help to slow the progression and maintain movement. I cannot use standard or even "accessible" gym equipment. I pay for fortnightly physiotherapy at £90 per hour. I pay for a personal trainer to work with me (trained by my physiotherapist) at £30 per hour. I have a specialist active-passive trainer and a standing frame, both of which I have purchased privately at around £4000 each. I use a combination of DLA and savings to pay for these. I also attend hydrotherapy once a week. I am extremely lucky in that I have a council-run hydrotherapy pool near me. When this was closed for 2 years I had to travel for an hour to use a pool at a cost of £10 for a 30 minute session.</p>

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		<p>*Holidays/travel: I do not often go on holiday as it is too complicated to organise, but when I do travel away from home I often have to stay in more expensive hotels than I would like as they tend to be the ones that have the accessible rooms. On a weekend trip to Paris, the wheelchair accessible rooms were in the highest price category and there was no discount.</p> <p>*Heating: Because I have very little muscle I am always cold and I tend to keep my heating on all the time.</p> <p>*Accommodation: When I first moved to London I rented a property which was large enough for all my equipment, to manoeuvre a wheelchair and with a spacious bathroom, within driving distance of my work, and with an extra bedroom for my PA. The yearly rent was the same as my annual salary. Eventually I received some discretionary Housing Benefit to cover the extra room but I needed DLA to live on.</p> <p>*Odd jobs/ house moves/ painting and decorating: I cannot do any of these activities myself, and my PA is engaged supporting me. If I have any odd jobs around the house I have to get in a handyman. When I moved house I needed to use a removals service rather than just hiring a van and doing it myself.</p> <p>*4. I don't see that this would make anything easier or harder to understand particularly.</p> <p>*Having three rates for care as currently stands neatly divides the levels of care need that individuals have. However the current rules are not necessarily correct as someone might need care during the night (because they need to be turned, can't sit up etc) but not have a great need during the day. It does not follow that the needs are cumulative.</p> <p>*5. For administrative purposes it may be simpler to have some automatic entitlement to benefit, however the current entitlements may not be the appropriate ones. Someone with a high level of spinal cord injury is very likely to have a very high level of care need, as is someone with Duchene Muscular Dystrophy or Spinal Muscular Atrophy. Why spend a lot of money, time and effort on filling out lengthy forms or attending interviews if it is not necessary? This benefit is not an out of work benefit and therefore there is no test of someone's ability to carry out work related activities, but rather it is intended to go some way to meeting someone's transport and care needs.</p> <p>*6. It is a shame that ILF has been abolished, and I wait to see what is intended to replace it with. If PIP were to operate on a similar basis to ILF then it might be welcomed.</p> <p>*I cannot speak for people with sensory or mental health impairments. I am physically unable to do anything other than speak, type and eat. Within years I will need to be helped to eat. I get that help and I live a full and active life. However, getting that help was not easy, and the postcode lottery of local authority social services is terrifying, and a barrier to movement (for instance to take up work). Local authority care may be</p>

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		<p>restricted to getting up, getting dressed, washing (a strip wash is acceptable), toileting (incontinence pads or a commode), feeding, and then getting to bed. This does not make a full and active life.</p> <p>*Essential activities are those which make a person feel human and part of everyday society. For me those activities are:</p> <p>*Shopping to buy clothes that I like</p> <p>*Shopping for food that I want to eat</p> <p>*Cooking</p> <p>*Having friends round for dinner</p> <p>*Doing voluntary work</p> <p>*Having a long, relaxing bath</p> <p>*Going to the cinema</p> <p>*Of course, I would not be able to do any of those if I could not get up and washed and dressed at a sensible time in the morning, or if I had to go to bed at 9pm, which happened when I had inappropriate care services.</p> <p>*7. I cannot comment on conditions that fluctuate. My own condition is progressive. It will get worse and there is no treatment. It makes little sense to reassess me, although I would readily supply a 3-yearly letter from my consultant if that is what is required.</p> <p>*8. If aids and adaptations are taken account of then it MUST only be those which an individual is already using. It would be dangerous to consider those that a person might "easily obtain". In my experience equipment and wheelchair services run by social services and community health are not good at meeting the needs of people with rare and progressive conditions. Forcing someone to have the wrong equipment is mentally destroying and it would not be appropriate for an untrained benefits assessor to make those types of judgements. Being made to use inappropriate equipment by an ill-informed OT led to me requiring a higher level of care and being unproductive at work for 6 months. Many newly disabled people, or those with progressive conditions, take time to find the right equipment and to adjust to using it.</p> <p>*However, it could be seen that some people, with what might be appear to be more severe medical conditions, with the right equipment are less disabled (under the social model). For instance a double amputee with the right wheelchair. But, that person will still have extra costs relating to being a wheelchair user. And it may have taken them a long period of rehabilitation to get to that level of ability.</p> <p>*9. No answer</p> <p>*10. It depends on the individual. In my case my consultant and private physiotherapist are the ones who know my condition the best, after me.</p> <p>*11. My condition is very rare. My experience of "healthcare professionals", either social workers, occupational therapists, physiotherapists, wheelchair therapists, GPs working in general</p>

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		<p>fields is not good. They tend not to have any knowledge of this condition or the little knowledge they do have is often incorrect as there are many different types. Many social services staff are compromised in their professional ability due to always having to think about budgets.</p> <p>*A good, independent OT should be able to carry out client centred assessment of need. This should, as far as possible, be in the individual's own home, or other centre (such as an advocacy or disability advice centre) of their choosing, at a convenient time.</p> <p>*12. Different types of impairment could have different review timetables, based on the prognosis of the individual's medical practitioner.</p> <p>*13. Make it easy and joined up to do so. Use modern communications techniques such as an online form. Be clear about the consequences of reporting changes, and perhaps have a buffer period of a number of months before making changes to benefit.</p> <p>*14. I do not think it is appropriate to provide information other than basic signposting. It could confuse the point of the benefit.</p> <p>*15. I do not understand this. What action are claimants expected to take? DLA is currently an in-work benefit aimed at paying for the extra costs of disability. "Action" does not necessarily lessen those costs.</p> <p>*16. If the PIP is an ongoing benefit then there should be no restrictions on what it is used for. This sounds like the distinction between social services Direct Payment and central government benefit payments could become blurred and confused.</p> <p>*Of course the PIP should be used to fund equipment that is not available through other avenues. This does not mean that those avenues should be cut.</p> <p>*17. No response</p> <p>*18. Very important. DLA is generally accepted as proof of disability for most concessions or access schemes, as well as nil cost VED, blue badge and Motability.</p> <p>*19. Some other national or local "proof of disability" system would need to be introduced. This is not necessarily a bad thing, as it could be very useful in many situations, particularly for invisible impairments. But it could be seen as a backwards step – going back to the old days of registration, and would need to be handled carefully.</p> <p>*20. Anything which is an assessment of entitlement for services which would currently include Council Tax Benefit, Housing Benefit, Social care. But this should not necessarily replace those assessments, but could augment to reduce effort on the part of the disabled person. If that person wanted to provide additional evidence for different benefits or services they should be able to do so.</p> <p>*21. No answer</p>

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		*22. No answer
EM798	18/02/2011	<p>1. Financial poverty Every penny has to go on the basics - a massive barrier to participation. Social stigma and exclusion</p> <p>*Including being made to feel ashamed of the need for financial/ health/ mobility support by government policies and media stories that over emphasise fraudulent DLA/ESA claims.</p> <p>*Physical barriers</p> <p>*The disability itself! Even with adaptations etc it is hard for non-disabled people to understand the full impact of living with a disability on every area of your life. External barriers such as lack of access and lack of public toilet facilities also create a huge barrier to participation.</p> <p>*2. I support the fact that DLA will continue without means testing, and continue to be focused on helping people with the additional costs of disability.</p> <p>*The direct payments are especially helpful with fluctuating conditions like MS when they can be spent in a way that best suits the individual to enable them to stay independent.</p> <p>*3. Transport - Very costly due to greater use of car, taxi & public transport if you cannot walk or cannot walk far.</p> <p>*Medical- Both prescription costs, and complementary medicine to help with conditions like Primary Progressive Multiple Sclerosis. This form of MS does not respond to disease modifying drugs and so the very limited treatment on offer centers on symptoms management to reduce pain levels and maintain mobility - complementary medicine can support this without side effects.</p> <p>*Heating - Being at home all day and with limited mobility means it is vital the house must be kept warm.</p> <p>*Personal Care - Care assistants, personal care items eg incontinence pads</p> <p>*Home Help - Cleaning, Gardening, Shopping, Childcare</p> <p>*Mobility aids and home alterations</p> <p>*Diet - Eating well to stay healthy costs more, as does purchasing supplements (vitamin & mineral)</p> <p>*Specialist Footwear or clothing*Insurance- higher premiums</p> <p>*4. I do not see any advantage to this change, and would be worried that it is not broad ranging enough to cover a variety of needs.</p> <p>*5. Yes, some conditions should mean an automatic entitlement or at the very least a simplified/ fasttrack application process if there is a clear diagnosis with supporting evidence.</p> <p>*6. Providing adequate, consistent financial and physical support should be a priority. Services are scant enough as it is, but the most vulnerable in society are now being targeted to try and reduce the budget deficit.</p> <p>*Disabled people have a right to Family Life and social activity.</p> <p>*Financial support through the mobility component of DLA enables people to maintain friendships and family</p>

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		<p>connections. The proposal to take the mobility component away from those in residential care would be a punitive and regressive step.</p> <p>*and remove the last vestige of choice, control and independence for thousands of people in residential care. I am asking the Government to reconsider this proposal as a priority. DLA was designed to be an equality measure to compensate people for the extra costs of living with a disability. We should be aiming for true equality, so that someone with a disability can decide what is essential for their everyday life.</p> <p>*7. With a condition like PPMS the fact it may fluctuate can sometimes be hard for people (including non specialist medics like ATOS Healthcare) to understand, but the effect it has on your life is constant and permanent.</p> <p>*How the condition is on your worst day should always be taken as the level at which support is needed and benefits awarded.</p> <p>*The hidden symptoms of conditions like MS can often be ignored or their impact underestimated, so combined with the disabled persons own assessment of how a fluctuating condition affects them supporting evidence from nominated healthcare professionals should be used in order to support decision-making.</p> <p>*People with long-term degenerative conditions like MS should</p> <p>*be exempt from reassessments, or certainly that reviews should not require a face-to-face assessment.</p> <p>*8. Aids and adaptations, such as an electric wheelchair or sticks by no means remove all barriers to participation, and disability-related costs.</p> <p>*Using aids and adaptations is frequently exhausting - you may be able to get somewhere but not be able to fully participate when you arrive as it is so tiring and stressful to get there. Often the use of an aid or adaptation may mean you have pushed yourself so much harder than an able bodied person to do a task that you are then less able to do subsequent everyday activities.</p> <p>*This is a huge problem for people with MS.</p> <p>*It should be noted that a disabled person uses an aid or adaptation but it is the disability itself which should be assessed.</p> <p>*9. The forms are very hard to understand. Disability can make it extremely difficult to complete complex forms (eg. with MS the cognitive symptoms and fatigue make the whole thing incredibly overwhelming, confusing and frustrating).</p> <p>*It is so stressful even figuring out what you could apply for, especially in times of crisis.</p> <p>*Information about the different rules surrounding who can apply for or be awarded what is very hard to find - it needs to be specified clearly, concisely and also with a simple chart which shows which benefit applies to what/who/how to apply. Packs which state clearly simple steps you need to take to help get</p>

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		<p>finances in order, access benefits, etc.should be given out.</p> <p>*A more positive experience could be had if you are not treated as if you are claiming JSA! A general attitude that seems to focus on catching fraudsters goes against the reality I have seen of disabled people coping incredibly well and not accessing the help they are entitled to, often because they can't or don't know how to.</p> <p>*Mishandling of claims and the onus being on claimants to sort it out with very little support is very distressing, especially as you are trying to claim at a time when often you have reached a point where your life has fallen apart and you just can't cope.</p> <p>*10. Understanding of MS by 'independent medical professionals' (such as Atos- provided WCA assessors) is often extremely limited, and people with MS are</p> <p>*therefore regularly wrongly assessed. As mentioned before, evidence from nominated healthcare professionals in order to support decision-making eg. specialist neurologist, specialist MS team.</p> <p>*11. It is expensive and unnecessary to make people with long-term degenerative conditions like MS attend a face-to-face assessment.</p> <p>*The medical evidence has already been gathered from many sources and usually over a very long period of time to get a diagnosis of MS. With Primary Progressive MS the condition is monitored at least at 6 monthly intervals by a specialist neurologist, not to mention the physiotherapists, occupational therapists and specialist MS nurses who see a patient.</p> <p>*Why spend extra money and cause distress to people who already are coping with a huge amount of challenges in their day to day lives because of their disability when decision-makers could more routinely gather supporting evidence from nominated healthcare professionals in order to support decision-making.</p> <p>*People with long-term degenerative conditions like MS should</p> <p>*be exempt from reassessments, or certainly that reviews should not require a face-to-face assessment.</p> <p>*12. People with long-term, permanent and progressive conditions like MS should be exempt from reassessments.It is pointless and damaging to the wellbeing of someone with PPMS to reassess annually as suggested..</p> <p>*Should reviews be made arbitrary for people with MS it should be at most:</p> <p>*a) a short phone-call or letter check-in to ask if there have been any material</p> <p>*changes in condition; or</p> <p>*b) contact with a healthcare professional nominated by the DLA recipient to ask for *evidence as to whether the individual's condition has changed materially.</p> <p>*In both of these circumstances, if no material change in condition is identified, there</p>

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		<p>*should be no need for any form of reassessment.</p> <p>*13. I am concerned about the suggestion of bringing in penalties for failing to report changes in circumstances. It is unclear what changes in circumstances would warrant a penalty for non-disclosure, and how evidence would be gathered on unreported changes in circumstances in order to impose penalties. It would be extremely concerning if someone with MS were to face a penalty for failing to report, for example, a change in their symptoms or a short remission, which they did not feel had resulted in a significant change in their level of need.</p> <p>*Rather than introducing penalties, the Government should encourage people to report</p> <p>*any changes by:</p> <p>*a) giving clear, accessible and easy-to-understand guidance as to what constitutes a material change in circumstances which must be reported</p> <p>*b) making it as easy as possible to report changes</p> <p>*c) offering clear information on what reporting a change in circumstances could mean for claimants.</p> <p>*14. Clear, consistent and easy to access advice online, on the phone and in an information pack.</p> <p>*Properly trained advisors who can really help are vital! Often calls to benefits agencies are with people who are not trained to a high enough standard to be helpful, give very differing advice on the same subject, don't log calls, and written requests are not responded to adequately and in a timely way.</p> <p>*15. There should be no compulsion/ penalties if this system is implemented.</p> <p>*It should be there to assist and enable, not act as a barrier to accessing support.</p> <p>*16. It is hard to find out what aids and adaptations can be provided.</p> <p>*Long waiting lists of months or even years for equipment or home adaptations is totally unacceptable and inadequate for people particularly with MS, as the condition may progress faster than the help is received- risking injury that is further disabling.</p> <p>*eg. whilst waiting for a home assessment to try and get a stair rail fitted in our rented home, there have been several significant falls and like many people we do not have funds to make the adaptations.</p> <p>*DLA is often used to buy vitally needed equipment when a condition like MS worsens.</p> <p>*17. Waiting times for assessments, equipment and support should be minimal.</p> <p>*Extra funds for carer support (respite care etc.) should be given, and be able to be fast tracked in urgent cases to prevent a crisis situation.</p> <p>*Personal care items (eg incontinence pads, bedsheets etc)</p>

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		<p>should be freely available not restricted.</p> <p>*18. I am very concerned about the Government's lack of analysis of the knock-on impact for families of these reforms, and the proposed £1 billion cut to the DLA budget which motivates them. If a substantial number of DLA claimants see their benefits reduced or removed as a result of the proposed cut, this could have a significant impact on Carer's Allowance and other 'passported' benefits, particularly disability premia.</p> <p>*19. The implications of the knock-on impacts of this cut on family incomes would be devastating for families such as my own if they cannot access other benefits and services. Most disabled people are lucky if they just about manage financially under the current system. The cuts will be put not only the disabled person but their partner and children at risk of poverty and debt.</p> <p>*20. We have had huge problems with inefficient handling of our claims.</p> <p>*I would support information sharing but only if it is transparent and that the individual has the opportunity to access and to correct any information held about them before decisions are made.</p> <p>*21. I am unsure & need further information on this issue to comment.</p> <p>*22. Dealing with any disability is vastly challenging, whether your own, a partner, a child or family member. The emotional, physical and financial burden is huge, and like a huge number of people I am distressed and angered at the proposed changes to DLA.</p> <p>*The Disability Living Allowance reforms could leave large numbers of people facing high costs of living with no support, remove their independence and ultimately force people below the poverty line.</p> <p>*Out of all social groups it appears that disabled people are being victimised.</p> <p>*I strongly oppose the apparently arbitrary target of reducing the number of claimants by 20%: the Government has presented no evidence as to why this target has been set. To claw back a relatively small amount of money will cause a huge amount of distress, illness and poverty to the most vulnerable in our society.*I am not against reform, but this is brutal and regressive and I urge the government to stop. It won't work, it will destroy lives and families ...leading to greater governmental financial costs in the long run and needless suffering along the way.</p>
EM799	18/02/2011	<p>1. Your response: lack of funds, support needs, access, insufficient accessible transport, having to pay double because they require the support</p> <p>*2. Your response: Yes, people within Registered Care should continue to receive this benefit, their mobility costs are no less than those of similar needs living in other housing/support</p>

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		<p>arrangements. This is coming at a time when commissioners are cutting funding, this change will have a negative impact on the quality of people's lives and leave this less able to access the community, is this not discrimination?</p> <p>*3. Your response: support, having to pay double because they require that support, transport (costly and unreliable), aids and adaptations, incontinence requirements</p> <p>*4. Your response: fairness of allocation and access to higher levels may depend on the quality of the assessment, rather than actual need</p> <p>*5. Your response: it should depend on the needs of the individual</p> <p>*6. Your response: A holistic view should be taken and consideration be given to needs and wishes of the individual.</p> <p>*7. Your response: Many people qualifying have significant support needs which are unlikely to improve with time, perhaps the assessment is done via the GP, saving time and unnecessary stress for the individual?</p> <p>*8. Your response: Yes, all aids that enhance the individual's life will come at a cost and needs to be covered, both in terms of aids held and those required to further benefit their lives.</p> <p>*9. Your response: Clearer accessible information and support to complete the form if required. No hidden agenda and clear criteria required.</p> <p>*10. Your response: Medical report via GP / other health practitioner</p> <p>*11. Your response: Yes, if repeated annually when prognosis is such that their needs will not decline, but increase.</p> <p>*12. Your response: Depends on diagnosis /prognosis and yes different types of review are necessary.</p> <p>*13. Your response: Many people receiving this benefit wont have the ability to report changes in circumstances, health professionals may be better placed to do this</p> <p>*14. Your response: Clear and accessible information available from onset</p> <p>*15. Your response:</p> <p>*16. Your response: it will vary from individual depending on their circumstances and available funds. Yes they should be able to access this money to fund aids and adaptations</p> <p>*17. Your response: Needs, family circumstance, support required.</p> <p>*18. Your response: The mobility component has left many people better able to access a range of community activities, including work placements, lease their own car, etc</p> <p>*19. Your response: Not sure what is meant by this question</p> <p>*20. Your response: Health and social care information including assessment of support (Community Care assessment)</p> <p>*21. Your response:</p> <p>*22. Your response: By not offering the benefit to those in</p>

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		<p>registered care, they are being discriminated against and will have less access to regular community access, potentially having low income and therefore fewer options. It will also have an impact on people's choices to access such support if likely to be less well off as a result. People who currently access this benefit have become accustomed to a certain lifestyle, which they will be unable to maintain. This in turn may lead to increase health needs, due to depression, challenging behaviours, etc.</p>
EM800	18/02/2011	<p>Hi Please see above. Thank you Yours Faithfully</p> <p>*1. Your response: Is having the Finances to take part in society and not feel like a outsider. By not being labelled a drain on society and that disabled people are scroungers, having the facilities and training courses available that equip disabled people to do various jobs that are tailored to their disabilities there is no point in a disabled person doing a job if that job is not suitable for their disability.</p> <p>*2. All of it. If it is not broken don't try and fix it especially as a cost saving exercise, which this is exactly what this is intended to do.</p> <p>*3. • Financial, • extra costs of gas, electricity, Food, prescriptions and the cost of living.</p> <p>*• Medical aids and adaptations to assist the disabled person to live a normal life.</p> <p>*4. When a person's disability gets worse you will have to jump through hoops to get the next level of benefit. *• Adding another layer of form filling making it more costly to administer and adding another layer of bureaucracy.</p> <p>*5. • Yes for health conditions like cancer, heart, Parkinsons, Huntingdons, MS, Dementia any condition that is life threatening or any condition that is debilitating • Or any one that has had an operation that has gone wrong and the hospital will not take responsibility for it.</p> <p>*6. • To be able to be independent as much as possible ie to be able to shower and dress in safety be safe in your own home, ie all disabled people and elderly peoples homes should be adapted to enable those people to look after themselves. • Human contact and community centres that provide help and activies for all disabled people.</p> <p>*7. By the disabled person and their GP and Medical professionals.</p> <p>*8. • All aids and adaptations should be included • And all options should be looked at whether the disabled person needs them now or in the future.</p> <p>*9. • Make the forms less daunting less pages, less intrusive, • Use plain English,</p> <p>*• A contact centre that has qualified staff that can answer or direct the individual to the right help.</p> <p>*10. • The disabled person as they know how they feel and what they can do, their GP and if they are under professional</p>

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		<p>medical care, ie Consultants, Pain Management, Lymphoedema Service etc.</p> <p>*• But not a Government Doctor as the only thing that they are concerned with is getting people off disability and saving money and they might not have the necessary medical knowledge to deal with the disabled person's complaint.</p> <p>*11. Your response: The difficulties of this is</p> <p>*• The Healthcare professional will work for the Government and it will be stressed to them to get as many people off disability benefit as possible and on to Job Seekers Allowance.</p> <p>*• Any one that is suffering from an terminal illness ie Cancer or Heart condition.</p> <p>*12. • The evidence is in the form that the disabled person filled out. It will be obvious from the form whether or not the disabled person is permanently disabled or it is only temporary disablement. • Doctors and medical evidence.</p> <p>*• The reviews should be tailored to the disabled person so the reviewer should have a detailed knowledge of that persons condition and if any issues overlap ie mental health with a physical condition. *13. • People don't report changes in their circumstances because they are afraid to do so because of loss of money and how they would cope. • To encourage people to report changes either good or bad if it is good and the person is getting better then a sliding scale and help in finding suitable employment so there would be less stress involved, if the person was not getting better but getting worse there should be more help. But do not stigmatise.</p> <p>*14. • All the other benefits that could possibly be claimed • Warm Front • Blue Badge • Debt advice or where to get help • Housing advice or where to get help • Rather than people trying to find out for themselves</p> <p>*15. • All hospitals should have a policy that when a person is diagnosed with a disability they pass on the relevant forms for them to access the disability process. • These forms should be in plain English.</p> <p>*• The forms should have help notes on every question and the forms should not be WAR & PEACE but should be concise and to the point.</p> <p>*16. • No as people's needs may change and they may require more or different aides and adaptations.</p> <p>*17. Parent or legal guardian must be present and informed of all areas of help and assistance that is available.</p> <p>*18. Yes more information about the passporting arrangements needs to be available.</p> <p>*19. • The implications for disabled people would be having to find out about these services via the phone or computer. • More stressful • Financial Strain.</p> <p>*20. • If the hospital diagnosed a patient as being disabled the paper work should go straight to the Welfare Services to cut out the DWP as this would cut out a lot of paperwork and time and</p>

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		<p>effort.</p> <p>*21. • Financial if the disabled person if judged to be fitter than what they are</p> <p>*• Government Doctors and Insurance Companies should not have the ultimate say it should be down to the disabled person and how they feel and their GP and medical consultants.</p> <p>*22. • It is going ahead no matter what anybody says this is a waste of time. • The only thing that this is designed to do is to save money at the expense of a minority group and the least capable of fighting back.</p> <p>*• Get the views of ALL Disabled people.</p>