

Disability Living Allowance reform consultation – email responses 401 to 600

Respondent Number	Date Received	Response
EM401	10-Feb-11	<p>Hello, My name is [REDACTED] and I currently receive DLA. Throughout the paper it is said that you will consider how fluctuating conditions will be assessed. At present I give info. on my worst days. (I suffer from Fibromyalgia and rheumatoid arthritis and depression and anxiety.) If I have a meeting with someone on a good day, i may be assessed as okay and be refused the reformed benefit, although I suffer pain daily it does vary. To have supported evidence from doctors and specialists is also all very well, however my husband is in the Armed Forces, none of the doctors I have seen in the past 13 years would be able to provide accurate information as they only see me for my medication reviews for a couple of years before i move on. DLA also takes into account aids and support that I should be able to access, will this continue? Living in Married quarters and moving every couple of years makes the addition of some support impossible, such as stairlift, eye level cookers and so on. So even though this would make life easier I am not able to get them, will the reform take this into account?</p> <p>*</p> <p>I also would like to point out that as the wife of a serving soldier, i have no choice but to do things that are extremely difficult, again dla excepts this, things such as carrying shopping, driving, using the lawn mower, ironing and so on. All is fine when my husbands here because he will take responsibility for these jobs, but as he is frequently away for a minimum of 6 months most years I HAVE to do these things. Will the reform be remembering these situations?</p> <p>*</p> <p>I look forward to a response and greater understanding of what the reform may mean for me and my family.</p>
EM402	10-Feb-11	<p>Sir I wish to add to your consultation with the following information. I am a [REDACTED] year old who has just been medically discharged from the police service after 28 years service. I could only continue to work as long as I did with the aid of my DLA.</p> <p>MS affects my mobility and I have 2 mobility scooters, both of these I had to buy with my own funds. These are very visual impairments, but what you cannot see is that MS also affects my vision, my hearing, my hands, my balance and my bladder . I have constant neuropathic pain, bilateral trigeminal neuralgia which you can only see when it completely overwhelms me, spasms and severe neuro-muscular and lassitude fatigue which is extremely disabling. Symptoms fluctuate daily and hourly and relapses can cause instant partial paralysis and last for days or months.</p> <p>In order to have some life I have to go to bed at 7 p.m. most days just to be able to have some energy for the next day but that is not guaranteed. My wife is my carer, as is my son and daughter. There is no cost for the state. The DLA goes to help me with my needs and this is the only cost. MS does not come with free prescriptions. It was only when I was diagnosed with diabetes that I could have free prescriptions as I require medication for that as well.</p> <p>*</p> <p>I have been awarded DLA indefinitely and had to go through various medical assessments. I have the support of both my GP and consultant Neurologist.</p> <p>*</p> <p>It would seem that the Government has already made a decision as to how much they wish to claw back from DLA. I would urge you to</p>

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		<p>reconsider your thinking. I do not believe that any individual has DLA unless they require it. It is such a hard process to go through.</p> <p>*</p> <p>When I have to go through your P.I.P assessment will I be able to bring reports from these professionals?</p> <p>Will your assessors be able to visit people in their own homes? They may not be able to travel to an appointment. This may only occur on the day of an assessment.</p> <p>*</p> <p>Will any of the officers on the consultation panel suffer from any long term fluctuating debilitating disease such as MS or MND? Because unless you live the nightmare you have no idea of what it is like. you have no idea of how a small change can make such a big difference. if you knew then you would not be putting people like me through this stress. This could ultimately cause so many people you have significant relapses. Please contact me if you require any further information. Kind regards</p>
EM403	10-Feb-11	<p>Dear Sir, I am a divorced mother of three, (my ex walked out 23 years ago as he found it too hard to cope!) the eldest of which has down's syndrome. I have now looked after my daughter who is now [REDACTED] on my own for this time. I have struggled to make ends meet but have got a degree myself and my two able bodied daughters are at university studying for degrees. This has not been easy - I find myself more and more isolated due to lack of funds to go out with my friends. At the moment I get two nights a month respite which is under threat by budget cuts. My daughter has to go most places with me - I've had comments that we are joined at the hip! If my daughter loses her DLA and therefore my carer's allow is under threat I would have no alternative but to look for full time work and my daughter would have to go into care. This would be substantial care as during the winter she suffers from severe asthma and would need 24 hr. care, for the last 3 years I have been unable to work for at least 3 months of the year due her condition, which has included high doses of steroids.</p> <p>*</p> <p>I believe that Carer's Allowance must remain outside of the Universal Credit . <u>Carer's save the UK £87 billion every year with the care they provide. I would ask you go along and try this lifestyle before cutting any benefits.</u> Yours sincerely,</p>
EM404	10-Feb-11	<p>Dear Sir, I understand that the Disabled Living Allowance (DLA) is to be abolished and replaced by a means tested payment, and that 20% of the total allowance is to be cut. My wife has arthritis and, as an indirect result, has lost the lower part of her right leg. Consequently, she is unable to stand, is completely wheelchair bound and requires hoisting into and out of bed. Currently, she is receiving the higher rate of DLA which we use to lease a wheelchair accessible vehicle from Motability. This is my wife's lifeline to the outside world and without it she would be virtually housebound and without DLA I fear we would not be able to afford this necessity. Apart from all the worries of being the main carer for my wife, this is one more burden placed on my shoulders. I urge you to reconsider the removal of DLA from the system and 'ring fence' it so that, at least, we have peace of mind knowing that we will not have to give up the vehicle. Yours Sincerely,</p>
EM405	10-Feb-11	<p>Dear Sirs My name is [REDACTED] and I am a full time carer for my husband who can no longer walk, and needs help with everything 24/7 365 days a year. I am very concerned about carers losing their Carers Allowance, although my husband receives the higher rate and I may not lose mine it would be devastating to a lot of other carers. This allowance allows me to have an occasional treat as this is the only money I earn in my own name as I gave up work to look after my husband, This allowance is nowhere near the cost for looking after my husband in a residential home, (if one</p>

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		<p><u>could be found</u>). I think it would be totally unfair for carers to lose their allowance. If I lost that allowance I would seriously have to consider working again and then my husband would be on his own all day. You try and imagine not being able to get up to go to the toilet, not be able to get a drink when you want one, not be able to answer the door or even pick up the post.</p> <p>*</p> <p>I would be extremely worried if my husband lost his DLA because someone who does not know him or assesses his needs differently, if he lost that we would lose an important amount of money that enables us to carry on and we would also lose our car on the motability scheme. We would not be able to afford to buy another car, also having the motability takes pressure of arranging car tax, insurance and servicing off me, as he has always dealt with that and I would find it stressful along with caring for him, I would always have to rely on someone else to take us out, and having to carry a wheelchair that would not be always possible. Hospital appointments would have to be arranged by taxi and a great expense or with hospital transport, he then would have to go on his own and he does not always understand what is being explained to him.</p> <p>*</p> <p>I strongly believe the government should not be making cuts of £1 billion to disability benefits. You are attacking the vulnerable and the people who do the hard job of caring. Carers allowance must remain outside of the Universal Credit. Means testing as this would mean leave carers without any recognition, We do an excellent job and believe me it is not easy. Yours sincerely</p>
EM406	10-Feb-11	<p>This is based on Deaf views and experiences.</p> <p>*</p> <p>Q1- Deaf never and never will have totally equal access to services i.e. Police, Banks, Hospitals, public transport. Call centres are developing- Deaf cannot gain equal access and have to rely on others to phone for them. Deaf will always fight for their access rights. We were totally unaware of this benefit change due to our Deafness and limited English skills. We are unable to hear background and relevant information i.e. the radio whilst driving like our hearing peers. Overall Deaf people miss out on everything. Our disability is ridiculed because people do not understand and it is an invisible disability.*</p> <p>Q2- To maintain quality of life. To avoid isolation and increasing mental health. I.e. . socialising, we have to have someone with us & pay for them to avoid isolation due to communication needs. We pay for items incorrectly due to lack of communication skills as it could have been bought cheaper or a wrong item and when we take it back, again we get told information we do not understand and then we give up. We pay for items that we should not have paid for in the first place thus keeping them as a wasted item. Deaf do unintentionally pay more for items that could be cheaper, i.e supermarket announcing 'bread at half price in aisle 10'. There are a lot of things we pay extra for and always without realising.*</p> <p>Q4- Not sure because it depends on the amount and a fair assessment. If it is 2 parts, how can the assessor justify which part for Deaf? How can the assessor who has no idea of Deaf identity/culture/way of life/barriers/frustration classify which part for each Deaf. Do you think just having the 2 amounts ...any problems? Yes, because the old DLA caused unfairness. PIP will have to be very clear and show which level is for each Deaf. Can the assessor who has no idea of Deaf identity/culture/way of life/barriers/frustration classify which level for each Deaf.*</p> <p>Q5 - Yes definitely - if a person is classed as Deaf i.e. shows that they cannot recognise useful sounds and speech even with hearing aid/s should automatically be awarded PIP. Or do you think ...asking for the benefit? It should never be based on the needs of a Deaf person. Deaf will always face barriers whatever the need.*</p>

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		<p>Q6- Assessor will need to be very aware of Deaf needs and rights who then must automatically award the new benefit. What activities ...an independent life? Ease of communication and equal access to ALL services without any barriers. For example a dream world would be that every hospital, Police, shops, leisure places, banks and everywhere to have a sign language interpreter in each. This will be impossible, therefore Deaf will meet barriers. Interpreters are booked to attend but they do not turn up or very often services do not book interpreters due to refusing to pay for costs. We need to be able to access to all services at all times rather than specific days when hearing people are able to have access 24/7.*</p> <p>Q7 - Deaf will always be Deaf and that will NEVER change even with a cochlea implant / hearing aids. Their 'health' in relation to ears will never change / improve. Once having a hearing loss, it will never be cured.*</p> <p>Q8 - For Deaf, it is not aids / adaptations- it is <u>society that makes us disabled</u> and always will be. Equipment is expensive for Deaf. Council cuts means Deaf will have to pay for equipment and repairs. Equipment is constantly changing and Deaf have to keep up. What aids ...into account? For Deaf People, we should never take equipment into account. It is an essential need for continuing life, for good mental health, independence and well being. PIP will cover all equipment changes for <u>life</u>. Should we only take aids ... them? Or should we take aidsget hold of easily? Equipment should NEVER be taken into account when applying for PIP. All equipment is constantly changing and time consuming and costs incurred to apply for equipment every time. Deaf already have barriers in communication therefore struggle and get stressed having to ask for help again and again.*</p> <p>Q9 - PLAIN ENGLISH! All questions in BSL. Separate PIP form especially for Deaf people. • How could we tell people ... likely to get the benefit? PLAIN ENGLISH leaflets, BSL DVD, Deaf people WILL get the benefit.*</p> <p>Q10 - British Deaf Association/ RNID / Sensory Services / any Deaf organisations. Ask them how to set the questions correctly for Deaf people. What information will we needcan or cannot do?Need to have questions that are relevant to Deaf , i.e, can you hear useful sounds? Do you use BSL? Do you understand people well? Do you need to pay for extra needs i.e. taking someone with you to avoid isolation? Questions MUST not be patronising and very clear in the question. A section for each disability, i.e. one for mobility, one for learning disabilities, one for Blind, one for Deaf, NOT Deaf and Blind together as it gets confusing as Deaf and Blind are absolutely and totally a different disability.*</p> <p>Q11 - If assessor visits me to assess, even with a Sign Language Interpreter, the first question I will ask will be 'Are you Deaf aware', if they say no, then I will refuse to be assessed until I am assessed by the correct person with an Interpreter. From experience, people who attend with Interpreter are totally not aware of our needs, thoughts, culture, experiences therefore will have a 'bad' attitude causing Deaf to get very upset. PLEASE do not use children, family members to speak on Deaf people's behalf. Is there any time ...own home or somewhere else? It has to be the Deaf person's choice. Make sure the room is private as Sign Language is visual and people will watch which Deaf are not comfortable with. Do not use open spaces when interviewing.*</p> <p>Q12 - Being Deaf is for LIFE therefore PIP is for life as Society will <u>never</u> change to meet our needs even if our independence improves a little. We will always face a permanent barrier. If you say our independence has improved.. ok .. what about society, have they improved, no, never. Should the way we look at a claim again...disability? *</p> <p>Yes. Like I mentioned, if the person is DEAF, it means for life as our hearing will never be cured!*</p> <p>Q13 - Again, for Deaf people things will never change as society will never change towards us. How can we get people ...in their lives? Deaf</p>

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		<p>people will never inform of any changes in relation to their hearing loss. The brain is adapted never to restore a person's ability to hear words and recognise sounds ever again. *</p> <p>Q14 - Equipment for independence. Communication support. Quality of life. Socialising to maintain good mental health and to avoid isolation. Would it help ... get it from? Yes, each Local Authority should have a list of Sensory Services/Deaf Services.*</p> <p>Q15 - From their own pocket and using DLA. Some are provided by Local Authorities but there is a long waiting list and plans are for cuts. If in future we pay for fire alarm, it could cost in total of about £200 when a standard alarm is £5. Smoke alarms have to be maintained and repaired at an additional cost. Should disabled people ...one-off cost? No. Equipment are maintained and repaired regularly anyway.*</p> <p>Q16 - If Deaf, there is no difference. Parents/Guardians of Deaf under 16 have DLA that must automatically be transferred to child when 16 as this is not always the case.*</p> <p>Q17 - Very useful for quality of life as we would otherwise not have known due to not being able to hear information. What can ... things better? A very difficult question to answer. You need to make all services have a sign language interpreter in EACH. At the moment people scheme. What would it meanor services? Poor quality of life.*</p> <p>Q18 - All applicants to be computerised. *</p> <p>Q19 - Is it relevant? It does not matter who we are. Interestingly enough, a Deaf person say they are Deaf first then....*</p> <p>Q20 - Deaf people are very worried because they are misunderstanding the changes. We worry that you do not understand our needs. Blind people have a clear indication of a walking stick and have speech, Wheelchair users clearly have mobility needs and have speech. BUT Deaf people are invisible, a misunderstood disability and have no or not clear speech. That is why society does not understand us causing us to be a forgotten disability. Deaf people have had bad experiences facing people who have a bad attitude towards their deafness.. example is a Tribunal with 3 people, one from DSS, one a GP and a Chairperson, the GP was ridiculing a Deaf Person by asking, 'how can Deaf get to the railway station and reading signs when they cant speak/read?'.. what a daft question and this must not be asked. Please have one section of the PIP form be aimed at DEAF people.</p>
EM407	10-Feb-11	<p>Dear Sirs I am a mother of a [REDACTED] year old disabled son. He has athetoid cerebral palsy and been disabled from birth. I have therefore been concerned with disability issues for a long time. The following are my comments on the consultation for reforming Disability Living Allowance. I have commented on the questions which I feel I am able to.*</p> <p>1. The main problems or barriers that prevent disabled people participating in society and leading independent, full and active lives are as follows : A .Lack of money B. Lack of transport C. Lack of aids to enable them to cope more easily with their disability But the biggest barrier disabled people face is the attitude most people have to disability. When considering a disabled person the first thought is what can't they do NOT what they can do and this is an enormous hurdle for them to overcome.*</p> <p>2. NO COMMENT*</p> <p>3. The main extra costs that disabled people face are the high cost of the aids which they need to be able to cope more easily with their disability. A person who is unable to speak needs a communication aid – a very expensive item. This aid then has to be maintained – it needs batteries approx. every eighteen months, new overlays when the others wear out and the cost of any repair, which can be very expensive. Communication is a basic human requirement and to have a communication aid is a necessity.*</p> <p>For someone unable to walk or move around easily a wheelchair is also a necessity and it usually needs to be an electric one. This is also a very</p>

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		<p>expensive item and needs regular maintenance which includes replacement batteries and regular servicing. An electric wheelchair obviously has a controller which because it is used so often needs repairing and quite often replacing about every two years.</p> <p>A disabled person unable to sit without support has to have another expensive item which is a special seating support system with a special cover. This is also an expensive item and the covers have to be replaced regularly in order to maintain the effectiveness of the system. When disabled people go anywhere they are unable to go without a carer. This involves extra cost as the carer has to be paid for. This is particularly relevant if they want to go on holiday as the cost for the carer to travel and stay with them has to be met by the disabled person.</p> <p>In some circumstances a disabled person needs a specially adapted car in order for them to travel independently. These are very expensive but very necessary to maintain independence</p> <p>4. NO COMMENT</p> <p>5. NO COMMENT</p> <p>6. The activities most essential for everyday life are those which enable a person to lead a life which is purposeful to them. These may be just being able to help with their own personal care or to go to a day centre or similar and be in the company of other people. Or to enable them to travel to visit places or people such as their relatives or friends. The more able need support to be able to do a job or help other people voluntarily. The main aim is to ensure they have freedom of choice wherever possible.*</p> <p>7. NO COMMENT</p> <p>8. The assessment of a disabled person's ability should most definitely take into account any aids or adaptations they use at that present time plus also any they may be eligible for and don't have. All adaptations should be included e.g.communication aid, wheelchair - electric or manual, seating aid, toileting aid, transport aid.</p> <p>9. NO COMMENT</p> <p>10. What supporting evidence will help provide a clear assessment of ability and who is best placed to provide this?</p> <p>The supporting evidence required to help provide a clear assessment of ability should be given by people who care for or who know the disabled person very well. There should be several such people in order to give a wide view of the needs they see the disabled person has in many and varied situations. They would of course be approved by the disabled person to speak on their behalf.</p> <p>11. A face-to-face discussion with a healthcare professional would be appropriate only if they knew the disabled person well. It is very difficult to be able to assess someones needs if they do not know the many and varied situations in which the disabled person finds themselves each day.</p> <p>12. NO COMMENT 13. NO COMMENT 14. NO COMMENT 15. NO COMMENT</p> <p>16. Disabled people currently fund their aids and adaptations mainly from personal finances which in most cases means their parents or other family members or by applying for grants or funding from charitable organisations.They usually get some help from government departments but it is generally not enough to give them the freedom to choose exactly what they want for themselves.</p> <p>17. NO COMMENT 18. NO COMMENT</p> <p>19. If the Personal Independence Payment was not able to be used as a passport to other benefits and services it is quite possible that the disabled person would not be able to access these in any other way as they would not have enough money to do so and no other means of getting it. This could have a very profound influence on their quality of life.</p> <p>20. NO COMMENT 21. NO COMMENT</p> <p>22. It is important that the assessment is done by involving people who</p>

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		<p>really know the disabled person. There should not be any kind of assessment of capability done at the time the form is filled in or a judgement of ability to perform various tasks at a particular time as this varies so very much with any person and so much more with someone with a disability. At all times the disabled person should agree that the person being asked to contribute their views should be approved by them.</p> <p>I would also like to comment here - as there does not seem to be any real provision in this consultation for me to do so anywhere else - about the very real concern I have regarding the possibility of the mobility part of the DLA being taken away from people living in Residential Homes. This would include my son who without receiving this very substantial amount each week would be very restricted in many things he now does each day to give him a full and purposeful life. This would also apply to the friends he lives with and to so many others in the same situation in Residential homes.</p> <p>I am quite willing to be contacted if you need any other information from me regarding this. Yours sincerely</p>
EM408	10-Feb-11	<p>DLA is a source of income that the majority of the disabled community depend upon to survive. Those that are able to work often use the benefit to maintain their job. Those that can't work often use it to buy food. Cutting the benefit will force those that work to give up their jobs and those that don't work to resort to crime. The loss of income will drive disabled people further into isolation and depression. Cutting DLA will in short increase the amount of money spent by the state on benefits, crime and the NHS. It is false economy. (I am responding as an individual).</p>
EM409	10-Feb-11	<p>Hello, I am responding to the Consultation on the proposed DLA reforms as an individual. I've briefly read through but one thing that jumped out at me was the following paragraph in the executive summary point 4.11 (page 8??)</p> <p>As well as providing cash support, DLA currently entitles or 'passports' the individual to other help and support. We recognise the importance of this feature and will take it into account in developing our reforms. In addition, we will consider how the benefit interacts with other forms of support, for example adult social care, and explore whether it is possible to share information at the assessment stage and eliminate areas of overlap.</p> <p>To me, it tells me that if those who use personal budgets/direct Payments, would that be taken into account? I mean I have personal budgets from social services, to help me to be independent, could then they say I won't need the mobility part?? Is there a risk that we'll get one or the other but not both? Kind regards</p>
EM410	10-Feb-11	<p>1) : basically non disabled people not understanding not prepared to give time not prepared to make allowances : being able to include the unseen disabilities such as speech and language impairments* : transport, paying for carers, but this is too general a question as very disabled person is an individual and has their own needs : you will put more disabled people on the lower rate : yes i think an automatic entitlement would be good, life is stressful enough without having to continuously write about what you can't do in a 'normal' environment : socialising, being able to be as independant as possible : well there are two types of disabilities, one is a temporary disability that is known to get better, the other is a life long one that no matter what is done will always be there : don't understand the question : any life long condition should be entitled automatically, make the question more straight forward, when questions like how often a day in minutes do they require this, that is an absolute ridiculous question</p>

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		: a specialist in the field of the disability, one who has already been dealing with the person in question : how degrading, to have to sit there and tell a stranger what you can't do : a child with a life long disability should not have to renew until they reach adulthood, when they then know if they can access society, : a simple form once a year asking if there are any changes?? : some information on how you decide who is worthy of payment? : avoid making it a requirement! Just provide some information : I don't know : that they are very vulnerable, and should not be harassed with barrages of questions : very important, yes make a identity card that gives you entitlements nationally not just locally : poorer quality of life : once a child gets a statement for sen they should automatically be entitled to dla, not extra form filling : : yes stop making cuts
EM411	10-Feb-11	1) : Not enough money. No jobs. Prejudices of the so called healthy people. Mistrust of the government that the disabled misuse the benefit system. The question itself is illogical because being disabled you are always dependent on someone. : Yes, the Motability Scheme should stay the same. : taxis, heating costs, electricity costs, medicine, money for massages for example ,personal help, personal care : This two component benefit involves too much administration and is not necessary. When somebody is disabled this person is disabled. It is impossible to give disability different labels. You will create a hierarchy of disability, which displays a lack of understanding of disability. : Yes, there should be an automatic entitlement because everything else means you chase people because you don't trust them. When you have an impairment or disability you are dependent on this money called benefit. : Most essential for everyday life is, for instance, shopping for everyday essentials. Disabled people want to go to cinema, to the theatre, museum etc. They want to meet people and they should be supported without creating hassle and stress for them because being disabled and the daily struggle with the ones own body is stress enough. : With your proposal it is impossible to achieve. : Look that people can have their aids and adaptations as soon as possible. You should include aids and adaptations people require. : Reduce the amount of questions and give only few understandable instructions. And take stupid questions out like" are you a danger for others or yourself?" When you are a danger for others you certainly would not notice or not admit to it and it is not relevant for having the benefit. Your response: Have the confirmation of the diagnosis of the doctor and talk to the patient him or herself and that is it. Why have to keep going through the same process and form filling over and over. Once assessed and the doctors report is made why ,when the disability is progressive keep putting stress on the claimant by keep having more medical assessments and the stress brought on by the worry of having the benefit cut or reduced. : This whole procedure will stress people out and it contradicts the personal independence living. As I said before you don't trust people and their diagnosis confirmed by the doctor, the persons who assess the reports obviously think they are more qualified than the experts. : Is the decision already made by you? I don't think that these reviews are necessary because a disability does not disappear just so and it does not improve either.If the illness or disability is progressive that says it all it is not going to improve so why keep assessing people.

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		<p>: By not penalizing them. everyone knows you have to report any changes but if you are on the maximum benefit and the disability is progressive then why all the hassle keep going over the same ground with form filling you cannot claim more than the maximum.</p> <p>: A small booklet with instructions and a few simple questions. *</p> <p>: Make it simple so that people can understand what they have to do. *</p> <p>: Yes.*</p> <p>: Children should have the right to fill in their forms themselves with the help of the parents if necessary. You have to consider that skills of children will change over time.*</p> <p>: Very useful.*</p> <p>: People would lose a high amount of other benefits.*</p> <p>: There is no need to put benefit and services together. That would not work because there are different councils and therefore different services.*</p> <p>: I think that the whole new proposal looks like a modern which hunt in order to sort people out, who misuse the benefit system. In my opinion the doctor should give the diagnosis and confirms this to your office and the person can apply for the benefit. There should not be all the different categories like how far can somebody walk, 10 metres or perhaps only 5 and then this person will have two pound more in benefit. That is stripping people off their dignity. Reviews and questions here and there should stop. A disability is a disability, not improving, not going away. People should not be forced to display their unseen disability to society in order to justify their entitlement for having the benefit. The procedure you propose and the previous procedure carried out by the DWP stresses people out because they are afraid to lose their benefit, people are dependent on this money, they plan their "independent" lives with this. The rule that when you are in hospital the benefit stops should be removed because you need this money even when you are in hospital. I think that you don't understand in the least how it is to have a disability and not being able to work and being mistrusted by the authorities. You imply a lot of stress on people. The benefit should be set by people who are themselves suffering from these disabilities because these are the people who know the needs of the disabled person and not one type of disabled person because many disabilities need different types of help. One cap does not fit all. How can you measure pain or fatigue only the sufferer knows this not someone fit able-bodied civil servant sit behind a desk in Whitehall.</p>
EM412	10-Feb-11	<p>Good evening, I must admit I am rather disappointed that the on-line system has failed so close to the deadline, but not surprised because based on the lack of an adequate response Maria Miller , i.e. the usual standard letter, it does make me wonder if it is deliberate*</p> <p>1.: The inability of politicians to understand the difficulties that disabled people have to cope every day, basically fighting for respect, understanding, work, poor transport or living on inadequate benefits. *</p> <p>2.: Yes the mobility element of the DLA must be kept for those in care homes, if the Government really means they want disabled people participating in society and leading full independent, full and active lives. The ability to travel not only to work but socially should be right of all people including the disabled by removing access to the funds to purchase, e.g., motability car will mean disabled people will become prisoners and dependent on care home bus or council bus, if there is one is available. In reality these transport facilities are limited and could not cover the needs of every individual to either, go when they want to either, work, the day centre, meet up with friends or family. Besides the fact that people in a care home are only left with £20 a week to cover all their expenses and entertainment needs</p> <p>3.: If you live in care home you are left with £20 per week to pay for basic essentials, like toothpaste, shampoo, this leaves very little if anything other essentials like transport costs, holidays, clothing, going out to meet</p>

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		<p>family and friends or buying presents for birthdays, etc. Quite simply in our case, we support our son who is in a care home with his extra costs, e.g., going out, his phone costs, internet and purchase of clothing and of course holidays, for example we have paid £1000 to enable our son to go on a holiday for the disabled. If he loses his of the motability car he would become a prisoner because neither he or we would have sufficient funds to buy a special vehicle to take to his various medical appointments, meet family and friends and or go on holiday*</p> <p>4.: It doesn't matter whether it is one rate or two rates it is about the fairness of the proposals and it is not fair to penalize people who are disabled who live in care homes and remove their ability to access transport through the motability scheme.</p> <p>5.: Yes of course, if someone has been brain damaged at birth, i.e. cerebral palsy, they do not get better, if anything they get worse as they get older and need more support. Why should somebody who has been brain damaged at birth have to keep justifying their condition.</p> <p>6.: The key activity for anyone, whether they are able bodied or disabled, is the freedom of choice to do what they want when they want. To achieve this freedom requires not sufficient income (more than £20 per week if you live in a care home) and mobility, i.e. adequate and flexible transport, which the current system provides. By removing disabled people's access to transport (this does not mean having a bus that can take you to the day centre) you remove disabled people's ability to participate in everyday life.</p> <p>7.: By firstly that people are born disabled should be given a fairer assessment process, they didn't choose their condition. The people who know them best should be making the decisions not some "unknown expert" who reads an assessment form and has 30 min session. It should be those people directly involved, the carers, the GP and social worker</p> <p>8.: No by implication this means you are saying that somebody has a wheelchair, they have mobility, but in reality they have restricted mobility and process would be totally unfair, does this mean somebody in a power chair gets allowance than somebody with a manual chair, where do you draw the line?</p> <p>9.: Whatever process is adopted, it must be recognized it cannot be a positive experience as once again disabled people, brain damaged from birth once again have to justify their condition.</p> <p>10.: The only people capable of this are the disabled person, their carer, GP and social worker</p> <p>11.: As previously stated, this is a retrograde step for those disabled from birth or living in a care home, they would not be there in the first, if it wasn't for the nature of their disability. From previous experience, these meetings can be very stressful, to a disabled person, particularly as many also have mental health problems as a result of their disability. Ironically, how will the disabled be able to travel from their care home to another venue under the Government's new proposals.</p> <p>12.: The review should include all the people involved with the disabled person, carers, GP, social worker. If disabled from birth the assessment should not be necessary.</p> <p>13.: It is understandable why people do not report changes because they live in fear their allowances will be removed, even though they have genuine</p> <p>14.: It has to be recognized many of the disabled people who need the DLA need the support of others to fully understand the process, basically this usually falls on the carers, which are now going to have an additional burden of worrying besides worrying about the person they are looking after.</p> <p>15.: There appears to be an assumption that all disabled people, especially those in care homes will have access to this information, they do not many do not have phones or the internet or the capability to access such mediums, again a requirement is another worry for the disabled!</p>

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		<p>16.: This often by using their mobility allowance or family supporting them with these needs, for example electric wheelchairs but to expect carers to take on the burden of the additional costs of purchasing especially, is totally unacceptable.</p> <p>17.: It has to be recognized children grow up and their problems and that for carers increase, especially as many parents of disabled adults are elderly themselves and with limited funds.</p> <p>18.: It is critical, as enables access disabled parking concessions and reduced travel costs.</p> <p>19.: It would restrict their ability to park or access special facilities for the disabled when parking and increase their costs, which they could not afford.</p> <p>20.: Why can it not recognized once a person is born disabled they cannot change their condition. Would it not be sensible for their local GP to be responsible for access to all allowances and aids, etc.</p> <p>21.: All disabled people are equal</p> <p>22.: I believe these proposals have not been thought and implications on disabled people in care homes has not been fully assessed and they are been treated as second class persons, compared to those who live at home.</p> <p>In addition, the whole process of consultation is unfair and flawed because:</p> <ol style="list-style-type: none"> 1) Insufficient time has not been allocated. 2) The majority of disabled people do not have access to the internet or the ability express their views, especially when the documents are complicated and lengthy. 3) The proposal have not been communicated to those that matter, i.e., the individuals, through a letter! 4) The response from the DWP and the Minister from the Disabled has been very poor and the use of standard letters is very poor. 5) Quite simply the proposals remind of when our son was first born and we have had to fight for everything he has obtained, access to benefits, access to care home, access to aids and this is now going back to the old days and will create an unnecessary amount of stress to people born with a Disability, by imposing more restraints on their freedom and access to funds to live a fulfilling life. <p>██████████, acting on behalf of my disabled son ██████████</p>
EM413	10-Feb-11	<p>I am an eighty year old who along with my seventy four year old wife have been full time carers for one of our daughters, who was left for eight hours on a trolley while the only Doctor on call was too busy with the weekend drunks to examine her properly, one of her problems means we have to have our heating on twenty four hours a day every day of the year. Yes we do have problems paying fuel and council tax and food bills, as we share a basic rate pension we get no financial support. No Mr Cameron we are not all in this together. under the old system we had visits from Doctors? with little grasp of English or medical expertise, they simply repeated the same question over and over again presumably in the hope of confusing the disabled person. Everywhere you look in local and national government there is massive waste and overspend. but it is much easier to steal from the poor and disabled, carers save governments Billions of pounds every year and are treated disgracefully sadly the only chance of anyone listening would be for carers to join with the students on the streets</p>
EM414	10-Feb-11	<p>My Name is ██████████ and I am registered disabled and a wheelchair user. Myself and many others have been advised to contact you and give our thoughts and opinions on the proposed changes to the DLA: I believe that this government is hell bent on saving money anyway and anywhere it can and picking on those like myself is an easy way of saving a few</p>

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		pounds. For me and many others the DLA is a life line and helps not only pay for care if and when needed but also provides us with a means of paying for our transport needs. If you live in the real world you would know that access to transport etc for disabled people is patchy at best. I live in rural Inverness where there are no accessible buses and a few wheelchair accessible taxis whose working hours are not set in stone. I need my car to help get around. I suffered a spinal cord injury in 2001 and I am paralysed from the chest down and cannot walk. To think that I will be once again subject to medical examinations that will not only confirm my condition but stand to reinforce the fact that I am disabled and will never lead a normal life distresses me. I urge those who are contemplating making these changes to look else where for cash saving and perhaps concentrate on making live more bearable for those like myself by enforcing the DDA. Kind Regards
EM415	10-Feb-11	My name is [REDACTED] and I am a mother and carer for my Son [REDACTED] who is 5 1/2 years old. He suffers from a receptive and expressive language difficulties, ADHD, behavioural problems and sleep difficulties. I am worried by the thought of losing some or all of the money that we get for [REDACTED] as it helps us to afford things for him that otherwise he would have to do without . Losing the carers allowance would impact on my own ability to effectively support my son and the other members of the family as he is a full time job. Without this money we would not be able afford the little extras for ourselves such as our car which we use to run [REDACTED] around. I dont feel that these cuts should be getting made against the disabled children as they are just innocents in this recovery of money and they need the support that this funding allows to keep them and their families together and not drift apart. To remove the carers allowance by means testing is ridiculous as this again targets those families with one partner that works and the other cares for the disabled child. If that partner earns over the limit will they both suffer - i think that they will which is wrong! The carers allowance must remain outside the universal credit. If not more families will struggle not only to cope but to stay together as a family. I look forward to receiving a reply to this email as soon as possible as the matter is such an important issue. Regards,
EM416	10-Feb-11	Dear Sir/Madam As the parent of a child in receipt of DLA I write in response to your public consultation document published on 6 th December 2010. I note that the DWP has not yet decided whether the new proposed Personal Independence Payment (PIP) Benefit (the successor to DLA) will apply to children under 16 years. It strikes me that there is no financial justification for extending the new proposed benefit to cover disabled individuals under the age of sixteen. The graph on page eight of your consultation document makes clear that the number of children receiving DLA has remained virtually static since DLA replaced Attendance Allowance and Mobility Allowance in 1992. The take up increase for children on your own figures is less than one quarter of one percent.....ie less than 200,000 new child recipients of DLA across the entire UK current population over the last 19 years. Another surprising aspect of the consultation paper is that it contains no estimate whatsoever as to the proposed cost of implementing PIP as compared with the current costs of administering DLA. The current system is administered largely on paper and over the telephone (with written input from GPs and Paediatricians) whereas the new system will be based on a face to face assessment by a "Departmental Approved Healthcare Professional". If these "Healthcare Professionals" are not to be trained Paediatricians then how will they be in a position to fulfil the aim of the PIP "to be fairer and more objective than the current discretionary assessment for DLA entitlement". In addition, what safeguards exist to support your contention that these Departmental Approved Healthcare Individuals will be independent and

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		<p>free from departmental pressure to cut the number entitled to PIP as has been the case with ESA where the number of appeals launched since the new assessment system for that benefit was introduced in 2010 ?</p> <p>Finally, the consultation paper makes much of the fact that those lucky enough to be in receipt of PIP from 2013 will be subject to "periodic review of the award". There is nothing in the consultation paper about how frequent these reviews will be and no mention is made of the stress that will be caused to both disabled children and their parents by having to undergo these face to face reviews. Given that the cost of DLA payments to children is static is it not cheaper and less disruptive to allow them to continue to receive DLA in its current form after 2013 regardless of whether the benefit is renamed PIP or remains known as DLA ? Why also does paragraph 40 of the consultation document propose to penalize disabled children just because they receive "support needs which are being met from public funds by another institution such as a school " ? Is it really practical to distinguish between support needs provided by public funds as opposed to, say, charitable donations in this context when dealing with disabled children ? Yours sincerely</p>
EM417	10-Feb-11	<p>Please find my response in the attached document. Because I am an interpreter in British Sign Language, and my wife is Deaf, and my deceased parents were Deaf, and I have many Deaf friends, and I am Chair of Trustees of a Deaf organisation, I am focusing on the place of Deaf people in the DLA discussion.</p> <p>I believe the current consultation is far too narrow in its scope. It should be an opportunity to take a holistic view of how to address the barriers and inequality faced by Deaf people who use BSL (British Sign Language) as their primary means of communication. Legislation and regulation treats Deaf people as either disabled or as members of a linguistic minority. It is time to put them firmly in the latter</p> <p>I am happy to clarify any points which are not clear to you, or to provide further information. I've done my response in a rush, so I apologise if it is not as coherent as I would wish</p> <ol style="list-style-type: none"> 1. Face to face communication with people who do not know sign language <ul style="list-style-type: none"> • Lack of immediate access to interpreters • Lack of free access to the telephone system, using sign language. n.b. the current text relay service is outdated, slow, and inaccessible to deaf people who are not fluent in using text • Obstacles placed by service providers which stop Deaf people gaining access using a 3rd party, e.g. a sign language interpreter or video interpreter. Banks, phone companies, and even the DWP itself are guilty of using the Data Protection Act to deny access, even though the Data Protection Commissioner says this should not happen. • Lack of access to routine and non-routine announcements via public address systems, radio, etc. Deaf people are particularly disadvantaged by announcements on public transport, which can severely inconvenience deaf people • Inaccessibility of official communication to those with lower reading ability • Inaccessibility of internet-based system to those with limited reading ability, education, and income <p>2. No. For Deaf people the cash benefit of DLA fails to address the obstacles they face. Legislation goes so far but there are far too many obstacles to be challenged. Deaf people need more services to support communication, particularly over the telephone system, and face to face communication. We need a modern video relay system, covering not just the phone system, but also daily interaction</p> <p>3. In cities with good public transport, it could be argued that Deaf people are better off because they usually have Freedom passes offering free transport</p>

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		<ul style="list-style-type: none"> • Deaf people who cannot use the internet to compare prices, or ring round to compare prices, pay higher prices for services and products • If a service provider cannot or will not fund an interpreter, Deaf people will have to pay for an interpreter. In reality because such events may be so short notice, Deaf people have to rely on inadequate notes, or on friends or family members to facilitate communication. This is a problem with GPs and significant commercial transactions. Deaf people tend to deny themselves a service because of cost, so do not incur a cost which others would not incur, e.g. evening classes <p>4. I believe this issue is irrelevant to Deaf people. They need services not benefits</p> <p>5. I believe this issue is irrelevant to Deaf people. They need services not benefits</p> <p>6. I believe this issue is irrelevant to Deaf people. They need services not benefits</p> <p>7. I believe this issue is irrelevant to Deaf people. They need services not benefits</p> <p>8. Yes, but this should consider whether the equipment meets current standards What aids and adaptations should be included Flashing door bells, vibrating alarms, visual/tactile fire alarms, video phones – anything which non-deaf people would not need Should the assessment only take into account ...easily obtain? The question barely makes sense</p> <p>9. For Deaf people who use sign language, a short form attesting to their inability to hear on any telephone with strangers, signed by a relevant professional should suffice</p> <p>10. For Deaf people, an audiogram and a signed statement by a relevant professional (see answer 9)</p> <p>11. The healthcare professional would have to be well-versed in deafness and sign language; otherwise the assessment would be pointless</p> <p>12. For Deaf people who use sign language, what would be the point of reviewing a permanent state?</p> <p>13. Use more graphical communication and Plain English. For Deaf people produce video clips for use on websites, DWP office videos, etc</p> <p>14. Of course</p> <p>15. Fund advice services in British Sign Language</p> <p>16. Social services and Access to Work fund equipment for Deaf people. PIP should fund equipment on proof of receipt</p> <p>17. I have no view</p> <p>18. It would be better to have a document which attested to a Deaf person's deafness and use of Sign Language, rather than go through the hoop of DLA/PIP. Deaf people need services not benefits</p> <p>19. More bureaucracy. See answer 18</p> <p>20. Everything</p> <p>21. Deaf people need services not benefits. Cutting DLA for Deaf people makes logical sense, but only if they receive better services at less cost</p> <p>22. Your response:</p> <p>Consultation on DLA and Deaf people</p> <p>The current consultation is far too narrow in its scope. It should be an opportunity to take a holistic view of how to address the barriers and inequality faced by Deaf people who use BSL (British Sign Language) as their primary means of communication. Legislation and regulation treats Deaf people as either disabled or as members of a linguistic minority. It is time to put them firmly in the latter</p> <p>I should not be surprised at the lack of radicalism in the proposed changes. It stems from a lack of imagination and expertise on Deaf issues within the DWP, and the reluctance of the Deaf world to open frank dialogue with government about how we could achieve a win-win situation. There is suspicion that government is really only interested in cuts, and not in new ways of working which will actually improve services</p> <p>I take some risk in offering a suggested way forward that will both reduce</p>

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		<p>expenditure and improve the lot of Deaf people. Those who challenge the legitimacy of DLA for Deaf people open themselves to criticism for seeking to deprive a disempowered group of income</p> <p>Commonly DLA is awarded to Deaf people on the basis of</p> <ul style="list-style-type: none"> • Inability to communicate with people who don't know BSL • Inability to hear public announcements • Inability to hear warning sounds • Inability to read and respond to official documents <p>Theoretically, a paid interpreter or supporter could address these barriers. In reality most of these events are so ad hoc and fleeting that it would be impractical to employ a supporter/interpreter. In those situations where Deaf people could spend their money, e.g. to attend a regular yoga class, the costs of securing an interpreting service would far outweigh the amount of DLA, and the resources of the provider. In reality Deaf people rarely spend their DLA on interpreting or personal support services.</p> <p>Support costs are picked up by:</p> <ul style="list-style-type: none"> • Service providers as part of their Equality Act, Human Rights Act, etc duties • DWP's ATW (Access to Work) • Social services departments • Voluntary sector <p>It cannot be right to give a benefit for a service that is provided at no cost to the individual. DLA should be for additional and unavoidable costs of disability. In my view the court test case that granted DLA to a Deaf woman (██████1994) was perverse because most of the costs of deafness are avoidable. Deaf people DO face obstacles to communication; they DO face discrimination; they DO experience inequality. But a cash benefit is not the way to address these issues</p> <p>The government should be looking at what can actually address the barriers faced by Deaf people, rather than what can potentially address barriers. Deaf people in employment, particularly office-based employment, receive AtW to pay for interpreting support. Commonly interpreters are under-employed in such situations because communications needs at work are often unpredictable. AtW now funds a better solution: video interpreting, such as provided by Significan't (see www.significant-online.co.uk) or Sign-Now (http://www.sign-now.com)</p> <p>Using a video relay service Deaf people can have access to the telephone system using BSL. The same service can enable Deaf people to interact with colleagues or customers in small face-to-face meetings. A handful of Deaf people are using video interpreting services for personal use, using DLA and, in rare cases, Choice & Control funding. Video interpreting is transformational for Deaf people, and really addresses many of the barriers they face. Why can't DLA for Deaf people be replaced by a dedicated communication allowance which will enable them to nominate a preferred provider. There are interesting models in other European countries</p> <p>The Department for Business Innovation and Skills is already in discussions about giving deaf people wider access to telecommunications. Rolling in the review of DLA should bring about a more effective and cheaper system than BIS fears</p> <p>We have an ideal opportunity to capitalise on the alignment of a review of DLA, BIS's review, and AtW. Deaf people need services not benefits</p>
EM418	10-Feb-11	<p>1.: The additional costs of transport or other assistance to allow attendance at work, social events, restaurants, theatres cinemas etc. Losing the financial ability to get the transport or other assistance would lead to being unable to continue working and isolation due to any ability to socialise.</p> <p>2.: A lifetime award should remain a lifetime award. The current reassessment process seem perfectly suited to its needs.</p> <p>3.: Extra transport costs e.g. taxis, adapted cars, and mobility scooters.</p>

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		<p>Extra costs for help with personal care and for maintaining the cleanliness and safety of both home and garden. Extra costs involved in buy pre prepared foods and ingredients due to an inability to cook for oneself. Costs involved in buying own mobility aids such as walking sticks.</p> <p>4.: I do not have any comments to make other than if 3 rates mean that claimants are more likely to at least get some help I support 3 rates. It is as easy to select 1 box from 3 as it is 1 box from 2 when doing the computer award of benefit.</p> <p>5.: I feel that there is a case for an assessment of individual need as a diagnosis of cancer, for example, does not mean that a person cannot care for themselves or they have mobility issues, although where a condition is known to be incurable there is an argument for an automatic lifetime award.</p> <p>6.: The ability to obtain or remain in work. The ability to be clean and comfortable in your person and your home. The ability to meet others outside your home and be able to take part in normal social activities such as cinemas and restaurants etc. A full and active life requires far more than having your body washed and fed although of course these are vital.</p> <p>7.: Accept evidence from specialists in the particular condition e.g. neurologists. Talk to the claimant fully or obtain evidence from them in other ways as to how the condition affects them over a period of time rather than on any given day or at any given time of the day. For example I have relapsing remitting MS and on more than one occasion I have told people that I feel fine in the morning and 3 hours later had to go home 'sick' because I am unable to function. Sometimes I can be 'fine' for a period of days and then return to extreme fatigue, pain and lack of mobility as opposed to just being extremely tired and achy all the time. That is what 'fine' means.</p> <p>8.: Aids and adaptations help manage the difficulty but do not take away the problem. For example I have an adapted bathroom with walk in shower because I could no longer use a bath; however I am sometimes unable to shower properly or shower at all because I am too fatigued to deal with washing and drying myself. I have a walking stick which I bought myself and this helps me walk in a straight line but doesn't relieve the fatigue. Also when I visit family I am unable to bathe at their houses because their bathrooms are not adapted. Overall I don't think aids and adaptations should be taken into account. Many of us use DLA to purchase the aids.</p> <p>9.: I obtained help from a disability charity to complete the form and worked for the DHSS in the past so I find it hard to answer this question as of course I had help with any issues and was aware of AA becoming DLA.</p> <p>10.: Reports from a specialist in the condition e.g. MS Nurse, a person who helps or cares for the person on a regular basis, a GP and obtaining proper information about the condition and all of its possible problems. Too many conditions cause problems that cannot be determined by just a physical examination.</p> <p>11.: I feel a face to face discussion as long as it is a full discussion which allows the claimant to expand on their problems and difficulties could be of benefit to people with 'hidden' aspects to their condition. However speaking personally I am finding the idea of a reassessment of my lifetime award very stressful and am actually unable to work because of stress along with my MS at the moment. My GP could confirm if asked that any stressful situation does lead to an increase in my symptoms and therefore I am more likely to be unable to work.</p> <p>12.: Reviews should be planned according to the genuine likelihood of improvement in the condition. Where a condition is incurable and / or</p>

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		<p>progressive a review would seem to be a waste of time. A statement from the claimant that there has not been an improvement in their condition should be acceptable unless it is reasonable to believe that the condition should be 'cured' within the timescale i.e. if it has been awarded in a case of physical injury or for a condition that may be relieved by medical intervention.</p> <p>13.Your response: A simple annual reminder such as with WTC would seem to be sufficient.</p> <p>14.Your response: I think people need information about the availability of the benefit and clear guidance on what the payment is intended to help with. Information on how and where to claim and assistance with making the claim should be provided. Information about the amounts of benefit and what other help you may also get would be very useful.</p> <p>15.Your response: It depends what kind of access was meant. Not every one is able to access information online and there may be literacy issues with written guidance. How long would it take to access advice and support if it meant meeting with a presumably heavily loaded social or health worker and would benefit be withheld until such help had been sought? The delay may well not be the claimants fault. The main thing would be to ensure that a robust system of social / health support teams were in place and able to provide help within a very short timescale. This would mean substantial funding I imagine.</p> <p>16.: I have bought my own walking sticks. I have never been offered one by the NHS. I am considering buying my own mobility scooter if my finances allow but DLA forms a very important part of my finances. My bathroom and garden path were adapted for me by way of a disabled facilities grant. Whether councils will still have the funds for these remains to be seen. I am not sure whether you mean a once only payment of PIP or using the funding from weekly benefit which most of us do already. An additional one off payment would help but not if it meant a reduction in weekly benefit due to an assumption that the problem had been solved.</p> <p>17.: My only comment is to consider what it is reasonable for a parent to do for their child at that age regardless of disability.</p> <p>18.: DLA has been very important to me as it meant I could claim Working Tax Credit and this has enabled me to work part time and part year. This helps me manage the fatigue element of my MS symptoms which for me is often the main problem. The level of my income means I qualify for free NHS prescriptions and Dental treatment as well as a spectacles voucher. Basically if I lost DLA for any reason I would be unable to continue working, be forced to claim ESA, be unable to pay my mortgage and council tax so either be homeless or at the very least claiming council tax benefit. Possibly I would be in rented accommodation and also claiming housing benefit. So I would simply move from one benefit to another and would no longer be contributing to the economy by way of tax and NI. Also the DLA has entitled me to a blue badge, the DFG for the bathroom and I had a storage heater installed under the warm front scheme.</p> <p>19.: see above.</p> <p>20.: I am not sure they could be combined. For example I am still able to work but do have extra costs and problems due to my disability so an ESA assessment would not be suitable for PIP and vice versa.</p> <p>21.: Unless any group have a reluctance to claim because of race, sexual orientation etc I don't see this as a problem. I am white British heterosexual woman so maybe I just don't know.</p> <p>22.: I am very concerned that this seems to be purely a cost cutting exercise and that the decision regarding level of need could be arbitrarily reached based purely on the most obvious physical needs for care and not based on emotional or hidden needs. The reducing the benefit bill by 20% is an extreme concern as it seems that 1/5 of us will lose benefit no matter what. What would happen if reassessments only brought a cut of 5 or 10 per cent?</p>

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		As I said previously I am already suffering from stress / depression because of the proposed changes and what they may mean for my life. This already has had an impact on my physical health and meant time away from work. This eventually can lead to a vicious circle of stress - physical symptoms - increased stress – increased symptoms etc.
EM419	10-Feb-11	<p>Please find response from parent of disabled child</p> <ol style="list-style-type: none"> 1. : An uncaring UK Govt and their Economic Policy is the main problem. Each disability is different and my daughter has a severe learning disability and will need lifelong care and support. Sadly the prime minister learnt nothing from being a parent of a disabled child. I don't agree that Personal Independence Payment (PIP) should be implemented. This proposed replacement is inhuman and is just piling more worry and misery on to us. 2. : Most of it – make form easier to fill in, more support services to help applicants make claim, involvement of medical assessment seems right but this would need to be fair and medical panel have the right knowledge and understanding to make correct decision. 3. : question is too generalised. My daughter needs lifelong care and support for her personal care needs and supervision – that does not come cheap. 4. : This question is impossible to answer. The benefit to the UK Govt is to save money because that is what this reform is all about, for disabled people it means being disadvantaged 5. : Yes automatic entitlement for some health conditions and impairments for DLA 6. : 1 Pay high rate care and high rate mobility (scrap the proposal for PIP) 2. The second part of the question is too vague to answer 7. : Having a fair system 8. : Absolutely not! 9. : Having available support through Health, Social Work and vol orgs. Use plain and simple language 10.: Family GP, own medical specialists and therapists 11.: Healthcare professional needs to be a competent public servant. If own Doctor is advising meets criteria for automatic entitlement then that should there is no need for another health care professional to make a decision. 12.: reviews for DLA should be kept to a minimum* 13.: I don't agree the system for Personal Independence Payment would be easier to understand* 14.: I don't agree that PIP should be implemented 15.: I don't agree that PIP should be implemented 16.: 1. First part of question is too generalised. 2. No.* 17.: developmental stages* 18.: Works well – why change it?* 19.: I don't agree that PIP should be implemented* 20.: I don't agree that PIP should be implemented* 21.: I don't agree that PIP should be implemented * 22.: I don't agree that PIP should be implemented
EM420	10-Feb-11	<ol style="list-style-type: none"> 1.: General attitudes to disability and really bad access to many buildings.* 2.: Yes, please do not throw the baby out with the bathwater. I know many people who have lied to get this benefit but I also know people who are able to battle on and live a more rounded life despite having a disability.* 3.: More heating, often quick foods as it is difficult to cook without help.* 4.: No, if you are going to tailor benefits to an individual's needs then why not keep the levels the same? Only 2 levels will not reflect the different levels of need that individuals have.* 5.: It should depend on each individual's need, as every medical

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		<p>condition is different for each individual person. *</p> <p>6.: The ability to look after one's basic needs, such as washing, dressing, eating, cooking, shopping and cleaning.*</p> <p>7.: There needs to be consultation with gps and therapists and work(if appropriate) as well as the individual.*</p> <p>8.: Yes, account should be taken of all aids that a person uses .I would like to see a partnership between the individual and government. A person should be expected to contribute to aids if they wish for a fancy one. The government should only be expected to provide basic aids.*</p> <p>9.: Have easier access to advice about filling the form in. Ask Social Service Departments to have easy form formats and give more time to help fill in the forms.*</p> <p>10.: Medical staff and social workers as well as the person Claiming the benefit.*</p> <p>11.: This will focus on what help an individual might need. It is important that parents or carers give input but they can often skew the needs of the individual.*</p> <p>12.: That should depend on the severity of the condition of the individual. The more severe the longer the period between reviews should be. The way reviews are conducted should reflect the ability of the individual to take part .It is really important that the individual is consulted about their needs.*</p> <p>13.: Hospitals and Homes could inform Government automatically when people are in hospital and when they are discharged. Individuals need to be told that Professionals will report any changes in their condition automatically, and this may spur people on to report any changes themselves. Also give more time limited benefits if this is economic so to do.*</p> <p>14.: People need to describe how their condition affects them But the time element of the current form is not easy to answer.*</p> <p>15.: Yes this would be helpful as long as resource is accessible.*</p> <p>16.: Yes and there should be more of a partnership between Health and the individual to enable people to buy aids with bells on if the individual wants such an aid but the therapist has assessed for a more basic aid, that would cut down on unnecessary threat to take therapists to tribunals.*</p> <p>17.: Listen to the child and the therapists involved as well as their parents .Parents are not always the best people to assess their children's needs in isolation.*</p> <p>18.: It has been important.*</p> <p>19.: It might mean that they would not be as good as maximising their health needs.*</p> <p>20.: Health assessments could be undertaken in conjunction with social work assessment perhaps in one centre.*</p> <p>21.: The new assessment needs to weed out liars but not deter people who have real needs. Have a phone line that people can ring to report people who claim falsely.*</p> <p>22.Your response: Don't throw baby out with bath water! The mobility component helps people access daily life and if withdrawn no other help would be forthcoming from Social Services with this particular focus.</p>
EM421	10-Feb-11	<p>1. Adequate levels of appropriate and trained support, transport, accessible facilities and activity venues*</p> <p>2. DLA supports individuals to manage their lives in the way they want to and means that there is always finance available to access transport*</p> <p>3. Accessible taxis are at least 30% more expensive than "normal" taxis.* In some areas Local Authorities are withdrawing free public transport for staff who support disabled people*</p> <p>4. This proposal is similar to DLA, why change*</p> <p>5. Individuals should be assessed individually and whether someone needs support and supervision to access public transport must be taken into account*</p>

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		<p>6. Ability should not restrict anyone's right to a full and active life. *</p> <p>7. By regularly assessing individual need*</p> <p>8. Assessment must take into account any aids used including the need for support from another person*</p> <p>9. Anyone who has a lifelong entitlement to DLA should not be reassessed.*</p> <p>10. Information from GPs and support staff must be included in assessment*</p> <p>11. None GPs know individuals well and can give good information*</p> <p>12. Reviews will always be set by DWP but never matched with people to complete them*</p> <p>13. People are not confused by DLA, why change ?*</p> <p>14. People will need Easy Read and symbol information as well as trained staff to explain the changes to individuals with profound disabilities*</p> <p>15. There is no need to make an imperative to access support*</p> <p>16. No*</p> <p>17. N/A*</p> <p>18. DLA works well for all who receive it*</p> <p>19. Will the PIP be an assessable benefit for local authorities to take into account for contributions ??*</p> <p>20. Most disabled people have their information known by many organisations, how many more organisations need to know the same information ?*</p> <p>21. DLA works well, why change ?*</p> <p>22. No</p>
EM422	10-Feb-11	<p>My name is [REDACTED] and I am a sixty-year-old woman; I have received DLA [very gratefully!] since 2006. I have chronic inflammatory problems affecting my joints and tendons, and also eyes, throat, lungs, skin---you name it! My main disabilities arise not from the chronic pain and discomfort, but from erratic vision and balance, and sudden bouts of overwhelming fatigue. I have to pace myself, and plan for any future activity by having a couple of restful days---then allow for extra tiredness after the event. Each day I make a list of what I would like to achieve, and feel fortunate if I can tick half of it the next morning. I have other health conditions, the main one being narcolepsy, which was diagnosed in 2003 after at least forty years duration. Its effects on me have always been exacerbated by other illnesses, so it is now at its peak owing to chronic inflammation. I have suffered depression on and off during my life, and there are times now when it is hard to tell if depression is making me feel tired, or exhaustion is making me depressed. I think it is mostly the latter, as I am generally a contented person. I mention my health to establish my personal knowledge of fluctuating and debilitating conditions. I am answering these questions [the ones I can answer from my own experience] as an individual, but I am also a volunteer with Amaze, a charity which helps the families of children with special needs. I assist and advise parents filling in DLA forms for their children. Usually I elicit the information and write it on their behalf, but they check it is accurate. *</p> <p>*</p> <p>1. People with disabilities such as my own feel variable and unpredictable malaise, pain, loss of function and overwhelming exhaustion. This is not society's fault! However, the provision of more public seating, even places to perch and relieve *</p> <p>strain on problem areas, or catch one's breath, would help considerably. Anywhere that queueing is a regular thing could use a ticket system and provide seats. Since the closure of all the small local Post Offices I don't send letters, as I have to get *</p> <p>to a main Post Office, then queue for an average of 15 minutes to buy stamps. This uses my daily quota of stamina, and it is not worth it when I could be pottering round my garden instead. The overheating on public</p>

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		<p>transport and in shops and other buildings is hard for some sick people to tolerate. Turning the heating down would make it more comfortable for everyone and save £millions. The noise level in a lot of shops is quite unbearable for a lot of people, especially those who feel unwell and may have great difficulty concentrating. I have voted with my feet on several occasions when a polite [though necessarily shouted] request to turn the 'background music' down has been met with 'We can't, it's piped in from Head Office' or some other facile brush-off. The nearest ear-friendly stores and online retailers now get my custom. The above comments also apply to pubs, which I nearly forgot as I don't get out much. *</p> <p>2. At present, DLA is not counted as income when you are assessed for other benefits, e.g. council tax benefit. I hope this will stay the same, unlike when Family Credit [not counted] changed to Working Tax Credit [counted] and although the payments were higher, as promised, the loss of council tax benefit made people worse off. *</p> <p>3. Small local shops cost more, but may be the only option most of the time. Shopping online saves energy but incurs delivery costs. If housebound, more use of heating, lighting and appliances. Extra washing if incontinent or using messy ointments etc. More washing powder and wear and tear on machine. Or cost of launderette if no machine at home; maybe having to pay for service wash, or pay someone to do the washing. Incontinence pads, extra bedding and towels. *</p> <p>Joint supports, special footwear. Taxis when public transport does not go near enough, or leaves one with a hill to climb. *</p> <p>Maintenance of aids e.g. stairlifts, wheelchairs. Paying for help with routine chores in home and garden, either because the tasks are impossible or too tiring to be practicable. Paying someone to help with pet-care, e.g. empty litter trays, walk dogs. *</p> <p>4. • Will having two rates ... levels of support? Definitely easier to administer! Probably having a sliding scale would be fairer, but too complicated. • What, if any, disadvantages ... cause? Main problem would be deciding how to deal with people who are currently receiving* middle rate of care component. *</p> <p>5. Based on needs etc. *</p> <p>6. People who suffer painful and debilitating conditions cannot lead full and active lives, and being told we should leads to further feelings of inadequacy. We can only do the best we can, even with benefits and support. People whose disabilities do not include exhaustion will gain most from any help offered. I suggest keeping the question about what activities you would do if you had help, but without the 'how many times and for how long' part. Encourage people to give as much information as possible about their disabilities on the claim form, and believe them. Emphasise that it is all right [even advisable] to have help from friends/family/charities etc. with form-filling. People who are feeling ill and tired have little spare energy to battle with a form, even such an important one. In my opinion, the more slapdash the form submitted, the more likely the applicant is to be in need of support. If possible, where insufficient information is given, or answers missed, perhaps instead of having the claim rejected the applicant could be invited to give more detail on certain points. Many people whose claims are rejected are too disheartened to try again, even though, with help and guidance, they could submit a successful claim and * gain the award they need. *</p> <p>Adequate rest/sleep. Eating nourishing food. Moving about as much as one can to keep muscles toned and joints supple. Having access to fresh air and daylight/sunshine. Keeping clean. Contact with outside world, by telephone, computer, television. Being able to keep home in a reasonable state, so one can have visitors without feeling shame and embarrassment. Some form of enjoyable activity, hobby or social interaction. Companionship when required, maybe a pet or pets. [It is very important to be able to keep the pets one had before illness struck---</p>

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		<p>having to part with a beloved companion is guaranteed to make the owner feel worse than almost anything else.]*</p> <p>7. On the claim form, stress the importance of giving full and detailed answers to the questions [on separate paper if not enough room on form.] Perhaps have a diary page where people with these condition can describe a week in their lives.*</p> <p>Encourage people to enlist the help of those close to them, who can remind them of things they may have forgotten. 'Brain fog' and poor memory are a feature of many variable and fluctuating conditions. The auto-immune syndromes cause periods of extreme weariness, and one's brain may switch off during form-filling if not prompted by a helper. When asking about physical capabilities, have a box for 'I can do this, but if I do it more than X times I will have pain/ have to rest afterwards'.*</p> <p>Take into account the opinions of GPs, but bear in mind that a lot of auto-immune conditions do not have visible signs, and many take years to diagnose. Often the only evidence will be the statement of the claimant and the people s/he knows, who witness the suffering and fatigue. Please stress at the beginning of the form that while it is advisable to send as much supporting evidence as possible, there is no absolute requirement for it. Detailed credible descriptions of one's * disabilities are enough. Most sufferers from auto-immune conditions are women [from what I have read] so to discount their unsupported claims without further investigation could be discriminatory. *</p> <p>8. Yes, if the aid or adaptation puts the user in the same position as someone without their disability. For example, a hearing aid that restores good hearing or spectacles that give useful vision. I do not think most aids fall into that category. An incontinent person can wear pads, but s/he still is aware of the problem and the danger of having a humiliating accident. Someone who cannot reach up or down because of joint disease or fatigue can use a 'grabber' to pick up objects, but this will still cause pain and more fatigue. Personally, if I am going anywhere that I know it may be necessary to stand, I take* a folding stick/chair, of which I have several varieties. So I can join in activities like carol- singing for charity by sitting on a high fold-up chair--- but I still have trouble reading the words [blurred] and turning pages [swollen joints and numb fingertips] and holding myself erect [tired], staying awake [narcolepsy] and breathing [asthma.] So, although I have a good* time, I will have saved myself up beforehand and allow a couple of days recovery afterwards. The chair enables me to take part, and passers-by would perceive me as 'normal'---but I am not, I'm just doing the best I can. If any aid would restore me to my previous glorious, unappreciated normality, I would give up my award like a shot.*</p> <ul style="list-style-type: none"> • What aids and adaptations should be included? As above, aids or adaptations that put the user in the same position as someone without their disability, or the way s/he used to be before ill-health.* • Should the assessment only ... obtain? There is no harm in recommending aids, and taking them into account if they are obtained and restore function. But people may have good reason for failing to use particular aids, and so they should not be assessed as if they do use them. To quote my favourite line from the consultation document:- "Disabled people are experts in their own lives---". Yes, we are. By all means consider any miraculous aids that are developed in the future.* <p>9. • How could we make the claim form easier to fill in? Some of the questions could be amalgamated to make it less repetitious. The 'how often', 'how many minutes' questions cause worry and bafflement. Add 'regularly throughout the day/night' and 'constant/almost constant' to the options. Also 'On best day', 'On worst day' for people with variable fluctuating conditions. I know the notes say you should explain if certain actions one can perform result in pain or fatigue, but it would help to add it to the options to tick. When asking questions that will probably involve</p>

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		<p>a long answer, provide plenty of space to write it.*</p> <p>• How can we improve likely to qualify? Television advertising. [Keep it simple and to the point. No pop music, no soap stars. Just large writing on the screen and a pleasant voice reading the same words. Tell people where to get application forms, phone, website.] Put posters and application forms in Post Offices, banks, supermarkets, doctors' waiting rooms, hospitals and other buildings. Billboards. *</p> <p>10. Statements from GPs, specialists, therapists, carers, social workers, employers, colleagues, teachers, friends, family, neighbours, parish priest, rabbi, cleaner, etc. Anyone who witnesses the applicant carrying out their daily life and having to avoid certain activities. Instead of asking for a statement, there could be the option of filling in a question sheet. People can *</p> <p>often tell if someone is in pain through their voice or facial expression or manner of moving, so ask about that. Does the person avoid social contact because of pain/fatigue? Do they have to rest a lot/have time off work/cancel activities at short notice because of disability? Does their voice fade during a long conversation? Do they stumble, wince, rub painful parts *</p> <p>of the body? Are they clumsy, do they drop things or bump into things, either all the time or when fatigued? If in company, do they gradually 'withdraw' because it takes all their effort just to be there and there is no energy left to contribute? Do they become miserable, irritable or tearful if they cannot find somewhere quiet to rest? Do they try to avoid shaking hands, or *</p> <p>do they hate to be brushed against or touched in other ways?*</p> <p>11. • What benefits or difficulties might this bring? The discussion would almost certainly be longer than the applicant usually has with a doctor. The healthcare professional should be able to spot the signs of illness outlined in my previous *</p> <p>answer, as well as knowing what questions to ask to elicit extra information.*</p> <p>"Disabled people are experts in their own lives and information they provide will continue to be vital".[Gathering evidence 29.] Only use healthcare professionals who agree with that statement.*</p> <p>The applicant may be nervous, tired and in pain. Years of inconclusive tests and feeling one is perceived as a malingerer [mainly 'invisible' conditions] can lead to defensiveness, overstatement or even apathy--- 'They won't believe me, so let's just get it over and go home'. Having a friend or similar at the meeting would help, if this companion were allowed to take notes, *</p> <p>and occasionally prompt the applicant if s/he got confused or tired or had lapses of memory brought on by the stress of the occasion.*</p> <p>• Are there any circumstances ...another location? It may be inappropriate for someone with mental health problems like severe anxiety and people who find it stressful and fatiguing to have to speak a lot. For someone with one of the fatiguing disabilities, attending the meeting may use up a week's energy. [Save yourself up-----meeting-----recovery time.] *</p> <p>Being cooped up in a hot stuffy waiting room while dreading a stressful encounter is a beastly experience even for people who are well.*</p> <p>It should only be done at home on the request of the applicant. If a person is housebound through disability or long-term sickness, they should be able to qualify for the awards anyway, through their own and supporting evidence, without having to jump through hoops/ prove they cannot do so.*</p> <p>12. • What evidence and/or criteria should be used to set the frequency of reviews? In cases where there is a diagnosed condition, the GP or specialist will have some idea of the likely course, and can advise on frequency. If a previously unidentified condition is later formally diagnosed, the GP, specialist or client could ask for a review if</p>

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		<p>appropriate.*</p> <ul style="list-style-type: none"> • Should ... impairment/condition? When a new condition or illness becomes apparent, [in addition to those already claimed], there could be an option to ask for a short review form, just to add the new condition. People with variable and fluctuating conditions could be sent a symptoms diary from time to time.* <p>13. The forms already say that changes must be reported, as do the award letters. If this is not being done, maybe there should be a warning on each page of the application form. Also, put it at the bottom of the posters, billboards, leaflets and television announcements. Like 'Interest rates can go down as well as up' and 'Smoking can give you cancer'. Everybody* takes notice of them. There could be an enquiry sent out each year as well. Say 'If in doubt, ask.' Changes which alter award levels are going to be fairly noticeable, but they may have come about gradually, in which case a regular enquiry would be helpful. I assume we are talking about improvements in one's condition---or are there plans to penalise those people who didn't realise they could have been moved to a higher award?*</p> <p>14. I think there is plenty of advice and information given already, but people may not take it all in. Put constant reminders of how important it is to read through the form and the notes that accompany it before filling in the form. If the applicant finds it hard to do this, or to take it all in, they can enlist someone to read it to them, write their answers as spoken or even fill it in on their behalf, so long as the applicant agrees with what is written. Advertise the fact that the use of help is allowed, and if there is a local charity or C.A.B. advertise it with a slip attached to the claim form.*</p> <p>15. Could some form? No. Many people are private and do not want to involve others in their personal business. Making it a requirement could make fewer people claim. If they make a claim and it is successful it brings a sense of achievement; unsuccessful claimants could be encouraged in the 'sorry' letter to try again, but think about using help this time.*</p> <p>16. People in receipt of DLA use it to fund these items. I am not sure I understand the second part of the question, but I think it is reasonable to expect people to use PIP to meet mobility/care costs, as that is what it is for. If an expensive item is required, perhaps advance payments of PIP could be made, or a [0% interest] loan made, to be deducted from future payments.*</p> <p>17. Parents claiming for children are very likely to need help and support for many reasons. They often obtain a claim form and let it lapse, because after a day [sometimes a 24-hour day] of struggling with the needs of the special-needs child, other children, partner, plus normal chores, they are too exhausted even to look at the form, never mind fill it in. It is vital to tell them they are entitled to enlist others to help, and point them towards any local agencies that provide this service. In my voluntary work I spend up to three hours chatting with a parent, taking notes, and eliciting the necessary information to fill in the form. Then I type it at home on my computer, and the parent reads and signs it. This makes me feel useful [had to stop paid work five years ago] and takes a huge burden off the family.*</p> <p>Continue to measure the child against others of the same age without their disabilities. Children with behavioural difficulties eg. abusive and violent outbursts, impulsive and dangerous actions, may be in robust physical health. Some never see their G.P. and have not been referred to a specialist because their school does not think they qualify for a statement of special needs. While teachers and schools mean well, they may witness a different side to the child from the one s/he displays away from school. The school's opinion and the lack of visits to a doctor should not over-ride the evidence of the parents.*</p> <p>18. This is important, and it seems to work as it is.*</p>

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		<p>19. More form-filling, more need for advising people what they can claim and how to do so.*</p> <p>20. Combine all benefits and services applied for, and share information to save the applicant having to fill in more forms.*</p> <p>21. As mentioned previously, women seem to be the many sufferers from the auto-immune conditions, including S.L.E., R.A., fibromyalgia, Sjogren's. *</p> <p>22. No, but thank you for asking, and I hope you have read this far.</p>
EM423	10-Feb-11	<p>To whom it may concern, I am writing to you regarding the Government's proposals to reduce the DLA budget and all the changes that will affect me and my family. I am a carer for my two disabled sons aged [REDACTED] and [REDACTED] who both currently live at home with myself and my husband. Due to my caring role I am unable to maintain a job away from the house and currently do paid work at home and some voluntary work. I am extremely worried that the future proposals will have a devastating affect on myself and my family, I currently receive carers allowance which helps as I earn a very low wage. I am concerned that I might lose carers allowance.*</p> <p>I am concerned that my son might be at risk of losing his disability living allowance, he has a severe learning disability and autism. I am extremely worried that he may not be assessed properly by a medical "professional". Indeed, last year this was the case, where his DLA was drastically reduced and I had an eight month battle to get it reinstated. Not only was this a major worry but it also had an affect on my own health and state of mind.*</p> <p>If I were to lose carers allowance it would have a major impact and I would not be able to continue caring for my son as I would not be able to afford to. If my son loses his disability living allowance this would also have a devastating affect as he would not be able to continue living at home.*</p> <p>I am most anxious about the future of my family, because if we cannot cope due cuts my son would have to go into care, where I would be very worried about him being looked after properly as he has severe behavioural problems and no communication or social skills. This surely is not the right thing to do and I would imagine would cost the Government more money in the long run.*</p> <p>This is why I do not think that the Government should be making cuts of 20% (£1billion) to disability benefits, as it would have devastating consequences for disabled people, their families and carers like myself.*</p> <p>I also believe that Carer's Allowance must remain outside of the Universal Credit, carers like myself save the Government almost £90 billion every year with the care we provide and it would be wrong to take Carer's Allowance away leaving them with no recognition of their massive contribution. Yours Faithfully;</p>
EM424	10-Feb-11	<p>Dear Sir/Madam, Disability Living Allowance is a Lifeline to Carers and the Disabled – It is imperative it is NOT changed to Personal Independence Allowance. I am very concerned indeed about the current situation on reforms; your consultation on changing Disability Living Allowance to the new benefit called Personal Independence Allowance: Which could lead to Vital Support being Withdrawn. *</p> <p>I am a carer to my daughter who suffers the severest form of perthes disease and is unable to walk at all/or weight bare due to her disability. Bone is rubbing on bone and cartilage is missing. She needs support by myself and uses her crutches to get from her bed to the toilet and is in extreme pain. She can only manage a very short distance on her crutches and then she needs to be in her wheelchair. When using the shower she needs to sit on a supporting stool; she also needs continuous support in and out of the shower and with her clothing. The Medical Team clarify she is unable to attend school due to the extreme pain and her severe mobility problems. I support her with her learning at home and</p>

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		<p>she has tutors, however the pain is so severe, at times, it is impossible for her to be educated by the tutors. She is on continuous medication every 4 hours tramadol, paracetamol and anti-inflammatory drugs. She is needing A full hip replacement, however we have been advised she will need to wait for between five and six years, until she is fully grown. My concern is that I depend financially on the D.L.A. allowance as I am unable to work as [REDACTED] needs me to care for her. Caring would be unaffordable for me. I believe firmly that the Government should not been making cuts of £1 billion pounds to disability benefits because of the devastating consequences it would have on both carers and the disabled I believe that Carers Allowance must remain outside the Universal Credit. Carers save the Country £87 billion pounds per year with the care we provide. Another concern is the disabled may be wrongly assessed and NOT receive vital support. The mobility allowance is imperative to us, is would be devastating for us to lose this; as [REDACTED] has to attend hospitals, and generally to get around, and due to the severe pain and mobility problems she suffers, it would be impossible to manage Public Transport. Without prejudice, Yours sincerely,</p>
EM425	10-Feb-11	<p>I have spent the last 2 hours going round and round the DWP consultation website. Having registered I could not then find a way of responding to the consultation regarding DLA reform online. So here is my response. *</p> <p>I am delighted with the introduction by Maria Miller who wishes to enable disabled persons "to lead full, active and independent lives". *</p> <p>Personal Independence Payment (PIP) - I have read the public consultation on the reform of DLA and I've tried to answer the 23 questions but I find I just keep repeating myself. In general I think reform is needed. Annex 1 is a table of conditions and impairments which currently lead to a automatic award old DLA. Perhaps this needs reviewing? For example why would a double amputee necessarily need the DLA higher rate with a mobility component? Perhaps life limiting conditions with recognized disabling progression would be more relevant ? *</p> <p>Many of the disabled community who currently qualify for DLA, at any level, view it as a compensation for a diagnosed condition caused by trauma or/ a disease with progressive, long-term, limiting loss of function. However, in my opinion, it should be viewed as a necessary financial contribution towards the extra expense incurred as a result of functional loss following a diagnosed condition.*</p> <p>Functional assessment for PIP: - Due to the vagaries of human nature a one-form-fits-all will be very hard to design and potentially full of pitfalls. The assessors, who I assume will be Healthcare Professionals (HP) and already trained in assessment procedures, must also be trained to avoid these pitfalls. In my experience these pitfalls usually occur when the assessment procedures become too much a of measurement of the physical competences thus ignoring holistic factors e.g. motivation. *</p> <p>Long Terms limiting Conditions [LTC], with a reasonable prediction of disability in a chronic and progressive way, should automatically be exempt from frequent, intensive, physical reappraisal of loss of function. Most persons with an LTC experience variations in their functional abilities on a weekly if not daily basis. The recipient of PIP should be educated /encouraged to recognize for themselves when to apply for a functional reassessment. *</p> <p>PIP & Quality of Life (QoL) The assessment criteria must include recognition of Quality of Life.*</p> <p>If awarded recipients should be offered guidance on ways of using it to improve their QoL. There is no point in providing the tools(i.e. an Allowance) without any training. e.g. mainstream gadgets to independent function. And training on information seeking e.g. traveline for Accessibility on public transport Yours sincerely,*</p> <p>PS. I am [REDACTED] years of age and have had a diagnosis of MS since I</p>

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		was [REDACTED]. I qualified as an occupational therapist in [REDACTED] and practiced in England and Scotland and worked in health and social services. My physical condition is such that I am reliant on an electric wheelchair and have 30 hours Direct Payments which allows me to employ carers for personal and social care needs.
EM426	09-Feb-11	<p>I wanted to write a proper response to your consultation, but am not well enough and get upset when I try writing it. I have Primary Progressive Multiple Sclerosis. So I am writing to say that I fully support the response to the consultation sent to you by the Multiple Sclerosis Society. It describes MS very well and why we need DLA and why the proposed changes will be awful for us. *</p> <p>It is hard to explain how much MS affects every moment of every day and how worried I am by the proposed change to DLA. I have a chronic, progressive condition that has been diagnosed by a neurologist. There is no treatment and no cure. As it is progressive it will get worse. I will have to 'prove' how unwell and disabled I am (how does a person 'prove' pain, vertigo, chronic fatigue?). I feel like I am being punished for being disabled and having to live on benefits. I wish I could write more, but hopefully the MS Society's response will help you to understand this terrible illness. Regards,</p>
EM427	09-Feb-11	<p>Dear Sir My name is [REDACTED], and I care for my daughter who suffers from a severe mental illness. She lives with me, and the illness is quite well controlled by drugs. She copes quite well, providing she does not have any degree of stress.*</p> <p>I am concerned about the proposed change from DLA to PIP for the following reasons.*</p> <ol style="list-style-type: none"> 1. The prospect of a medical test by a stranger may cause her stress which may make her ill again. (This has nearly happened in the past).* 2. On a good day she may seem all right, but on other days may feel very confused and anxious. She is at currently not well enough to work, even part time. The stress would make her ill again. But an assessor who sees her on a good day may not realize this.* 3. I think the proposed changes would lead to increased hospital admissions for mental health sufferers; caused by stress and anxiety resulting in relapses.* 4. I think it would be very difficult for an independant assessor to accurately assess the level of disability, of a stranger with mental health problems. The disability may not be visible. I hope this is helpful. Yours sincerely
EM428	09-Feb-11	<p>Dear Sir/Madam, I am extremely concerned about the Government's proposals to cut DLA and possibly Carer's Allowance. I have multiple sclerosis and am wheelchair-bound and my husband is my carer. Due to my illness I had to give up work years ago and my husband had to retire early. Now he is 65 and receiving State Pension he no longer receives Carer's Allowance, despite the fact he still cares 24/7. This is something that should be looked into as why should a carer who is saving the Government billions of pounds a year have their allowance stopped because they receive a State Pension. As for myself, I receive high rate mobility and care components of DLA and to have this payment reduced would cause me extreme financial hardship, already having our income reduced due to the Carer's Allowance being stopped. *</p> <p>I understand the Government has to make savings but carers and people like myself rely on these benefits. As much as we would like to work, due to illness, disability, etc. we are not able to. I hope careful consideration is given to making cuts to the DLA and Carer's Allowance as this would affect the most vulnerable people in our society. Yours faithfully,</p>
EM429	09-Feb-11	Question 1 Lack of mobility, inaccessibility, social isolation, dependence on others, lack of carers, low incomes, lack of finance to for the help required, low pensions as unable to work and build up pension,

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		<p>depression – so can't join in, discrimination against 'invisible conditions' like Fibromyalgia and ME, stigmas, cognitive difficulties make social integration uncomfortable, can be seen as 'needy', lack of transport, lack of support, lack of local shops, can't plan anything as you never know what symptoms will occur the next day. Pain brings many other symptoms for example, anxiety, nervousness, irritability, fatigue, vision problems, depression, skin complaints, nausea, sleep disorders, weight gain, memory loss, poor concentration, dizziness, breathing problems, poor circulation, poor diet.*</p> <p>Question 2 DLA should not be means tested or taxed. It should be the responsibility of the disabled person to decide how to spend their funding as every condition and person has different symptoms and needs. Personal choice should be paramount.*</p> <p>The low medium high components in 'mobility and 'care' should remain the same (or preferably be increased) DLA should be paid weekly or monthly The levels of DLA should remain the same or be increased. Annual increases in line with inflation should be awarded. To have the choice to add reports to DLA claims from NHS and Private GP's and Complementary and Alternative professionals should remain. The choice to use different Complementary and Alternative treatments and medicines must remain. A high number of people cannot tolerate some chemical drugs and have no choice but to access different types of treatments and medicines. Being able to ring the DLA to advise them of any new circumstances for example, new health conditions that have been highlighted that require increased care and support. Also to ring DLA with any reductions in symptoms.*</p> <p>Question 3 Carers; Extra heating (ill health creates poor circulation) and more regular baths (helps with pain) ; Special diets and nutritional needs; Alternate and Complementary therapies to relieve pain and suffering; Holidays – extra costs for disabled needs; Prescription costs; Transport – taxi's, reliable car – means regular new purchases, Motability ; Vitamins and minerals and other NHS and non NHS medications; Cleaners; Need support for everyday chores and outings; Incontinent pads; 'Special' clothing for ease of dressing and undressing; Requirements for particular 'beds, mattresses, bedding, chairs, sofas, flooring, A&A's.; Paying someone to make beds, shopping; banking; hairdressing, nail cutting, dressing, washing up, making meals, washing, showering,; Aids and adaptations in home; Someone to remind you to take medications and other necessary medicines; Someone to be with you at hospital and GP appointments and any other health related appointments*</p> <p>Paying someone to: change light bulbs, move an item of furniture, get something out of the loft, general DIY jobs, clean windows, put rubbish/recycling out, washing up, hang washing on drier, post a letter, cook meals, get a newspaper, go to the post office , gardener, washing windows, washing car, buying items people are unable to lift, *</p> <p>Question 4 • Will having two ... support? Having two rates will not give any incentive to work towards a lower rate. It is less frightening to know you can go from a low rate to a medium rate, before being so unwell you have to go on the high rate. It will be more complicated, more frustrating and very unfair with only two rates It will be impossible to fit everyone into a two rate system because of different conditions and symptoms. It is important to be able to request a higher level when symptoms increase. • What, if any, disadvantages ... cause? Having only two components is very unfair, as health conditions are all very different and require different needs depending on individual symptoms. Having two rates will not give any incentive to work towards improving health where possible, and working towards a lower DLA level. I think there should be 3 components for care and mobility*</p> <p>Question 5 People who are terminally ill, should get automatic entitlement as should visual impairment and the hard of hearing. Where conditions prove that they will not improve, these could also be automatic</p>

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		<p>entitlement.*</p> <p>Question 6 By giving people DLA they at least have an opportunity to improve their quality of life in some way. It is not possible to live a full and active life with many conditions and this needs to be accepted. DLA would have to be doubled at least for people to become more active and in some cases this still wouldn't be enough. If you entitled to DLA it means you have health conditions that requires financial help in way of care and support, it is as simple as that. *</p> <p>Question 7 All health conditions vary, it is the nature of ill health. DLA claimants should be able to provide letters of support from health professionals in the NHS and Complementary and Alternative treatments to support their claims. Also from friends, carers, family, social groups. DLA claimants should be allowed to have the flexibility to support their health condition.*</p> <p>Question 8 No aids and adaptations should not be taken into account as they are very personal to the person and are required at certain times of ill health. A&A's can often make people feel more depressed if they are installed permanently in their home. It should be a personal choice. • What aids and adaptations should be included? None • Should the assessment only take into .. and can easily obtain? No (see above)*</p> <p>Question 9: • How could we make the claim form easier to fill in? Many questions are repeated in the claim form and this is unnecessary. The form is too long. For people completing the DLA form, it is a very distressing and depressing process as it remind us of our symptoms and how ill we are. It maybe inevitable but you should be made aware of it. Nobody would complete a claim form unless you really needed to and this is why so many people do not claim it. A shorter form and shorter processing period is required. • How can we improve information ... to qualify? Advertise it in GP surgeries, hospitals, physios, advice centres, CAB's, ask GP's and consultants to suggest claiming it.*</p> <p>Question 10 Reports from GP's, consultants. DLA claimants should be able to provide letters of support from health professionals in the NHS and Complementary and Alternative treatments to support their claims. They should have the choice and flexibility to seek supporting evidence from anyone who helps them with support for their health condition. DLA claimants are not scroungers, they are disabled and require financial support to reduce their mobility and care issues, to reduce suicides because of ill health and lack of support and to live.*</p> <p>Question 11 • What benefits or difficulties might this bring? Some conditions have cognitive issues and this would make any interview very difficult for many people. Face to face discussions can be frightening for people who suffer with anxiety or other mental health issues. Face to face discussions are difficult when you are in constant pain Discrimination could occur against those who cannot describe their condition because of ill health or because they are not able to articulate their symptoms Because of mobility issues people can't get to DLA offices for interviews. But also, people may not want interview held in their houses. Surely GP/Consultants and other health professionals reports are evidence enough!!!!• Are there any circumstances ... another location? See above There could be difficulties where people live alone There could be difficulties where women live alone Cultural and gender differences should be considered at all levels. *</p> <p>Question 12 • What evidence ... frequency of reviews? See 7 above. All health conditions vary, it is the nature of ill health. DLA claimants should be able to provide letters of support from health professionals in the NHS and Complementary and Alternative treatments to support their claims. Also from friends, carers, family, social groups. DLA claimants should be allowed to have the flexibility to support their health condition. • Should there be different types ...condition? See 7 and above*</p> <p>Question 13 The individual should have the responsibility to advise whether their condition has improved or deteriorated. All changes would</p>

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		<p>be highlighted in DLA claim forms anyway. You need to trust them. The terminally ill should not have reviews.*</p> <p>Question 14 There should be independent organisations to give advice on how to claim. Don't change the name it is confusing for people. It is an under claimed benefit presently.*</p> <p>Question 15 No requirement should be made, people don't claim because it is such a depressing, long and difficult process to go through. People are able to take responsibility for themselves but could be encouraged by GPs/Consultants. Transparency throughout the process is crucial.*</p> <p>Question 16 How do ... aids and adaptations? They apply to the local authority, savings, hospitals. DLA does not provide enough funding in DLA for A&A's. Should there be an option .. one-off cost? If a car is essential for example, this should be acceptable.*</p> <p>Question 17 Don't know.*</p> <p>Question 18 It is important access is given for blue badge support and should be automatic on high mobility. Reduction in council tax should be awarded to claimants. *</p> <p>Question 19 This should not be considered.*</p> <p>Question 20 Don't know.*</p> <p>21. Have mentioned this above in answers. Different cultures should be considered at all levels. Transparency is essential.*</p> <p>22. There are too many questions in your survey which will be off putting for many people, especially those who should be giving you feedback on this survey. There needs to be an element of trust between the DWP and disabled people. Support for DLA needs special attention for those living alone. Symptoms can increase when living alone and therefore greater support is required. The DWP needs to understand how 'invisible conditions' cause great pain and anxiety. I just hope you read the comments in this consultation, DLA is crucial to life or death to many people with ill health. People on high salaries who do not require DLA funding should be given the option to return it to the DWP.</p>
EM430	09-Feb-11	<p>1. Lack of understanding in wider community of their needs and how to interact with them, no supported places, lack of joined up thinking and support of those best able to help them, hidden masses that if have a cognitive impairment have been pushed into day centres. Lack of skilled care.....*</p> <p>2. no*</p> <p>3. For those with a mental disability Managing day to day life, having a secure residence and abnkn of care, hygiene, access to medical care, we can help people who are blind but no one knows how to interact with my child!*</p> <p>4. I know some people claim their child/young adult can do less than really can and want to claim the higher allowance, this might lead to the same thing unless there are clear guidelines for attainment and assessing mental impairment*</p> <p>5. YESSSSSSSS I am sick to death of re explaining and re visiting my son's condition. It is devastating enough to have a disabled child without being asked continually to go over what he can't and won't ever be able to do*</p> <p>6. Can they be left alone? If not that is your answer..... I can not leave my child unattended ever!!!!*</p> <p>7. Employ people with experience of the conditions and experience of caring for those with those conditions*</p> <p>8. Should the assessment ...they use? Yes*</p> <ul style="list-style-type: none"> • What aids and adaptations should be included? communication aids if you can't communicate you are totally isolated and have no way to impact on your own care, a basic human right • Should the assessment only ...easily obtain? Yes, some people stop their child developing by refusing to work professionals and use aids offered. * <p>9. • How could we make .. easier to fill in? Yes, I am a reasonably</p>

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		<p>intelligent person but I found the form baffling*</p> <ul style="list-style-type: none"> • How can we improve ... likely to qualify? By being clear up front about life long conditions againstoh I have a bit of back trouble....if half of thesae people had amn understanding of real disbality they would eb too embarrassed to apply* <p>10. Family first, medical, school , photos if need be, atrue and honest assessment by a trusted group of individuals as we have to rpovide in school when we more money for a particular child*</p> <p>11. • What benefits ... bring? They can offer ways to improve life and the condition and monitor for imprpovemnt*</p> <ul style="list-style-type: none"> • Are there any circumstances ...location? If the person is dying or has degenerative disease* <p>12. • What evidence ... reviews? Frequency should depend the condition, if it is a life long condition then every 10 years, but for less severe conditions, a sore leg/arm every six months*</p> <ul style="list-style-type: none"> • Should there be different ...condition? yes* <p>13. Spot checks or visits, laising with professionals involved with the person so that info is shared directly based on receiving the benefit*</p> <p>14. yes and link to adulthood if the child is claimant, a life long condition is not going to change so there should be more joined up thinking*</p> <p>15. Arranged at benefits office and tyed to attendance unless medically unable to attend *</p> <p>16. My family, help me.....Should there be an option ... one-off cost? Depends but often the person like my son will still need long term 24hr care*</p> <p>17. Children can develop , be sensitive to parents feedback but also make sure parents are actively helping their child niot using them as funding stream.....sad to say but I have ssen this*</p> <p>18. Yes link up with person cnetred planning and make them personalized as we have to in education*</p> <p>19. A very hidden and closed life, you may as well build and island and let them all live on there... how is that joined up thinking*</p> <p>20. as suggested above track through NI number and have link with medical and school services*</p> <p>21. Impact of certain industries and their effect on peoples health, making people who have disability thorough work entatlied to support from company*</p> <p>22. Please, please review mental health and how you ask questions and what people seem to know about, look for people who have experince (I don't mean degrees or diplomas) that have actually met worked or some cases brought people with long term mental illness.....they can't change but it can be managed better. Please stop asking me the same questions about my son.....i know he will never do a lot of things many parents take for granted `I don't need to be reminded at every review, or every time I fill in a form or have to speak to health, education or social professional. There are such damaging things said and ignored around mental health....please change this, disability is not just what you can see! Thank you</p>
EM431	09-Feb-11	<p>Dear Sir; I wish to add my opinion to the proposed reform of DLA. I am a recipient of DLA, receiving high mobility and middle care rates. I have no connection to other campaigns, groups, or individuals associated with this consultation.*</p> <p>Since reform was announced by the coalition, I have felt very, very upset, frightened, apprehensive, and have lapsed into severe depression. The reasons are simple : disabled people have been stigmatized by the media and press (loafers, scroungers, swinging the lead etc.). The 'drip drip' effect of releasing statements from the government, without explaining how, or who, will be affected, makes me as an individual VERY scared for my future. To receive DLA, I completed extensive forms; received documentation and evidence from my GP, CPN, Consultant, and other health professionals. I then received a home visit</p>

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		<p>by a doctor from the DWP. This process took 6 months, which was extremely debilitating. My initial award was one year, and then two years upon renewal, then an indefinite award, as my medical condition is permanent and life-long.*</p> <p>To subject me once again to the renewal process is the single most frightening episode I can imagine. After my experiences with the DLA process, I am now resigned to the fact that my physical, and more importantly my mental health, will not be able to withstand review, medicals, etc.*</p> <p>So, in conclusion, I can state that DLA did, and does, have a dramatically positive effect on my life. It offers me independence, security, and a level playing field with everyone else in society. Reform of this benefit, and the proposed 20% cut in caseload (800,000+), is having the effect of making me feel isolated, bullied, vulnerable, and frightened. Personally, I have decided that my health could not cope with the proposed changes. It is as though Dickens, and the workhouse mentality, have returned to society. I, for one, will not be holding out my bowl, begging for "more". The proposed reforms will come, regardless of this consultation, and when my letter arrives, I will not be applying for the new PIP. In reaching this decision, I realise that my standards of living will reduce. My wife will no longer receive Carers Allowance; my motability vehicle will return to the garage; and I will join the growing list of the disabled poor. The positive side is that I will no longer be frightened of the letter arriving; or whether society views me as a scrounger.*</p> <p>My honest independent suggestion is that the reforms have merit: yet, the lack of details as to who will be effected is disgraceful. Why do those current recipients of DLA have to go through the renewal process? Why not start afresh with new claimants? Migrate those currently on DLA straight onto PIP, at an equal rate. Get out to the public as much information as possible about who PIP may benefit disabled people. Stop the drip drip of info: it just scares people. And if you say that the intention is to reduce the "caseload" by 20%, then say that 20% of claimants will lose benefits. This way, disabled people can, like me, make an informed choice. To be frightened of what the future holds is truly a very, very bad feeling. And that is the effect of your proposals. It has frightened many, many people. Yours Sincerely;</p>
EM432	09-Feb-11	Just make sure that the genuine DLA recipients dont lose out. We're not all £30,000 scroungers
EM433	09-Feb-11	<p>I have just read the documentation that has been put forward to make changes to the DLA - it is identical to what my local authority has announced when it comes to dealing with my mother's care. Handing it back to the people, by changing the name of the benefit, whether it be Direct payments, a Universal credit or PIP - it doesnt mean that it will work and that people want it. By all means look at what you are spending, make changes etc but please 'dont hand it over to us'. I am worn out and tired of caring for a disabled parent as well as keeping an eye on two disabled sisters as well as working full time, I dont need to have to manage more than I am already doing, I dont want to have the power to make choices as to which carers we use, I dont want mum to have to undergo tests to see if she 'deserves' the new PIP, I dont want the stress of arranging visits so that I can be there as I am her voice, yes there are people out there that dont deserve the benefit and I hope you catch them out but please, please stop justifying your changes as giving the power back to the people, most disabled people rely on a carer to make decisions, balance bank accounts, filling in of forms and do the running around, believe me when I say we dont need this added stress of proving whether or not mum deserves to be able to pay for a chiropodist as after 15 years of caring I cannot do it any more. that having the higher rate of mobility means that we have a decent car to take her to the appointments that she can still get too. from a personal point of view we have lived with</p>

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		mum's disablement as I say, for 15 years. she is part of a ever growing number of stroke victims left with severe disabilities and yet no two stroke victims are the same so how do you determine whether or not they deserve the benefit, and what Mrs [REDACTED] in the Manchester office dictates as being deserving probably wont match what Mrs [REDACTED] in Southampton decrees as you are relying on human beings to make decisions and every individual is different. the stress of these changes to the ordinary, humble person isnt calculable and I hope that is realised when you read all these responses. thank you
EM434	09-Feb-11	<p>I am 66 yrs old and I care alone for my profoundly deafblind daughter aged [REDACTED] yrs who needs total care.*</p> <p>I believe that the Government should not be making cuts of £1 BILLION to the disability benefits because of the devastating consequences to disabled people including my daughter and my self as a carer, If my daughters money is cut then I can not afford to make up any short falls, I struggle as it is because as a pensioner I am expected to care for her with no financial help, if she does not have enough income to allow me to give her a decent life then I will be forced to put her into residential care where they will have to meet her needs, which will cost thousands per week because of the level of care that she needs. And I am sure that I am not the only parent who is going to be forced into this action when they can't meet the needs of the person they care for because of short falls in money I do hope that you will rethink this</p>
EM435	11-Feb-11	<p>To whom this concerns, Disability Living Allowance (DLA) is an essential financial means of helping disabled people establish something near to the life style of others that are free of disability. Often disabled people are the most vulnerable in our society. The assessment process for awarding DLA is thorough, in my opinion. To review all the unfortunate recipients will be unnecessarily stressful for them and unnecessarily costly for the State. To reduce the amount of DLA paid is to attack the very people a 'caring' society should be supporting. I have yet to meet a person receiving DLA who would not gladly 'lose' DLA if they could also 'lose' their disability. We know we have got to bear the financial pain created by the mismanagement of our finances by those in our society that should have known better but to attack the most vulnerable who can least afford to pay is not 'fair play'. Yours faithfully, Carer of two relatives disabled by severe mental illness</p>
EM436	11-Feb-11	<p>1.Your response: being able to go out when you want to, without a carer I am housebound.*</p> <p>DLA helps me to have a car through motability (I don't drive, my carers do that for me), without it I would not be able to go far most Taxi's can't fit in my wheelchair, buses are not much better by the time bus comes I'm usually exhausted even using the wheelchair so a car is a vital life line to me.*</p> <p>2.Your response: Motability and the care allowance.*</p> <p>3.Your response: Care assistance, car fuel, heating bills, equipment even items such as reclining chairs, specific mattresses. *</p> <p>4.Your response: I don't know*</p> <p>5. Your response: It should always be based on the needs and circumstances of the individual, for instance I have multiple disorders, each one on their own may not necessarily be considered a big problem but all of them together are debilitating.*</p> <p>Another example is that some arthritis can be more severe in one person than another.*</p> <p>5.Your response: Being able to get out of bed, being able to wash and dress, being able to go out into the community, for instance before my care package was put into place I was housebound mon-friday whilst my husband was at work and the first time a carer took me out on a shopping/leisure call, I was scared of being in town , it has taken me 12 mths to build that confidence up as I only have that call once a week, but</p>

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		<p>to me it is valuable and I'm sure others feel the same. Going to church is an essential part of my life too, without the help of others I would not be able to go there. In the winter being able to avoid heating is paramount to controlling many conditions.*</p> <p>6.Your response: By listening to the applicant, by having experienced people with a good understanding of disabilities and chronic illnesses to carry out the assessments having qualifications doesn't always mean one has understanding, people who work within the community such as social workers with occupational therapy skills are often the ones who have a clear understanding of how disabilities and chronic conditions affect a person in their daily routine.*</p> <p>7.Your response: I don't think they should, I have a wheelchair but without someone to push it I can't use it. To use a mobility scooter without someone with me endangers me as I can't see oncoming traffic due to not having full range of neck movement. Adaptions help improve safety but for instance I have rails in my shower and a shower chair but I still need assistance in that I can't put weight through my wrists and arms to stand up safely and due to instability of my joints, my legs can still go under even when holding onto a rail. Some aids such as splints I can't use unless someone helps to put them on, my leg braces have to be removed by a carer, there are times when aids could exacerbate a condition, during a flare up for instance, to have something weighty and rubbing on skin let a lone joints is agony. Other examples are hoists, carers are still needed to get people into the hoists. I feel this area needs to be assessed according to each person, some can use adaptions and aids comfortably themselves but not everyone can.*</p> <p>8.Your response: I am not sure how the forms can be made easier, I think information is clear enough, but it is exhausting having to fill in the papers every 3-4 years every time I fill mine in not only do I get flare ups with my hands and neck but I also find I get very down as every time I complete a renewal form in I feel real bad about myself, it reminds me that my body is useless and I feel very inadequate as a human being when I do my renewals not to do them in such detail so often would be better, is it possible to have a declaration done for renewals rather than repeating it all the time as the other thing it highlights is how one has deteriorated in the last few years which doesn't serve the disabled person in a positive manner at all.*</p> <p>9.Your response: GP's, Occupational therapists, Social workers, health professionals such as recognised Chiropractors, care support workers*</p> <p>10.Your response: In long term conditions and or in complex ones like my own it would take a long time to go over everything, meeting someone who doesn't know your history could have a negative impact. In one meeting it's almost impossible to remember how everything affects you, for instance in my case as there is multi disorders, there is so much variety of symptoms the danger would be that some would be forgot and maybe only those symptoms that are prominent that day may only get reviewed. Also there would need to be choice to as to who, ie, a woman may prefer a woman not a male and depending what a persons issues are telling your difficulties to a complete stranger could be very embarrassing and may cause one to leave out some essential info.*</p> <p>11.Your response: If a GP or specialist states that their patient has a chronic condition that will gradually deteriorate, maybe a medical declaration from a GP or specialist could be used with a visit from a Healthcare professional to witness the applicant signing a declaration.* Possibly different types of reviews could be used maybe as I have just stated. I think maybe the reviews should be tailored to the impairment/condition*</p> <p>12.Your response: When I first got DLA I had low rate care I remember once ringing to say I was getting worse, the department told me, that the only way they could do anything about that is to request an earlier review but to do so would risk my losing the existing award. How does that</p>

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		<p>encourage anyone to ring. I am getting worse all the time but I'm already on High rate so to ring and say I'm getting worse will result in my having to start all over again to attain the award I am already on but leaves me vulnerable in that the person looking at the award may have a different opinion than the previous and reduce or remove the award and then all the appeals process start. *</p> <p>13.Your response: I don't understand Personal Independence payment to qualify an answer to that.*</p> <p>14.Your response: Whatever system is put in place it needs to be clear and simple, the advice and requirements need to be transparent.*</p> <p>15.Your response: Themselves with their care allowances, I utilise my care allowance to meet my costly heating in the winter primarily and also use to keep the fuel going in the car, I also use it to cover extras such as proper fitting shoes, I also use it to fund my Broadband service which enables me to bank and shop on line *</p> <p>16.Your response: ??*</p> <p>17.Your response: For me the importance and usefulness has come in form of Motability and the blue badge scheme. I don't know what else would be available with this allowance.*</p> <p>18.Your response: The loss of Motability, it is a fantastic service for the disabled, I dread the thought of it being no more.*</p> <p>19.Your response: I don't know because I don't know enough of benefits and services.*</p> <p>20.Your response:*</p> <p>21.Your response:</p>
EM437	11-Feb-11	<p>1.Your response: It obviously depends on what type of disability an individual has. Following an accident I suffered a Spinal Cord Injury, level C6 tetraplegia and now rely on the assistance of my wife to lead a life which unfortunately will never again be independent, full and active. It is however my life and I am grateful for the help and support from various professionals who have helped my wife and I. Public Transport is not an option for me personally as I get stressed in a crowded situation. I rely on my car to get around.*</p> <p>2.Your response: I know that everything has a shelf life, but I feel that the impact of having a carer and the support received from that person should be an integral part of the new assessment. Equally should an individual not have that support then the implications of that would need to be assessed.*</p> <p>3.Your response: Heating costs, Gas and Electricity. Costs of adaptations to the home, either minor or major. Petrol costs, as my car is my transport for everything. Clothing with regards to bowel and bladder issues. *</p> <p>4.Your response: Having three rates for the care component provides a good balance reflecting the care needs. There is a finer line between two rates as to which category you would be deemed eligible. Does this mean that the upper rate being reduced towards the existing middle rate and the middle rate being reduced towards the lower rate?*</p> <p>5.Your response: The needs and circumstances of an individual must obviously be the basis for claims but there is a case for some health conditions to be fast tracked. If everyone requires to be assessed then the timescale of receiving that assessment may be drastically increased.*</p> <p>6.Your response: Information from various health professionals should assist in prioritising support. Existing cases will have a history from GP's and hospitals. In my own circumstance it is essential for me to be able to get out of the home, be it visiting relatives, going to the cinema or simply visiting a shopping mall. The latter has every facility required should anything go wrong.*</p> <p>7.Your response: We all have challenging times, however some days are more challenging than others. Another problem in my own case is that even when I am at a low ebb I try to hide this from my family. Again, case histories of individuals would shed some light.*</p> <p>8.Your response: I understand that aids and adaptations change a</p>

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		<p>disabled person's lifestyle but I do not believe that they should be taken into account when assessing eligibility. The underlying disability remains the same and it could be the case that disabled people who have used aids to maximise their mobility may feel that this could affect their entitlement to DLA or PIP. In short an individuals needs could be assessed on their ability using an aid rather than the fact that they require that aid in the first place.*</p> <p>9.Your response: It is important that you get advice from a wide spectrum of disabled people, their carers and bodies who help disabled people.*</p> <p>10.Your response: Once again evidence of an individuals ability or disability will be available from case notes of GP's, hospitals etc. Also the individual person's carer could provide invaluable information regarding day to day living together with support provided. In the case of Spinal Cord Injured the individual often has more knowledge than their GP or healthcare professional.*</p> <p>11.Your response: It would be important for a new applicant. Also the healthcare professional would require relevant experience in the person's disability and be prepared to listen to other professionals who have experience in that particular condition. I should add that in my own circumstances a face to face meeting would only serve to emphasise that my situation is static as there is no cure for a Spinal Cord Injury. *</p> <p>12.Your response: Reviews would need to be tailored to the individual based on their type of disability. Again, reviews would need to be carried out by a professional experienced in that particular individual's disability.*</p> <p>13.Your response: I am certain that individuals do not read through all of the documentation they receive, therefore do not know the implications of not informing the department of any changes. This must be emphasised clearly at the outset be it in bold red print or whatever means available.*</p> <p>14.Your response: Carrying on from the previous question. The questions must be clear and unambiguous. Advice on how to answer properly each question would be necessary either by a helpline or information about outside assistance from professionals who would give advice, such as Citizens Advice.*</p> <p>15.Your response: This is very difficult as many people are not computer literate or may be visually impaired and forcing people to access advice could have a negative effect. Older people in particular are very proud and do not like to ask for help. I really do not know how you would encourage this minority.*</p> <p>16.Your response: Again this is a difficult one as provision of aids is only the beginning. There are maintenance costs to think about. Some disabled people require many aids and adaptations while others do not. Is it reasonable for those with greater needs to spend all of their allowance on these items as many require financial support in addition to the cost of aids and adaptations? Once again it is tailoring support to an individual's requirements.*</p> <p>17.Your response: I am afraid I am unable to answer this question although the criteria must be similar.*</p> <p>18.Your response: There is advice widely available as to other entitlements either in advertising in newspapers or television or the government's website. In the latter you would obviously need access to a computer.*</p> <p>19.Your response: Why would it not be possible for PIP to be used as a passport to other entitlements in the same way DLA is at present?*</p> <p>20.Your response: Many individuals like myself undergo regular check ups and annual testing for any complications through scanning, renal imaging etc. This information could be shared by appropriate departments.*</p> <p>21.Your response: I am unable to answer this question.*</p> <p>22.Your response: It is important that the Government recognises the importance regarding extra expenditure for disabled people. It is also important that parts of the DLA model remain in the PIP document.*</p>

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		<p>I fully understand that many individuals are using the system unlawfully and hopefully this will be detected under the new process. Unfortunately I also feel that many disabled people who are entitled to the benefit may lose out. In my experience genuinely disabled people make light of their situation and this may be misconstrued under the new assessments. *</p> <p>Thank you for letting me have my say about the proposals.</p>
EM438	11-Feb-11	<p>Dear Sir Disability Living Allowance reform *</p> <p>I welcome the opportunity to respond to this important consultation. However, I am disappointed that such major reforms, which will impact a huge number of people, have been allowed such a short consultation period. The nine weeks allowed for this consultation is three weeks short of the recommended 12 weeks outlined in Government guidance. Compounded with the fact that this was spread over a holiday period, this significantly reduces individuals' availability to add their views to the consultation. *</p> <p>Regrettably, this has contributed to widespread scepticism about the Coalition Government's stated commitment "to supporting disabled people to lead independent and active lives." It appears, on the contrary, that the primary motivation for this reform is simply to reduce the DLA budget by the stated 20%, regardless of the impact this will have on a large sector of society for whom DLA can make the difference between impoverishment and a decent quality of life. *</p> <p>It is also disappointing that the Welfare Reform Bill is expected to be published before, or very shortly after, the consultation period has ended. It will therefore not be possible for consultation responses to be fully considered in order to give the Bill the appropriate democratic scrutiny that is needed for changes that will impact on such a large number of people. *</p> <p>I wish to highlight the following key comments: *</p> <ul style="list-style-type: none"> · 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. * · I 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. I object to the approach to reform as a manifest cost-cutting exercise, despite the fact that this is likely to leave thousands of working age disabled people unable to meet the additional costs many face as a result of their disability. * · I strongly oppose cutting DLA for people in residential care: this is a highly regressive step which will deny people in care a small slice of independence, and will save a sum equivalent to less than one day's worth of interest on the Government debt. * · The lack of clarity over whether children and those over the age of 65 will be reassessed is of extreme concern to a large number of DLA recipients. I call on the Government to clarify its position on this as a matter of urgency. * · The decision to focus on „those with the greatest need" risks leaving a large number of people with no help at all. This approach neglects that the additional costs of living with a disability do not necessarily correlate with the functional impact of someone's disability. DLA is a vital source of support for those whose needs do not qualify for social care, but nevertheless face significant additional costs and barriers to participation as a result of their condition. * · I am very concerned about the proposal for new, objective face-to-face tests. Serious problems have been encountered in assessing people with fluctuating conditions and hidden symptoms through the Work Capability Assessment and lessons must be learnt to ensure that such problems are not replicated in the Personal Independence Payment (PIP) assessment. *

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		<p>· I believe that periodically reviewing all awards, especially for those diagnosed with long-term degenerative conditions, would be an unnecessary use of government resources, as well as causing undue stress for individuals. *</p> <p>· I urge the Government to carefully consider the impact of these proposals on whole family units, including in particular informal caring networks. *</p> <p>· Changing the name from Disability Living Allowance to Personal Independence Payment and re-branding the benefit does not seem to be making the best use of resources at a time when wide ranging austerity measures are being introduced. *</p> <p>The consultation paper neglects to mention the Government's proposal in the Comprehensive Spending Review to withdraw the mobility component of DLA from people living in Local Authority funded residential homes. *</p> <p>With regard to this, I support the statement by Baroness Campbell of Surbiton in the House of Lords debate on the Comprehensive Spending Review on 1st November 2010. Baroness Campbell said: *</p> <p>"This proposal is seriously flawed for four reasons. First, it will have negative and costly effects on disabled people's health and well-being, their ability to develop social and community networks and their capacity to move on from residential care to be, as the Government want, independent, participating citizens, not dependants. Secondly, it conflicts with the Government's policies for personalisation, independent living and encouraging disabled people to gain or retain employment. Thirdly, it is based on a misunderstanding of the purpose of modern residential care and the potential of disabled people living there. Fourthly, it is incompatible with the UN Convention on the Rights of Persons with Disabilities." *</p> <p>Withdrawal of the mobility component of DLA would be a devastating blow for the 80,000 people to whom this would apply. Some would no longer be able to fund their own vehicles, effectively restricting them to their homes and reducing or eliminating their capacity for social inclusion. *</p> <p>My great fear is that many of the people to be affected by these proposals will not have been able to respond to this consultation and I urge the government to take this into account. Indeed I feel ashamed that a UK government has seemingly adopted such a cavalier attitude towards such a vulnerable group of people. I trust that this will be taken on board so that in future disabled people and their representative organisations are given adequate timescales to consider and respond to consultations of this kind, which for many may have major life changing consequences. *</p> <p>I thank you for taking the time to read my submission and trust that my concerns will be taken into account. *</p> <p>Yours faithfully [REDACTED]</p>
EM439	11-Feb-11	<p>Dear team, I was and still am a carer now (although unpaid) and this has taken 41 years of my life! A very long time and I lost my I.D. lost the career prospects, the living wage, lost the chance to be a parent, lost paying full N.I. stamps and had little respite, hence 3 nervous breakdowns. So I write with experience and some of it to the detriment of my well being and mental health. It is a fact carers save the tax payers of this country of ours millions of pounds per year. They put compassion, commitment and make our society one which takes us above "a dog eats dog" society. It came to my notice the government don't even recognise that being a "carer" their mental and physical health deterioration is not connected to this role. How remiss of them. *</p> <p><u>Concerns</u> Should you start to stop or reduce some of the D.L.A. when it is proposed that it changes to P.I.P. you will cause a great deal of financial hardship, worry, depression, reduce mental health, and physical</p>

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		<p>health too in my opinion. This will have an impact on families' Independence and will pose a risk of family break up. More people will need to go into care and this will be expensive in the long term and not cost effective if all that those who make the rules are concerned with. More fragmented families will swell those already apparent in this country.*</p> <p><u>Employment</u> To take away the D.L.A. in any form will in effect take away the "masked subsidy" in gaining employment and keeping in work for the sake of the well being and self esteem of those who are able to attain a job in this dire financial climate. Should you expect employers to incur this subsidy by topping up their pay? This is the real world and firms like wide profit margins. So great thought must be given to this aspect. How do you expect disabled people to support themselves if they have to take low paid jobs if you take away their "safety net" and a chance to attain a "LIVING WAGE"? *</p> <p><u>Mobility</u> If you don't have an adequate component to cover all aspects of travel you are up the creek without a paddle. Some people can drive and some not fit to drive when ill, disabled or on medication to prevent them. So do you expect those who need a car and driver (carer) to pay towards this if "caterer's component" is stopped? How do you envisage the not "fit for purpose public transport network" to carry them when only one wheelchair user can get on a bus if all are low floors. WHICH THEY ARE NOT! Will people have to get taxi's and note a lot of taxi's are not "fit for purpose" either. Will you expect councils to put on purpose built transport to get them door to door as public transport WILL NOT ALWAYS DO THIS? Should you stop or reduce money to an extent that transport for them is not viable you will isolate people and cause more depression and disharmony also social exclusion. However, you will save money towards your target of proposed cuts at the expense of other's quality of life (existence) *</p> <p><u>Qualifying period</u> When you are ill, have an accident, or become disabled and have no bread winner/s or back up money in the bank you NEED the P.I.P. at the time of NEED not in six months or a year's time. Business people and those who provide care services WILL NOT WAIT a year will they! Why don't you think these proposals through or are you and those who make the rules immune to adversity or very rich? If money is not provided at the time of need this could lead to compounding the suffering and disability if aids, wheelchairs, and adaptations are not put in place quickly. A fall could cost the the N.H.S. thousands of pounds and take up hospital beds, let alone insult to injury. Where will the carer be then? How will they cope? How can they work and care? Carers often don't cope giving 24/7 care do they ? Just refer back to my beginning paragraph please.*</p> <p><u>Penalties</u> If over 28 days in hospital or care the P.I.P. will not be paid for over 16's and 84 days for under that age. Please state why? The bills for payment towards a car or adaptations wheelchairs, other aids, or other commitments will still continue. Do you expect others to waive those expenses incurred to them? *</p> <p>Thank you for reading this email and you can contact me at : [REDACTED] *</p> <p>Yours sincerely, [REDACTED] (retired, voluntary worker, and widow) *</p>
EM440	11-Feb-11	<p>1. 1. I am Mother to a Disabled Son, he is aged [REDACTED]. He was born with a disability one that he will never get better from, he will never be able to work. He will never be independent. *</p> <p>2. On top of muscle weakness that my Child suffers, that affects his ability to walk normally, manipulate things with his hands, go up stairs etc., he has a learning disability, and is severely Autistic, I worry that this will not be assessed properly by an independent medical specialist. His condition can fluctuate in severity, sometimes it is far worse than other days, I worry an independent medical professional might assess him on a better day and would fail to take into account the worse times. *</p> <p>3. My family and my life chances have been altered greatly, we dont have</p>

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		<p>holidays or a social life as it is; for over ten years so far, any work I have been able to do has been part time, at a very very low wage, for some time now I have had no work at all, because there is no child care available to him that I may be able to work. - in a full time job in the 1990s, I was earning £23,000 a year, so to be earning less than £5,000 in the 2000s rather indicates the impact of caring. I love my Son and it is right that I should be the main Carer, but If my Son lost his disability living allowance, or it is reduced and my Carers allowance was reduced, our lives would become absolutely impossible. I make the former points because I want it to be realised that it is not just the Disabled person or Child that should be considered, it is the impact on the Carers too, should DLA be so altered. At this point in time the DLA does seem to take into account the needs for a person to have a Carer and the levels of Care given, it seems that the new benefit will take no account of this. *</p> <p>4. I do not believe the Government should be making cuts of one billion to disability benefits because of the devastating consequences for disabled people and carers like me. *</p> <p>5. I believe that Carer's Allowance must remain outside of the Universal Credit. Carer's save the UK £87 billion every year with the care they provide and it would be wrong to take away Carer's Allowance from some carers by means-testing it, as this would leave some carers without any recognition of their contribution. It should not be treated like a standard benefit, unlike receiving benefit for being jobless, I cannot stop being a Carer, unless my Son dies, or I do. It is wrong that it is a taxable benefit. *</p> <p>6. If I could no longer care for my Son, and if the State took on his care, it would cost the Tax payer over £200,000 a year, I think the financial aid we receive is a tiny amount compared to this. We don't expect to be able to have a life style that we might have aspired to, we don't expect to have holidays. but without the mobility allowance, we would have no car, we would be prisoners in our own home. *</p> <p>7. The consultation takes no account of the pressures and enormous levels of stress that the caring for a disabled person can cause, the lack of sleep, due to the disabled persons brain differences, the exhaustion, the stresses caused by the person or child having no sense of danger. Studies show that Carers lives are very often shortened by their Caring roles, that they are more likely to suffer mental health issues themselves as a result, we pay with our health and well being, for the Government to be loading us even more is intolerable. It is inhumane, we have enough to worry about, constantly. *</p> <p>8. The consultation almost seems to be suggesting that the needs of a disabled Child are less than an adults, it seems to be suggested that due to a Special Needs Schools possible involvement then the Childs needs for DLA are less, if this is what is thought, then it would show a complete lack of understanding or care of the difficulties that the Carers, the family, the Child face. As explained in the previous points, our life chances are very altered, the affect is not just on the Disabled Child, but on the whole family, please remember that the Child may have siblings too, and their needs impact on those around them. It should also been borne in mind that Carers allowance as it is, does not take into account the levels of care that are given, or the impact that the care has on the Carer, and their family. This is not to denigrate any Carer in their role. *</p> <p>9. Carers of disabled Children are in a minority, we are probably one of the smallest minorities that there is, as a consequence we are neglected, ignored, treated inappropriately, Society can be very cruel, people can say the most appalling things about the sometimes unusual or different behaviour, or looks of a Child, or Person, life can be very cruel, we look to the Government to treat us with some care, not to be a source of even more stress. *</p> <p>10. I am very fearful that the costs of the changes, the cost of the Medical Professional will wipe out any money that the Government thinks it will save. There is something very worrying, almost unpleasant about the</p>

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		<p>thought of taking ones disabled Child to see a Medical Professional that has no knowledge of ones child, so that it can be confirmed that they are disabled enough so we can receive financial help. It just seems rather inhuman....my Child will not have any idea what the visit is about, could a Paediatrician not be able to confirm the level of disability?. *</p> <p>11. Finally this consultation seems to be so centred around independent living, which is very admirable, but there is a great deal of neglect for those who under no amount of help will be able to live independent lives, there is no recognition for the Carers.*</p> <p>I just really really hope that more thought is given into these changes. I know that the big driver is to save money, but the measure of a good Society, and the worth of a Society is how it treats it's most vulnerable.</p> <p>with thanks and regards</p>
EM441	11-Feb-11	<p>1.: confidence, lack of staff support, public transport problems, not enough money to attend day services, public attitudes to disabled people, closure of 'job clubs' and lack of specialist employment services. *</p> <p>2.: For it to be non means tested, not to affect the amounts of other benefits you receive, for people with terminal illnesses to get it without question after diagnosis.*</p> <p>3.: extra transport costs as often have to use taxis as public transport can be difficult to access, higher bills as may need to have more heating on, wash clothes more often, replace clothing more often, may need specialist food items, need specialist eating and drinking equipment and mobility equipment. Need to have someone accompany them on trips and activities*</p> <p>4.: Unsure as current DLA has 2 rates so think it will stay the same. *</p> <p>5.: Terminal conditions, amputations, complex severe learning and physical disabilities.*</p> <p>6.: Eating and drinking, personal care, household chores/cleaning, shopping for food and personal items, dealing with finances/benefits/bills/letters. Jobs/day services, social activities. *</p> <p>7.: medical reports from GP, care managers and social workers and family members as to how the condition affects the person's life at different days and times of day. *</p> <p>8.: Any aids and adaptations that the person needs to complete everyday activities e.g. wheelchair, crutches, glasses, shoes, frames, care-call systems, assistive technologies, OT equipment. It should take into account any aids and adaptations that will and do enable them to live an ordinary *</p> <p>9.: Questions in claim forms must be clearer and in plain English, where you ask about people who live with you make it clear if you mean people who just share communal facilities or just family members. Some examples of types and illnesses and disabilities that will qualify.*</p> <p>10.: GP, family members, care managers, support staff, day centre workers and employers. *</p> <p>11.: Some people are non-verbal, some people who live in shared properties may not want someone coming into their home, will travel expenses be provided if expected to travel to the meeting, will staff costs be provided if you need someone to support/accompany you. *</p> <p>12.: Should be based on professional's assessment of how long the impairment will affect the individual i.e. if long term or forever then only reassess perhaps bi-annually. If the impairment is temporary due to injury then it should be reassessed after the medical professional believes it should have healed/stopped affecting them. *</p> <p>13.: send a form out yearly asking if circumstances have changed.*</p> <p>14.: As much as possible. What illnesses/ impairments are likely to mean benefit is received, very clear and plain instructions on how to fill in the form. If a review will be required then this should be made clear. *</p> <p>15.Your response: *</p> <p>16.: Usually by using their DLA, Yes I think a one off payment to ensure that all required aids and adaptations are purchased will mean that</p>

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		<p>people can live their lives to their full potential. *</p> <p>17.: As they are constantly changing may need reassessing more often. As they are growing may need more equipment and clothing to meet ever changing needs. *</p> <p>18.Your response: don't know. *</p> <p>19.Your response: Lack of funding if people stop attending so more services may be forced to close. *</p> <p>20.Your response: Don't know.*</p> <p>21.Your response:*</p> <p>22.Your response:</p>
EM442	11-Feb-11	<p>1. Being in Pain and knowing that this is with me forever. Not having two days the same, so planning ahead is a definite no *</p> <p>2. Being awarded indefinite, as this has taken the worry away as my condition is lifelong and wont get better. The motability scheme, as this is very comforting and saves a lot of worry and undue stress*</p> <p>3. Everyday living costs as not being able to work but we still have to live and in some cases support a family. Disabled adaptations for our homes and so we can make our life's more comfortable*</p> <p>4. • Will having two rates ... support? Yes, as long as they are fair and consistent to all*</p> <p>• What, if any, ... cause? Very difficult if not impossible to put some conditions and peoples lives into categories. Especially without discriminating against people or conditions*</p> <p>5. Some should defiantly be automatic as their impairment/conditions are for life and that wont change. Having to reapply even yearly is an added worry and stress that can make conditions/symptoms worse*</p> <p>6. This cannot be catorgirised as each condition differs and the answer will always be dependant on the condition. Also people suffer differently with the same conditions. Home life i.e. cooking, cleaning, washing, night times are all very important things to consider*</p> <p>7. This has to be a priority as most conditions vary. You would need to make an assessment on a weekly basis rather than by day by day. Or give an open box for the claimant to explain how their life in a week/month is affected*</p> <p>8. Should the assessment ...adaptations they use? Yes*</p> <p>• What aids ... included? Prosthetic limbs, wheelchairs if used everyday. *</p> <p>• Any that claimants already have as not all possible aids will help everyone, that's why they haven't got them already*</p> <p>9. • How could we ... fill in? More open boxes for the claimants to complete in their own words on a topic with just a few prompts not lots of questions.*</p> <p>• How can we improve ... qualify? State qualifying lifestyles/conditions/symptoms*</p> <p>10.A Letter from GP or family member*</p> <p>11. • What benefits .. bring? They will be able to see for themselves. Easier to see than explain*</p> <p>• Are there any circumstances ... location? They wont know the person so may not understand fully their lifestyle. It may be a good day so the person would be assessed on good days not general or bad days. This can be added worry for claimant *</p> <p>12. • What evidence ... reviews? This has to be dependant on condition and severity of symptoms *</p> <p>• Should there ...condition? Yes i.e. if condition is lifelong then yearly or 2 yearly would be reviewed enough. If condition is newly diagnosed then a more frequent review would be needed. Or if treatment is undertaken a more frequent review needed. Though to remember that every review will worry claimant and possibly make then worse for period of time*</p> <p>13. Make a clear-cut penalty for no reportees*</p> <p>14. Yes, clear advice on the claiming process with details on rates, timescales etc. Also any local help already available in their area for their</p>

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		<p>condition*</p> <p>15. I feel GP's already provide this kind of support and information and so be unlikely to help*</p> <p>16. Yes to met a one off cost. People use their DLA money to fund adaptations. Most councils don't have the money to help or people don't meet the criteria which is often far to down the line and doesn't take into account different circumstances*</p> <p>17. They have 24 hr care from parents. No daily living costs pressures/worry. They don't have a home to run and they don't have problems getting a job because of their condition so rates need to be adapted to consider this*</p> <p>18. Blue Badge scheme has been much easier to access and takes away stress and worry. If people qualify for Personal Independence Payment then certain things should be automatic like blue badge scheme. This could be like the income support system currently in place, if you get income support you automatically get free school meals, council tax benefit etc*</p> <p>19. It would cause more confusion and upset. There would be more forms to compete and more waiting for results of application.*</p> <p>20. Information gained for Personal Independence Payment, could also be used for Incapacity benefit, income support, disability section of council tax, disability section of working tax credit. All benefits with a disability section.*</p> <p>21. Everyone is equal and as long as process and benefit is available for all disabled with all conditions then equality groups are included*</p> <p>22. *</p> <p>A lot of people work short hours because of their disability, under the new rules these people could be worse off because they work, though shorter hours and for less pay this that doesn't make them any less disabled. It will be totally unfair if under the new rules that people will be worse off if they don't work, because they are unable to work but may not necessary qualify for being someone who is vulnerable and needs the most support. This would be discrimination! Not all GP's know or understand their patients and what happens in their everyday lives, as they may not have seen them for a long time, as their condition is unchanged. All the current paperwork on your files for claimants of DLA MUST be used in the new system, as most conditions wont have changed. Married disabled couples often support each other and therefore may not have the support needs of others. This doesn't make them any less needy. In a lot of conditions no two days are the same. There is no way of predicting this and this makes forward planning almost impossible. People with Lifelong conditions should be given a different assessment as their condition is forever and they have enough to cope with without added stress of reapplying for benefit*</p> <p>How will 'greater needs' be defined??? As every condition affects people differently. This could be deemed as discrimination as everyone who qualifies for Personal Independence Payment will have a disability and surely there is no such thing as being disabled and others being a little disabled. Disabled means the same thing for all of us. The people with lifelong conditions who are on an Indefinite award of DLA, will these people be likely to get Personal Independence Payment and then awarded a longer review period because they have been deemed under medical advice and the governments department to warrant an indefinite award already. This wont have changed just because the benefit system has!</p>
EM443	11-Feb-11	<p>Dear Sir, My name is [REDACTED] and I live in [REDACTED] with my wife [REDACTED] who is registered disabled and receives DLA. I care for her on a fulltime basis as she suffers with a lack of periphial vision and Hypersomulance, both as a result from a major stroke in 2005. Her poor eyesight means that she is unable to leave the house alone plus her fatigue and Hypersomulance stop her from walking anything but very short distances</p>

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		<p>every few days. Should Carers allowance be ceased in the future and my wifes DLA be reduced or cut we will only have the allowance of an unemployed couple to live on, which will mean a very confined and solitary lifestyle for [REDACTED] and myself.*</p> <p>With no savings or other means of income we will not be able to afford anything but the most basic of lifestyles. I shall not be able to work or leave [REDACTED] home alone as she cannot negotiate the stairs in our house and is unable to use the cooker or carry hot food or drink in the house. We are fortunate to drive a car supplied by Motability at the moment, otherwise we would have to rely on a poor public transport system to move from one hospital or Doctors appointment to another. [REDACTED] currently suffers with a Rectalseal which involves us making regular trips to visit her consultant for tests on the far side of [REDACTED]. Her need for quick access to toilet facilities means that public transport is quite unsuitable for her to travel on.*</p> <p>We are very concerned hearing that there are major reviews of the way that people such as [REDACTED] are likely to be assessed in the future and the lack of information regarding the position of Cares is causing [REDACTED] further stress which she finds very hard to deal with. I hope that you will be able to clarify where people such as us stand with reagrds to our finances very soon and look forward to your reply, regards,</p>
EM444	11-Feb-11	<p>1.: The inability to consistently perform physical and mental tasks needed in social and work settings. Lack of money for the extra needs brought about by the inability to walk far, keep warm, buy medicines needed, buy adaptations require etc.*</p> <p>2.: 3 levels of care and two for mobility*</p> <p>3.: Heating, Prescriptions costs, Transport, Adapting homes, Buying easy to cook food, Having help with housework and keeping houses and gardens tidy, More expensive holidays*</p> <p>4.: If having two levels means that the lowest rate of care disappears, many people will not be able to have help to do essential things such as having a decent meal*</p> <p>5.: Terminal illnesses should have automatic entitlement; Other illnesses should be based on need.; People undergoing surgery and aftercare should have a time limited entitlement to help*</p> <p>6.: Eating, Being warm, Personal care*</p> <p>7.: Believe the people who fill in the form, Listen to those who know them best, If someone can't manage any whole day in a week, they can't manage life as an average person in work or at leisure*</p> <p>8.: Aids and adaptations should be considered as should the cost of providing and replacing them. Adaptations that can easily be obtained should be considered.*</p> <p>9.: Different forms may need to be used for different types of illness...physical, mental, fluctuating*</p> <p>10.Your response: GP, Social worker, Physio, Partner/ good friend*</p> <p>11.: Patient 'trying to please', People with fluctuating conditions may look well on the day then crash the next day, People with mental health problems may deny their problem, It's inappropriate if someone has a terminal illness or is undergoing aggressive treatment at the time*</p> <p>12.: Some conditions are life long and unlikely to change. Why pursue these people? Frequency based on the known patterns of the illness. Different reviews according to conditions. Learning disabilities don't go away. A bad back or other physical condition may get better.*</p> <p>13.: Send reminders to those who are most likely to have improved. If the medical conditions are recorded, practice will tell how long an average person with that condition will take to recover or improve.*</p> <p>14.Your response: How to fill in the form well the first time without having to go to tribunal. How to put down examples of the needs they have. It must be part of the claiming process or else people will be filling forms in themselves and having to spend more energy and worry going to costly tribunals*</p>

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		<p>15.: The 'Big Society' is taking money from charities so demand would outstrip supply. Help has to be impartial.*</p> <p>16.: Yes, a one off cost should be available*</p> <p>17. Your response: *</p> <p>18. Your response: Very useful in getting extra money for benefits, for example. Useful in helping disabled people be able to work by providing extra money for travel etc.*</p> <p>19.: DLA should be high enough to not need extra premiums etc in other benefits. Blue Badges should still be awarded to those who need them*</p> <p>20.: Medical information should not be shared. A level of incapacity for care and mobility could be passed on.*</p> <p>21. Your response: Some conditions have a preponderance of women so if they are the conditions to 'fail' the new test many women would suffer.*</p> <p>22. Your response:</p>
EM445	11-Feb-11	<p>I claim Disability Living Allowance (DLA) and am extremely worried that I may lose the benefit, or face reductions to the amount that I am entitled to. DLA money enables me to get around independently and also pays some of the extra costs I have to meet because of my sight loss. Without this money I would be stuck at home more, and face real problems in paying for essential items. It enables me to buy items for an easier way of life, so that I can try and keep up to date with technology with the help of aids and to go out and meet others, not only socially, but professionally who can help me make the best of my life.*</p> <p>The Government announced in the Budget that it intended to review the assessment for DLA, as well as achieving savings of over £1 billion by 2014. A consultation on this was published in December, which closes on 14 February.*</p> <p>The consultation proposes that the Care Component of DLA, which has three rates, will in future have only two rates. It doesn't say whether these two new rates will be lower than the current ones, but people like me may lose DLA Care completely. It also says that everyone who currently gets DLA will be reassessed, presumably so that many thousands of us fail the new assessment; lose some or all of our DLA.*</p> <p>I am greatly concerned at the proposed removal of automatic entitlements to specified DLA components for people with certain health conditions or impairments. For example, people who are deafblind, and from April this year, people who are severely sight impaired, have automatic entitlement to the Higher Rate Mobility Component. The DWP proposes to end this, with every case requiring separate assessment (except people who are terminally ill). I would also point out that this is not just about DLA, there are wider repercussions. If people lose DLA, they will also lose exemption from the overall benefit cap that is being introduced, as well as often losing entitlement to the Disability Premium and Severe Disability Premium in other benefits. The Government has said it wants to target DLA on those people with the greatest needs, presumably meaning they will remove it from people with low or moderate needs. Local Authorities are cutting their support to disabled people all over the country, increasing charges and tightening eligibility criteria for care and support. If DLA is removed from disabled people they will in all likelihood find no other support is available to fill that gap. It is also appalling that the Government is proposing to remove the Mobility Component of DLA from 80,000 people of all ages living in residential accommodation. This seems to be based on a misplaced belief that Local Authorities will meet the mobility needs of all these people which, considering the 28% cut in council budgets over the next four years, is fanciful indeed. The Prime Minister said last year in his Party Conference speech that in terms of cuts to public spending, those with broader shoulders should bear a greater load. He also said a fair and civilised society gives money to help the poorest in society- people who are sick, who are vulnerable, and the elderly. I do not believe that the proposals on DLA fit in with this vision of fairness, and ask that you make my views</p>

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		known to the Minister for Disabled People, and consider the points I have made in advance of debates on the Welfare Reform Bill.
EM446	11-Feb-11	<p>Dear Sir/Madam, My name is [REDACTED] I am a [REDACTED] year old male with learning disability and I am in receipt of Disability Living Allowance . I believe we sure keep DLA well I want to keep my DLA I don't think we need a new different type of benefit to DLA I think the DLA benefit is fine as it is I'm sure that hover disability people will agree with me. The reason why I am doing this instead and not send you my answers from DWP easy to read DLA consultation document is because the questions in that document are base on the new benefit and it would have been stupid and pointless of me to answer any of them questions and it shows you where I stand on this matter b Many Tanks [REDACTED] *</p>
EM447	11-Feb-11	<p>1. <u>Responses to your Questions as Numbered*</u> Communication, mobility, supervision, aids, discrimination, fluctuating conditions.* Access to further benefits.* Help, supervision, housing, mobility, activities.* No, too simplistic so liable to leave some people out of the "loop".* Case by case so that noone is left out* See 1 above* Flexibility* Yes, as appropriate & consider those that may be eligible & easily attainable* Use common sense. Claim form will have to be all embracing. New benefit clarity will be enlightened by a Help Line* Family & paid carers, in that order, as with the 2005 Mental Capacity Act* Healthcare Professionals are typically weak in assessing the whole person especially mental capacity. So a 2nd opinion system must be available. Circumstances are too often wherein the individual is e.g. frightened.* Work out a points system. Different types of review should be set according to the person.* Train Carers-both family & paid.* Must tell people the whole "story".* See 13 above & set up a Help Line* DLA pays as now as best it can.A one-cost optional element would be welcomed.* None.* Stay as now.* More bureaucracy.* Share information across the board.* Be careful not to discriminate.* Do not leave out proper needs for any disabled person. The whole person must be in mind always.</p>
EM448	11-Feb-11	<p>Dear Mr Cameron, I am the mother of a child with Down Syndrome, and I am writing to express concerns about, and to provide feedback into, the public consultation upon Disability Living Allowance (DLA) reform. *</p> <p>* I wish to raise general points about the proposals, as well as a specific concern about proposal item 40 "<i>whether or not we should take into account a child's support needs if they are being met from public funds by another institution, such as a school</i>".*</p> <p>* Regarding proposal item 40, regardless of funds used to support children with Down Syndrome in school their families incur large number of unavoidable specific costs associated with the children's care. These are costs that are also each over and above costs for a non-disabled child. Hence, when the phrase 'for older' children' is used below it refers to the fact that children with Down Syndrome typically require additional care and equipment, incurring additional costs, to a much later age than is the</p>

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		<p>case for a non-disabled child.*</p> <p>*</p> <p>Families of children with Down Syndrome incur additional expenses, over and above those incurred with a non-disabled child, in the following areas:*</p> <p>Mobility – our children are less mobile, tire more easily and lack road safety awareness: *</p> <p>Transport to appointments & parking; *</p> <p>Specialist buggies for older children; *</p> <p>Road safety equipment for older children;*</p> <p>General Health and Safety – our children lack safety awareness: *</p> <p>Road safety equipment for older children;; *</p> <p>Locks, stair gates and similar for older children *</p> <p>Night safety equipment for older children; *</p> <p>Need for constant supervision in each room in the house, which will often involve extra paid for childcare;*</p> <p>Night and sleep issues – our children are impacted by a wide range of night and sleep issues, including refusal to go to bed, highly disturbed nights going on up to 16 years of age, bed wetting, vomiting and night disturbance. This incurs additional costs such as: *</p> <p>Sleep Apnoea alarms – for breathing problems affecting sleep; *</p> <p>Decongestants; *</p> <p>Additional night laundry – up to 6, 7 times a night; *</p> <p>Bed rails for longer than children of the same age; *</p> <p>Greater breakages; *</p> <p>Restless Leg Syndrome / night disturbance incur the need for extra massage or physical activities such as dance or swimming, each provided by a trained specialist, incurring additional cost; *</p> <p>Shocks and scares can provoke cessation of breathing, this can involve admission to hospital;*</p> <p>Additional laundry and cleaning costs: *</p> <p>Greater electricity use; *</p> <p>Greater washing machine use, more frequent replacement; *</p> <p>Need to have more much bedding and clothing than for another child; *</p> <p>Much greater use of baby wipes beyond the age of three;*</p> <p>Special correspondence in relation to medical appointments, a child's Statement of Special Educational Needs, or communication with schools: *</p> <p>Incurs additional PC, printing and writing material costs;*</p> <p>Specialist food and feeding equipment – since so many of our children are impacted by significant sensory issues and / or allergies; *</p> <p>Specialist clothes, because of our children's low muscle tone: *</p> <p>Shoes; *</p> <p>Body support corsets;*</p> <p>Specialist therapy equipment – this is always expensive since it need to be purchased through specialist agencies and, like toys, sustains higher level of breakage than for other children: *</p> <p>Specialist putty; *</p> <p>Chewy Tubes; *</p> <p>Computer programs; *</p> <p>SLT resource books and materials; *</p> <p>Adapted bikes; *</p> <p>Adapted swimming kit; *</p> <p>Trampolines; *</p> <p>Specialist chairs / tables / pens / writing slant; *</p> <p>Specialist classes such as music, dance, swimming needed as Occupational Therapy;*</p> <p>Specialist training and courses for parents (and carers); *</p> <p>Specialist childcare such as Little Angels, an agency employing staff specially trained to look after children with special needs; *</p> <p>Additional holiday related costs: *</p>

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		<p>Specialist holiday centres such as Symbol (Symbol UK, a specialist speech and language therapy agency) camp, which incur direct charges and indirect additional transport costs; *</p> <p>Higher rates of travel insurance, especially if heart condition; *</p> <p>Need to ensure disabled child friendly, safe accommodation, which usually means more expensive accommodation.*</p> <p>This listing of these costs for families of children with Down Syndrome does not mean that every family always incurs every single cost. However, all such families unavoidably incur the great majority of these additional costs. *</p> <p>To repeat, these costs are not only unavoidable, but they are also each over and above costs for a non-disabled child. They also represent costs incurred <u>outside</u> of school. In addition, school holiday periods are not covered by provision in school, so that holiday respite or childcare would need to be by a paid trained specialist, or by specialist play centres manned by trained staff – there are already too few of the latter, and many are currently closing.*</p> <p>A further specific concern relates to the proposal to introduce eligibility for support only 6 months after diagnosis. In the case of Down Syndrome, diagnosis is at birth, while children with Down Syndrome typically require often intensive medical intervention within their first 6 months of life. This incurs significant additional costs. A three month delay in eligibility for financial support is already damaging, extending this to 6 months would represent further damage to families at their time of greatest vulnerability, and would additionally risk the long-term health of children.*</p> <p>We are also concerned about the proposal to assess need through face-to-face meetings with an independent healthcare professional who may have little understanding of the impact, nature and complexities of Down Syndrome, which would be necessary to allow an in-depth analysis of an individual's circumstances to be carried out. We would like to know who the DWP are working in collaboration with while they develop an objective assessment of individual need for people with disabilities. We would further like to understand which independent specialists in health, social care and disability are contributing to the process to develop an objective assessment. Do any of these specialists have considerable experience of Down Syndrome in particular?*</p> <p>In a more general sense, we have wider concerns about aspects of the proposed DLA reform, as follows:*</p> <ul style="list-style-type: none"> · Costs associated with Down Syndrome are not only about healthcare, but reflect a range of support and care needs, which must be taken into account;* · It is exceptionally rare for a person with Down Syndrome not to have expensive additional support needs as an adult;* · Finally, families with children with Down Syndrome are already placed under significant and measurably damaging financial pressure. Families of children with Down Syndrome have been shown to suffer: <ul style="list-style-type: none"> · Reduced earnings – diminished by 1/3 with a child with disability;* · Greater incidence of marital break up and divorce;* · Negative impacts upon siblings, often necessitating additional sibling childcare, if a principal carer has to attend additional appointments.* <p>* The consequences of taking away some of the already inadequate levels of DLA financial support, many of which will incur additional costs to the State, include:*</p> <p>Children with Down Syndrome becoming adults with less independence, needing more expensive care, since they will be more socially isolated and physically dependent; *</p> <p>Greater financial stress upon families, in particular restricting the capacity of both parents to attain full time employment, thus reducing family</p>

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		<p>earnings and tax and NI contribution; *</p> <p>An increase in the numbers of children needing greater, and more expensive, institutional care; *</p> <p>An increase in rates of separation and divorce among families of children with Down Syndrome.*</p> <p>We would welcome a simpler assessment process for families, who have so many difficulties and pressures, but urge you to take the above specific costs and general concerns into account as this public consultation feeds into the reform process.*</p> <p>Yours faithfully,</p>
EM449	11-Feb-11	<p>Hello, I've been given this address to write to re the proposed changes to DLA.*</p> <p>I accept that changes have to be made due to both economics and to try and reduce fraud, but i'd ask that you consider the effect on the genuine cases.*</p> <p>I'm completely blind, live alone, suffer from depression to the point when i can become suicidal. Without the DLA i'm getting now i'd be more or less completely housebound, unable to look for work, unable to pay people the cost of accompanying me if i need to go anywhere unfamiliar, E.G. hospital appointments, church, to social activities and so on, nor could i meet the costs of people visiting me to help with personal care and to help me run the house properly. As this would all be denied to me, and as i have the kind of family who can't be bothered, i would be left alone most of the time with the obvious possibilities caused by the depression. A situation could easily arise where i may get to the point where i would be tipped over the edge, but because there'd be no one to call on i'd get no help, i may be left for days or even weeks before i was found.*</p> <p>I'm not saying this for you to feel sorry fvor me, this is a situation many might be left in if DLA were to be drastically reduced or completely withdrawn.*</p> <p>I've heard it suggested that the money might be taken from the person and given to the local authority to spend on care, but in that case the person would not be able to arrange his/her own mobility needs as friends and family are not going to help at their own cost, nor would the person have complete control over his/her own needs as far as care is concerned; there is also the danger that hard pressed authorities might try to divert part of the money to other purposes.*</p> <p>Given this, i'd ask that you consider leaving DLA alone but making the application process more stringent soas to prevent fraud as much as possible; including mandatory medical examination as part of the application process..*</p> <p>I do hope you will take my views as a person heavily dependent on DLA for essential needs into consideration while making any decision.</p> <p>Faithfully yours;</p>
EM450	11-Feb-11	<p>Please find attached my response to the DLA reform. Please note that I am responding as an INDIVIDUAL with a disability and not on behalf of the organisation. However, I can be contacted on this e.mail address if necessary *</p> <p>1. TRANSPORT: if you have a car through Motability all the mobility component of DLA is used, leaving nothing to use to acquire a power chair on the scheme as well. This would enable an individual more independence and remove the need for a PA/extra support and would be particularly beneficial for a disabled parent. FINANCE: for extra support, equipment or adaptations. If you do not meet Social Service criteria for these you have to fund them yourself. For example, now my condition has altered I cannot use the bath, but have no funds to spend on alterations and do not qualify for any help.*</p> <p>2. A statement from family/friend etc., evidencing and confirming the extent of the person's disability and how it affects their social and</p>

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		<p>independent life. Also, it should continue not to be means tested.*</p> <p>3. Transport by taxi or cab, because even if there are accessible buses locally often people with mobility difficulty cannot walk to the bust stop and are not near enough to seating at their destination. An electric wheelchair would be the answer, but the cost cannot be met as it is extra to the mobility allowance.*</p> <p>4. will having two rates ... support? Yes*</p> <p>5. There should be no automatic entitlement and an award should be based on the ACCURATELY assessed needs of the individual applying, preferably by a health professional with experience of an holistic view, i.e. occupational therapist.*</p> <p>6. With informed accurate assessments promptly arranged and fairly and professionally carried out. Which activities ...life? As in proposal 25, plus consideration of the disabled person's role, for example, the problems in parenting with a disability and the extra pressures and expense that entails.*</p> <p>7. By making the process of notification by disabled people to the DWP less daunting and 'big brother'. Plus there should be REGULAR assessment at the disabled persons request without a wait.*</p> <p>8. Should ... adaptations they use? Yes, but remembering that a lot of disabled people 'cope' without equipment or adaptations for as long as possible even though they need them and will need to be encouraged to address their need. What aids .. included? walking aids/wheelchairs/bathing aids/home equipment, including that used by disabled parents to enable independent child rearing. Should assessment ... obtain? No, vital consideration should be given to the disabled person's eligibility to obtain funding for equipment or adaptations and help given to them to get it (see question 1)*</p> <p>9. How could we make the claim form easier to fill in? By having headings asking for information about specific tasks and not repeating the same question. How can we improve ... qualify? By being specific and saying in clear, simple language on the front of the form who can apply for DLA. A straight forward guidance sheet should be created giving the Disability Helpline (0800 882200). This number can be used to help get the information to the public and save unnecessary applications and time wasting.*</p> <p>10. A GP is not usually the best person to provide supporting evidence as disabled people are not always 'ill' and may not visit the doctor. The family or close friends are useful in highlighting everyday barriers and problems that a disabled person may treat as 'ordinary', when in fact their daily living is very difficult.*</p> <p>11. what benefits ... bring? a benefit would be the opportunity for the disabled person to show how disability affects them day to day. A difficulty may be the health care professional basing the interview on the 'medical model' and not the 'social' one. Therefore it may be more appropriate for the person to be interviewed by an Occupational Therapist with an holistic view, together with an impartial disabled person recruited for the purpose of clarity.*</p> <p>are there any circumstances ... location? If there is no advocate or family member to support them to speak up with confidence about their disability and how it really affects them.*</p> <p>12. What evidence ... reviews? Every person should be reviewed annually with no exception Should there ...condition? No, all annually.*</p> <p>13. To train staff in user friendly attitude and with assurances to disabled people at their regular review that informing the DWP of changes could actually result in benefits being raised. If, for any reason they were reduced information and support should be given about alternative sources of funding to enable them to manage.*</p> <p>14. Yes. But signposting to proficient, responsive, proven and adequately funded local organisations. Financial support needs to be found to allow these information networks to function.*</p>

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		<p>15. Local up to date information on eligibility would need to be available from impartial local organisations linked to other services, i.e. Blue Badge applications. You would have to avoid the medical model professionals offering encouragement, instead disabled people need to be able to self assess with the support of their peer group as advocates.*</p> <p>16. How do ... adaptations? See question 1. Currently out of their own income Shouldone off cost? Yes. A one of payment could improve and change a person's independence for the better, but a review would still be needed at a regular interval.*</p> <p>17. What are ...children? Although procedures may be constant to enable daily living they often take longer with a child. So "how long will it last" is not a good question as a condition would vary day to day. Also some conditions are obviously long term, i.e. acute cerebral palsy, bowel and urine dysfunction.*</p> <p>18. How important ... entitlements? Not useful at all – people feel grateful for the one service (entitlement)*</p> <p>Are there arrangements? Encourage people not to feel they are "putting" on the welfare state, but that it is their right to access funding to gain and maintain their independence.*</p> <p>19. Poverty, social exclusion and a loss of self esteem, often leading to ill health and the person's disability becoming worse because of a loss of personal independence.*</p> <p>20. All information concerning the person should be accessible on one database, i.e. local council Blue Badge issue and disability registration list, plus data held at the DWP on the person's award.*</p> <p>21. The overriding impact should be on how disability affects the PERSON'S DAILY LIVING, not the equality group they are in.*</p> <p>22. The language used is too bureaucratic and not generally understandable to the general public, it needed to be simple and clear. The proposals are well thought out and appropriate. However, I would suggest that disabled people entrenched in the Social Model of disability are involved in both the new assessments and appeals of DLA (PIP). They can then be regularly consulted and referred to when questions arise when out of the ordinary 'barriers' are being considered. Remember that genuinely disabled people, mostly since childhood, often play down the extent of their mobility and daily living problems as they have encouraged during their lives to 'cope' and find it hard accepting that by admitting they find certain activities difficult that they are 'less' or 'different. Health professionals employed to conduct the reviews or assessments need Disability Awareness Training and to be accompanied by a specially recruited person with a disability. This would be a good job opportunity for disabled people who would otherwise be unqualified for employment in another area.*</p> <p>Lastly, why didn't you send information about this consultation to a cross section of disabled adults and parents of disabled children who are currently on DLA? I only found out about this consultation as I work for a Charity supporting people with a physical or sensory impairment.</p>
EM451	11-Feb-11	<p>'Disabled persons' (like 'Learning Difficulties') is frequently a vague, amorphous term. It can be applied to Professor Stephen Hawking and also to my son who was statemented as having a mental age of between two and three years, although he was chronologically in his early twenties. It is therefore imperative that people like my son should be recognised as needing one-to-one support before he is able to participate in meaningful, creative activity within society. Without such support, his very low mental ability would otherwise cause him to be excluded from any such participation.*</p> <p>When a person has a recognised condition such as Down's Syndrome, then changing DLA becomes a pointlessly expensive exercise. My son will always be vulnerable and require a 24 hour level of support. It is not a condition which he is likely to 'grow out of'!</p>

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		<p>From my own experience - a rapid wearing out of bed linen, and even the springs of his favourite armchair, due to my son's tendency to 'rock' vigorously. Similarly, his trousers and pyjamas have to be frequently renewed. There is the obvious increased use of electricity because of the incessant use of the washing machine.*</p> <p>5 There should be an automatic entitlement when a recognised lifelong condition such as Down's Syndrome is diagnosed.*</p> <p>6 When the disability has been diagnosed and its full extent recognised then the necessary level of support must be provided. Taking our own case as an example, our son requires sensitive, active support workers who will facilitate him to access activities in the community, such as a simple form of gardening. These activities must be communal, otherwise the person with a disability will be doomed to an extremely isolated and lonely existence.*</p> <p>7 Such an assessment will require an input from various people who know the disabled person best i.e. carers, support workers (when there is good continuity of support these should have considerable insight into the needs of the disabled person, and also an awareness of issues relating to fluctuating moods and behavioural problems) Although, of course, they would not earn the accolade of being termed "healthcare professional"! *</p> <p>9 So many people, already in desperate need of help, seem to have been kept in ignorance of benefits to which they are entitled. Perhaps the first 'port of call' when a condition is first diagnosed should be the doctor's surgery. There should be a person in every G.P practice who should have sufficient training to be fully conversant with the benefits a patient should be able to access. At present, information about benefits appears to be very diffuse and haphazardly distributed. We ourselves only found out about DLA by mere chance several years ago.*</p> <p>10 The knowledge of those people who know the disabled person best - carers, support workers, case managers, G.P.s/Consultants.*</p> <p>11 Who is this healthcare professional likely to be? On the surface, it might appear that this might result in a sound 'objective' assessment, but there can be problems endemic to people with learning difficulties. They might display only their best behaviour on such an occasion. Often their own G.P.s have merely a superficial knowledge of them (such are the inevitable constraints of the N.H.S. 10 minute appointment system). It is usually the day-to-day carer and support worker rather than the doctor who has a true knowledge of the capability and behaviour patterns of people with learning difficulties.*</p> <p>12 If there is a recognised, diagnosed condition, then frequent reviews are a pointless expense. My son's Down's Syndrome and autistic tendencies are a lifelong condition, and not something which the passage of time will change. The extra chromosome which causes Down's Syndrome is a <i>biological</i> fact.*</p> <p>Yes - the best form of review would be an 'assessment discussion' perhaps concerning the individual's increased needs, which would take place between carers and support workers who have the daily responsibility for the person with learning difficulties, and overseen by the case manager.*</p> <p>17. Frequent reviews might be far more productive when assessing children, as the developmental process is far more fluid. Children can progress or regress, and these factors need to be considered very carefully.*</p> <p>18. I do not feel that the lower rate of DLA functions as a 'passport'. The higher is absolutely vital, as it has enabled us to access the Independent Living Fund, without which our lives would be unbearable!</p>
EM452	11-Feb-11	<p>Dear Sir I have read through the consultation document and agree that there needs to be some updating and changes made. *</p> <p>I am a carer for my husband, who has Complex Post Traumatic Stress Disorder with acute anxiety, he has been ill for over 20 years. Obviously he is in receipt of DLA and until I became a pensioner I received Carers</p>

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		<p>Allowance. Several years ago my husband applied for DLA on the old style form, it was not suitable for people with mental health problems. The latest one is better. I hope this new PIP form will include questions suitable for those who suffer from mental illness.*</p> <p>I have the following concerns about this consultation:*</p> <p>Regarding the medical assessment from an independent health professional, something like this would cause my husband even more anxiety. Also the illness changes from day to day (even hour by hour) so how would the professional take this into account if it was a good day? *</p> <p>Although I am no longer receiving Carers Allowance it would have a great impact on others to lose it. Especially where no one within the family is able to work. It helped us pay the extra costs involved particularly the heating bills as when someone is ill at home the heating is on all day.*</p> <p>Carers save the UK £87 billion each year by the care they give; they need to be recognised for the part they play in saving the UK money. How will a carer be eligible for carers Allowance with the new PIP?*</p> <p>The government should not be trying to make £1 billion cuts to disability benefits as it will have an impact on the vulnerable, namely the disabled and their carers and in some cases carers would not be able to continue caring. Some might consider long term care which would cost more in the end. *</p> <p>Some disabled people would have their benefits cut or removed which will lead to a loss of independence; some will become poorer and have a poor quality of life which could lead their health to go downhill.*</p> <p>People in long term care may lose the mobility component which would mean they would be unable to afford taxis to take them out to socialise and visit relatives. Socialisation is so important for a persons well being. *</p> <p>There doesn't seem to be any detailed consideration regarding carers in the PIP. *</p> <p>There need to be a more flexible approach to the qualifying period for eligibility for the new benefit, not six months rather than the three it is now. When someone becomes seriously ill suddenly in a family it often means the relatives have to stay at home and give up work to care for them, possibly giving up paid employment. This will mean a substantial drop in income. Yours sincerely</p>
EM453	11-Feb-11	<p>Hi there, I was diagnosed with MS in September 2005 in May 2006 I had to reduce my working hours which has lead to a drop in pay. I am now in the lucky position that I can work from home one day per week too. Additionally I have a mortgage and will have for the next 21 years. I rely on my mobility car and my DLA money to ensure I can keep some normality in my life. I am getting very stressed by this proposed reform. I spend all my energy at work and do not have the energy to respond to this consultation at home as I am in my bed. So this is all I can manage in my lunch break. I have however managed to read the MS Society's response to the consultation (although it has taken me days!) and fully support this as an accurate and fair response to how this reform will effect people like myself. Regards</p>
EM454	11-Feb-11	<p>1. Your response: If you remove those on the lower tier they will not be protected by the Disability Discrimination Act and they will lose ALL other benefits provided by society for instance a Disabled National Rail Card. Therefore the DWP will be providing this barrier in removing the lowest tier. *</p> <p>2. Your response: You are strongly urged to keep the three tiers and you are urged not to apply new rules retrospectively *</p> <p>3. Your response: The issue is not one of cost, it is about status („I am disabled“) – you are attempting to say those that were classified by YOUR OWN ASSESSORS as disabled are not entitled to that status, a status which society recognises not just the DWP. And it is about social mobility. In mental health a person can seem normal when not presented</p>

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		<p>with stressors. They find that they can start a job but have difficulty with the work load or a colleague and it triggers their problem so that they eventually drop the job. In these cases the ability to hold disabled status is useful because the capacity to hold a full-time job is diminished and thus their income. *</p> <p>With regard to cost may I note that living costs in London are much higher than the regions. With the loss of DLA status, the loss of society status, the loss of funding to Councils the difficulty at this time of charities to cope, the rise in VAT the change in the inflation monitor and the compound effect of all the budget cuts the last thing that the person presently (accurately) on the lower tier of DLA needs if for you to remove them from it. The idea that "we want to see that those "MOST" in need of DLA receive the benefit" is outrageous. Forget the consultation then, and just remove the two lower rates! *</p> <p>4. Your response: Though this is a consultation document, a „proposal", you make it a 'fait accompli' that there will be two bands. "The benefit WILL have two bands." This attitude immediately undermines that this is an open consultation. You do not say "the intention is". Elsewhere you indicate that there is to be a 20% cut in the DLA budget. It appears that the intention is not the improvement of the DLA but to cut the DLA whatever the consultation information you are presented with, immediately undermining the consultation process. If it is your intention to move everyone off the lower rate, why are you bothering with the consultation? *</p> <p>Problems Let's say you implement the 2-tier system. *</p> <p>1) There is a statistical problem. *</p> <p>Let's say the bands at present were £10 £20 £30. Therefore anyone remaining on DLA in the lower band after the face to face meetings will have to be moved into the middle rate. Let's say the assessors removed 50% and moved 50% to the new lower rate. *</p> <p>Originally we have 100*</p> <p>10 = £1000 *</p> <p>Now we have 50*</p> <p>20 = £1000 *</p> <p>That is even cutting 50% of those on DLA and moving 50% to the new lower rate the DWP SAVES NO MONEY *</p> <p>My example is a hypothetical but the principle remains. Even if you cut 75% off the lower rate and move 25% to the new higher lower rate you will only save HALF the intended savings. *</p> <p>2) The purpose of the three band system was to make it easier for assessors to allocate the budget. The new two tier system makes that harder. You will claim that it makes the system simpler. It does not and it saves you less money than you anticipate (see point 1) In other words a proportion of those allocated to the new DLA will be receiving more money than what the previous assessors had thought correct to allocate. *</p> <p>*</p> <p>3) In removing the lower rate, you remove those on the system from being a person „registered disabled". They will lose, in addition to the DLA amount: *</p> <p>The right to a discounted national rail pass, the rights to a Bus pass if under the age of 60, the rights to visit cinemas, theatres, attractions and any other services from charities and those who have protection under the Disability Discrimination Act *</p> <p>4) You are going to apply the new system retrospectively. This raises a serious ethical point given your stated intention to cut the DLA by 20%. *</p> <p>You must assume that the greater majority who are presently on the lower tier were accurately assessed and were entitled to DLA and entitled</p>

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		<p>to be classified as „registered disabled“. It is morally and ethically wrong for you to retrospectively remove that status purely on the grounds of the need for cuts. Whilst I disagree with the removal of the lower tier if this does happen I would strongly advise you to apply it to new claimants, not present claimants. *</p> <p>5. Your response: If a person has clear mobility problems, or a long term medical problem carrying out an in depth personal assessment is not advised. Assessors are fallible and the cases to the CAB and the FRU will rocket. *</p> <p>[Aside I was once on IS. I had to travel from London to Liverpool twice to arrange then attend my mother"s funeral. The Social Fund allows specifically for the claim of travelling expenses to attend a funeral.. It was declined by the independent assessor on the grounds that I was "able to borrow the money from a friend"] *</p> <p>The DLA is a social benefit, not a medical benefit. Let"s say a person is delusional and phobic, and paranoid. And let"s say they have a problem going on public transport and prefer to be accompanied. It is not for a medic to decide if it is an absolute necessity for that person to be accompanied. The fact that someone is on Olanzapine does not prove this *</p> <p>point to anyone. *</p> <p>Assessing a mental health problem. It is possible for someone to be in remission at the time of the assessment only to find themselves having an episode of the problem three months later. I suspect that if the assessor declines the award and the social status (the ability to go out in public) changes but not the medical status (the prescription) that person will remain excluded from the benefit. Because it is a social effect not a medical condition, and it is also difficult to see face to face with someone the long term mentally ill should be given the benefit of the doubt. No note from a psychiatrist to a GP is going to say "this person has difficulty being alone on public transport" *</p> <p>It is better to allocate as follows. If a person is on long term medication for a mental illness, and at the time of diagnosis that person was correctly diagnosed and they are on continuing medication, the fact that they may be in remission at the time of assessment, they should be given the benefit of any doubt. Classically once a patient has been diagnosed a subsequent psychiatrist does not keep reassessing the clinical diagnosis rather they attempt to keep the person in remission. Usually a long term mental patient does not always manifest nor be able to articulate a set of social problems – it is only when the stressor appears, that the problem appears and it is not going to manifest in a face to face meeting in their home. Again this is a GOOD reason to keep the three tier system. If an assessor is not quite sure what to allocate the three tier system will allow them to assess the client at the lower rate. That leaves the client to inform the DLA of a change in circumstances, for a re-grading. The concern is that if you remove the third tier which after all at the lowest possible assessment is only about £75 per month, a person with a mental problem that was not accepted is going to find difficulty being put on the system when the circumstance changes. *</p> <p>6. Your response: The treasury has already indicated you will deliver a 20% reduction in the DLA *</p> <p>Your proposal should be to protect the needs of those presently on DLA. I cannot stress too strongly the need for you to keep the three tiers. It"s better to freeze DLA for two years for everyone, and let inflation save you the money, than to cut the third tier. *</p> <p>7. Your response: Those with clear mobility problems and those with a long term mental illness *</p> <p>Should not be repetitively reassessed. Those first entering the system should be given an open assessment as present with a follow up after</p>

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		<p>one year *</p> <p>8. Your response: *</p> <p>9. Your response: All documents I have seen from the DWP are very clear and well presented with simple English. They need to discriminate six payment groups and the forms need to keep the ability to make this discrimination. The forms should indicate places such as the CAB, Age Concern who are willing to assist in the correct filling in/ supporting documentation. *</p> <p>10. Your response: This is a major problem. I have found that the medical profession are not particularly adept at assessing a social implication. Part of this is the focus of the medic and part of this is the difference in the social class of the medic and the patient. However, if a person says they are on medication, or seeing a psychiatrist for example, they should provide documentation. But a psychiatrist only sees a patient in a room. I would find it problematic if an assessor had to write to a psychiatrist "is it the case that this person likely to have difficulty travelling alone on public transport" It's better to look at the original clinical diagnosis e.g. Delusional Disorder and the assessor then ask themselves " is it likely that a person with delusional disorder have problems being in a confined space with strangers". The assessor has to make another additional step. Not "is it the case that this person MUST ALWAYS be accompanied with someone when travelling" but " is it the case that this person is better off, in a better state of mind, best able to cope "if they were accompanied" . Under these circumstances the client MUST BE GIVEN THE BENEFIT OF THE DOUBT. Assessing social need to being given DLA is extremely difficult and the present assessors have probably done a good job. This is why I keep stressing the need to keep the three tier system. Otherwise you make the assessors ability to allocate correctly much harder. *</p> <p>11. Your response: Mental health problems are notoriously difficult to assess as in the classical exchange with someone who is about to be Sectioned. *</p> <p>Psychiatrist : "Tell me are you hearing voices" *</p> <p>Schizophrenic: "I think it is you that must be hearing voices" *</p> <p>It requires about 8 years of medical training to reach a point to make a really accurate clinical diagnosis of a mental state. Then the medic is not best placed to make a social assessment. Then the patient may be in remission, then they may not have accurate insight. It should be assumed that the mentally ill do not cope very well with stress and people, especially strangers no matter how they appear at an interview. Once again I would stress that it is better to keep the three tier system. If the assessor has a doubt they can allocate the lower tier but leaving it open to a re-application. The DWP should recognise that the present assessors have probably done a good job in a difficult field and moving the system to two tiers enters a mine-field of difficulty. *</p> <p>12. Your response: Because the stated aim of the reform is to cut people off DLA (the 20% intention) I am concerned that the focus on a review is to kick people off the benefit. Whereas the aim should be to support those correctly claiming. Therefore the DWP/Treasury needs to change its mind-set. At present clients are requested to request a review to make sure they are receiving the right level of DLA. In some cases to move them up the tier. Whereas I suspect the aim here is to remove people or move them down the tier to save money. That is I suspect the review is for the DWP's benefit (to cut costs) not for the disabled person's benefit. Whilst this mind-set is in place these reviews will tend toward the wrong outcomes, so the biggest feed-back here is to change the Treasury mind-set here. *</p> <p>13. Your response: Two themes come up in my feedback to you – a) the cutting of the third tier and the b) knowledge that you plan to cut people off the benefit and the knowledge that you plan to take away 20% of the</p>

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		<p>budget. Therefore there is presently a breach in trust between the DWP and those agencies who are trying to help the socially disadvantaged. Under these circumstances you are LESS likely for people to volunteer for review since it appears that it is your aim to take away DLA from many people. [Like the populous in Egypt the people are not stupid where the government stands on DLA and they are not going under these circumstances to volunteer for review]. Under the present climate if I was a CAB advisor I would say to the client "there is a good possibility that your request for a re-assessment may go against you and given that there is only a small change in your situation I would advise you not to apply for a re-assessment" *</p> <p>14. Your response: 15. Your response: 16. Your response: 17. Your response: 18. Your response: 19. Your response: *</p> <p>20. Your response: 21. Your response: 22. Your response:</p>
EM455	11-Feb-11	<p>Dear Sir, I am a mother of a [REDACTED] year old with an Autistic Spectrum Disorder known as PDA. I currently receive middle-rate DLA for my son and carer's allowance. I am really worried about the news reports suggesting that there may be cuts to these allowances. Because autism is not a visible disability like being confined to a wheelchair, we don't seem to be recognised for things like a Blue Badge (yet my son's failure to understand safety issues means he is an accident waiting to happen should we venture into a public car park). I am very concerned that if the cuts impact on our DLA and carer's allowance, we will have to sell our house which would greatly impact on our stress levels and negatively impact our son who cannot handle change.*</p> <p>Whilst my husband is working full time, and looking into the possibility of taking a second evening job, it is not currently possible for me to take on a job. Every week I have a variety of appointments or review meetings for my son and I have to be on standby to go to his school to deal with continence difficulties and behavioural outbursts. I am also up many times during the night caring for my son who does not seem to need more than a few hours sleep. This leaves me physically and emotionally exhausted.*</p> <p>Due to the nature of my son's condition, he is totally unpredictable. If you were to meet him for a short time to assess him, you may fail to see any of his difficulties, then only a few minutes later, he might physically attack me, break something, run off, soil himself or have a severe temper outburst. Over time, we are finding that he can sometimes control things until he feels he is in a safe environment to 'de cloak' and let out his stress and I know that this is common amongst many people with autism. I rely on my carer's allowance to put food on the table, replace/repair damage caused by my son and to pay bills. We are already stretched to the max and only just able to make ends meet.*</p> <p>I don't feel that the Government should be making cuts of £1 billion to disability benefits as this could have massive consequences for disabled people and their carers, who are already under considerable stress, just functioning on a day to day basis. I believe that Carer's Allowance should remain outside of the Universal Credit. Carer's save the country billions of pounds every year by providing care and reducing the burden on the health service. Thank you for taking the time to read my plea.</p> <p>Yours faithfully</p>
EM456	11-Feb-11	<p>I give below comments in relation to various questions in this document:*</p> <p>1: Access to certain types of transport - particularly rail stations, many of which still have multiple stairways to connect platforms. Also, some buildings where a ramp is not a possibility, only steps.*</p> <p>3: Paying for outside help with certain tasks eg. gardener, decorator etc.*</p> <p>4: Too little flexibility.*</p> <p>5: Yes as certain conditions have inherent problems which are ongoing and permanent.*</p>

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		<p>6: Ability to care for oneself and get out and about.* 7: Speak to the person.* 8: Any aids etc should be covered.* 9: Claim form is far too long and ambiguous in places.* 10: GP/Consultant/Partner* 11: Person may be nervous and/or not very articulate which could result in incorrect or incomplete information.* 12: Review should take into account type of condition and whether lifelong, incurable, etc.* 13: Some changes can be on a daily basis eg. feel good one day then really ill for another week so would not be reporting on a daily basis.* 14: Clear and concise questions with straightforward guidance notes.* 15: All GPs to be aware and advise patients if they would qualify.* 16: I have purchased aids and adaptations from my DLA money.* 20: Multi-agency communication would be the obvious answer.* 22: I was not aware of this consultation until advised by a fellow sufferer who had seen it on the internet. What about people who don't have access to the internet, how would they be able to respond?</p>
EM457	11-Feb-11	<p>i care for my youngest son who has a diagnosis of PDA I also care for my eldest son who has just received a diagnosis of Asperger's Syndrome. I currently only receive DLA for my youngest.I am very concerned about losing Carer's Allowance because the person I care for might lose their benefits I am worried because if my son loses his DLA because his condition changes daily due to aspects of every day living altering the way he can cope with daily demands. His condition changes daily and if caught on a good day or if i have explained well to him what will happen he may cope very well having someone give him a medical. i would like to add how they can test an individual regarding the autistic spectrum. This will make professional assess them and fail to take account his worst times The impact of losing my Carer's Allowance on top of this will have a devastating impact on my family we will no longer afford to pay our basic bills, or affording to do anything as a family i will lose my car and will lose a very understanding employer. I believe the Government should not be making cuts of £1 billion to disability benefits because of the devastating consequences it could have for disabled people and carers like myself. I believe that Carer's Allowance must remain outside of the Universal Credit. Carer's save the UK £87 billion every year with the care they provide and it would be wrong to take away Carer's Allowance from some carers by means-testing it, as this would leave some carers without any recognition of their contribution. Thank you for your time Yours sincerely,</p>
EM458	11-Feb-11	<p>1. I am writing on behalf of my son [REDACTED]. [REDACTED] has just turned [REDACTED] and is a severely disabled both mentally and physically. I am main carer and a single parent. I am very concerned about [REDACTED] losing benefits under these changes and the dramatic effect this would have on the tight financial situation [REDACTED] and myself live in. * I am worried that these changes could lead to reassessment which could undermine the complex care arrangements for [REDACTED]. In particular that a medical professional might fail to understand the full extent of his health condition and disability. * Losing Carer's Allowance would lead to difficulty paying basic bills, or affording to do anything for myself, and could mean caring becomes unaffordable and that I couldn't carry on. In addition this is likely to result in an additional burden of responsibility, both financial and emotional on carers - often people who are at the limit of their tolerance. I have already had spells of stress related illnesses resulting from the management of my sons care. * I strongly believe that the Government should not be making cuts of £1 billion to disability benefits because of the devastating consequences it could have for disabled people and carers like myself. People who are</p>

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		<p>after all some of the most vulnerable and deserving of state support. *</p> <p>I believe that Carer's Allowance must remain outside of the Universal Credit. Carer's save the UK £87 billion every year with the care they provide and it would be wrong to take away Carer's Allowance from some carers by means-testing it, as this would leave some carers without any recognition of their contribution. Yours Faithfully</p>
EM459	11-Feb-11	<p>1.Your response: there are many problems/barriers and it depends on the individuals own illness as to what problems they have. For example people with m.e and/or fibromyalgia have symptoms change day to day hour to hour and they can never predict how they will be each and every day. they cannot make plans for fear of having to change them, appointments run the risk of being cancelled at the last minute. They have the pain, pain that is all over and restricts mobility, restricts social life (I should say 'what social life?') there are many. Many people are like this in this country and all face these same problems day after day. they are not avoiding participating and being independent and would love to lead full active lives but when pain and illness directs lives it makes it very difficult. *</p> <p>2.Your response:. *</p> <p>3.Your response: again it depends on a person's illness. It could be transport costs-paying for extra fuel in personal vehicles to get out and about (a social life), attending appointments, buying ready prepared vegetables if they have problems preparing food, paying for exercise, for example swimming if it helps provide a little exercise.*</p> <p>4.Your response: no it will just make it more complicated and provide more worry. Disabled folk have enough to worry about in having to justify themselves to the powers that be without having to face the added worry of 'new' things to have to 'fit' into*</p> <p>5.Your response: *</p> <p>6.Your response: it is not possible to put this into a general box-each person has a different idea on what is most essential to them for everyday life for example one persons weekly swim would be essential for their mental well being while another would say a trip to the local library (if its still there). In general the essential would be a home over their head, to be able to pay bills and buy in food and stay warm and free from worry that the powers that be will take away their benefit and that they will have to justify all over again their claim to a 'doctor' that does not know them or their history.*</p> <p>7.Your response: by taking note of the individuals doctors information-not by saying you are waiting for the doctors information and then totally ignoring it in your decision making process. People with long term problems see their doctors a great deal. Often people with long term problems keep journals. It would be a comfort to people with long term conditions with fluctuating conditions-especially 'invisible' conditions, that there are actually believed rather than spend their time with the feeling they are being treated as liars and potential benefit frauds.*</p> <p>8.Your response: with respect many people have found that just because they have aids and adaptations the powers that be have used this to say they do not need extra support. *</p> <p>It would be reassuring to people who do not know how, if the new system could provide advice and support in how and where they can get aids to help them. If this were the case the system would have to be run by people who actually know the problems people face and not by faceless civil servants who know nothing of illness and disability*</p> <p>9.Your response: at present the forms are very repetitive, the individual has to repeat their condition and problems with every single question-leading to the wider disabled community feeling that it is designed like that in order to trip someone up in what they say. This is very disheartening and makes filling in the forms a very long, drawn out process. Surely if someone puts at the beginning of the form their condition and all associated problems (physical and mental) then surely</p>

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		<p>this needs not be written down countless times throughout the form? If they have a problem in walking (i.e. severe pains in legs then it stands to reason this provides problems in walking outside, walking inside, getting in and out of bath etc).*</p> <p>Also the use of silly jargon would be good 'DLA currently entitles or 'passports' the individual to other help and support.' Keeping everything in plain English makes things so much easier.*</p> <p>10.Your response: as i have said the persons own GP and any consultants they are seeing are those best placed to help give this information as well as those that live with the individual. How can an independent person in one meeting and a collection of set questions accurately and fairly assess an individual?*</p> <p>11.Your response: 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.*</p> <p>I think it would cause (and already causes) difficulties to individuals-the whole thing of having a person meet with a unknown 'healthcare professional' causes a great deal of stress and increased illness to people already facing daily difficulties. I can see no benefit in making folk go through this when more than adequate information can be obtained from the individuals GP and consultants. As mentioned before how can this healthcare professional be in a position to judge someone they have never met before?*</p> <p>12.Your response: those with long term chronic conditions should have fewer reviews than those with acute conditions*</p> <p>13.Your response: this is very difficult to answer-there will always be people out there who will not report changes in circumstance, either if they are getting worse or getting better.*</p> <p>14.Your response: as is now-prescription information and GP's report, contact for GP/consultants*</p> <p>15.Your response: this question needs to be in plain, simple English please...*</p> <p>16.Your response: they use their money...made up with their DLA, how else will they fund it?*</p> <p>17.Your response:*</p> <p>18.Your response: it has not been useful at all-it points people towards other benefits but that's about it. I know people who have found out about other services-such as physio or getting the bathroom adapted to a wet room-by way of their neighbours.*</p> <p>19.Your response: they would be in the position they are now-limited information*</p> <p>20.Your response: GP/consultant information could be shared (with the individuals consent) with regard to incapacity benefit and services-local social services for example. This would (should) make the process less stressful and a worry if people do not have to keep constantly repeating themselves.*</p> <p>21.Your response:*</p> <p>22.Your response: I would like to point out some general things.*</p> <p>The wording *</p> <p>We want to make Personal Independence Payment a more active and enabling benefit and we are exploring ways to help individuals to 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 *</p> <p>-to be honest this smacks of government interference in peoples personal lives. Not everyone wants or does not need help in managing their condition-many discuss their condition with their GP/consultant and do not need to discuss their condition with a government appointed</p>

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		<p>professional.*</p> <p>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 itself... independent healthcare professional*</p> <p>It is disrespectful to ignore a person's condition and only look at the impact it has on their lives. this brings to mind people who have had 'medical's with ATOS (independent healthcare professional)-poor people who have struggled to the 'medical' despite asking for a home visit and who are then told they have failed the 'medical' because they can obviously walk and are placed as fit for work. This is a disgrace and many people see the new DLA going the same way.*</p> <p>The respect for those who are chronically ill is absent in this society. A society that cast the focus on the 'benefit cheats', the ill are treated as liars and wasters and suffer the indignity of being forced to see these 'independent healthcare professionals' while their own doctors are being ignored.*</p> <p>Disabled people in our society are second class citizens and will remain so.</p>
EM460	11-Feb-11	<p>1.Your response: Lack of understanding into their disabilities and other issues that may occur along side the disability such as mental health issues.*</p> <p>2.Your response it should stay the same for children as you cannot assess their needs against adults this is really for people who have been on benefits for some time and may not necessarily need the dla anymore perhaps if you kept it the same for children and gave them all the support in their early years it may reduce the amount of children turning into adults who want to be on benefits.*</p> <p>3.Your response: For us it's not so much the physical money but the time needed to take care of someone with a disability.*</p> <p>4.Your response: I don't know how you can fairly assess these types depending on disabilities my son has hearing problems asthma and severe eczema resulting in a daily routine of applying creams and inhalers cleaning and maintaining hearing aids and reassuring him at night it doesn't effect his daily living as we do it for him we ensure that by doing this he does have a normal daily routine which is important for his independence and to feel accepted from reading your proposals it seems that he would not receive anything or very little due to it not effecting his life disabilities effect daily lives full stop now matter how severe or mild it is how the disability is dealt with and support that makes the difference. Some people who need the payment for making their lives better may miss out for not meeting the criteria. *</p> <p>5.Your response: yes hearing and sight problems should be automatically entitled and so should children it is enough with peer pressure without having to manage with a disability as well if the children get the support and are encouraged at an early age they will go on to what to achieve not matter what their difficulties.*</p> <p>6.Your response: That depends on the individual keeping day centre open and services in the community open will give better access to support.*</p> <p>7.Your response: I don't think you can people need to be accessed on a regular basis with the help of gps and other health professionals.*</p> <p>8.Your response: All aids need to be taken into consideration including when people need new ones and when perhaps they stop using them including hearing aids I noticed weren't mentioned.*</p> <p>9.Your response:*</p> <p>10.Your response: Care professionals involved in that person's care.*</p> <p>11.Your response: Difficulties may be over viewed you can't get a picture of what a person struggles with on a one off meeting.*</p> <p>12.Your response: every 6 months*</p> <p>13.Your response: review every 6 months this is sounding more like direct payments as this form goes on.*</p>

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		<p>14.Your response: What they are reciving the payment for as it seems like a direct payment scheme is money going to be given if people can only provide information on what services they are accessing to help support them.*</p> <p>15.Your response: yes but unfairly*</p> <p>16.Your response: the health service pays for my sons aids I don't see why I should have to pay for them or him as it isn't his fault*</p> <p>17.Your response: that their parents will do they can to keep them having a good life they cant work so they should receive all the support they can get to enrich their lives thus giving them a sense of purpose so they can go on to want to work.Childrens needs change so quickly too.*</p> <p>18.Your response: very*</p> <p>19.Your response: no access to services*</p> <p>20.Your response:*</p> <p>21.Your response:*</p> <p>22.Your response: I feel that chaning the system is long needed as people are on bennifits who could work but it seems that from this proposal that children will miss out as I have mentioned I am in receipt of lower dla for my son aho has a hearing impairment we don't need to access services for support but the money comes in handy for extra things I can get to support him or the extra time we give to him my partner and I have always worked and made tax contibutuions judging from this proposdal because my son has a normal life he wouldn't qualify for any help how does this seem fair I cannot by in anything that will help my son further but he will still have an hearing impediment and have to live with the effects this will have for the rest of his life. To what job he has and how people accept him in the future I say invest in the children especially disabled children and give them the oppitunities to see that having a disability doesn't stop them from achiving and encorraging them to want to have a sense of purpose in life.</p>
EM461	11-Feb-11	<p>To whom it may concern, As am a mother of a Multiple Sclerosis patient age [REDACTED], I am writing to raise concerns re the abolition of the Disability Living Allowance and the gov't plans to reduce claimants by a staggering 20% with its replacement Personal Independence Payment.*</p> <p>* For the MS community there are specific worries. To be entitled to PIP you have to have a sustained level of disability for six months prior claiming and be able to guarantee that it will continue six months post-claim. Fair enough you might think, but for those with the relentlessly fluctuating (clue's in the name) Relapsing/Remitting MS this poses severe problems. The face-to-face 'objective' assessments proposed could fail to capture a person's mean or even median level of disability, but also invisible symptoms such as debilitating fatigue. In turn for those with progressive forms of the disease, the new periodic assessments replacing 'indefinite' payments will only add stress and uncertainty for the claimant and unnecessary cost for the government. Surely this is the reform at its most insulting; repeatedly reassessing those with an incurable degenerative disease. I would therefore strongly urge you to reconsider this reform in relation to those people who through no fault of their own have an incurable degenerative disease.</p>
EM462	11-Feb-11	<p>1.This is impossible to answer as Disabled people are not a homogenous group. You cannot compare the issues of a person with communication or mental health illness with a person who cannot walk. If made to say a problem I would say finance, as there are considerable extra costs to being disabled.*</p> <p>2.I disagree very strongly that the appliances should be irrelevant as now. I use a wheelchair, motor scooter, sticks depending on circumstances. You are still disabled if you happen to have an aid. It would be short sighted to penalise people for using the best equipment available or they can afford. *</p>

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		<p>3.Again which disabled people? The list is endless. Cost of transport, cost of appropriate clothing, equipment, continence aids, special furniture, domestic help, laundry costs.*</p> <p>4.Two rates are appropriate as long as the rules are clear and there is a real distinction. Currently the rules are secretive and feels like a lottery.*</p> <p>5.Current illness list is acceptable. I think use of habitually resident is sensible I agree payment could stop if in public funded hospital but should get it back when discharged.*</p> <p>6.You seem to have lost sight of the fact that this allowance was to help people work if possible and get out and have a life. The question implies some people are more deserving an active life than others?*</p> <p>7. *</p> <p>8.If you reduce payment for the successful use of a wheel chair you may encourage people not to bother. It shows a complete lack of understanding that you can view the successful use of a wheel chair as not being disabled. Appears a cynical way of reducing costs. If you suggest equipment as an alternative to payment, who will pay for them? Currently DLA is used to buy equipment.*</p> <p>9.The current form is a long nightmare to fill in. It's also very repetitive. It also makes people feel undignified. It should be shorter and easier to understand. I think it is unrealistic to have each form filled out by a health professional, a huge added cost.*</p> <p>10.The individual and local GP and specialist. *</p> <p>11.Many people will not want to discuss their personal bodily functions with a person they do not know. It's bad enough on paper. Face to face will be intimidating to some . If the person has a mental disability who will be advocate, .The cost seems large two people per interview?*</p> <p>12.Reviews should be set depending on the disability. It is obvious that some disability will not get better, so why waste time on review?*</p> <p>13.Clarity is the key. Most people are not clear why they got the current DLA so don't know what to report. The current system is secretive so it's not surprise people don't know when to get in touch.*</p> <p>14.Again clarity. You need clear guidance on what it is for and how you qualify*</p> <p>15.Very vague question, what action is a person supposed to take. Is this now a payment were the government expects a return? *</p> <p>16.It is essential that mobility payments should still fund cars. Other adaption's should also be available. However how does that work if you think using an adaption makes you ineligible for payment?*</p> <p>17.I think an integrated approach is acceptable to include school. However danger that each institution will just pass on the cost.*</p> <p>18.No knowledge*</p> <p>19.Your response: No knowledge*</p> <p>20.Your response: No knowledge*</p> <p>21.Your response: No knowledge*</p> <p>22.Your response: How can consultation be done seriously when there is no question about why you are filling it in or who you are. I also think the general nature of the questions is unhelpful. I say again how can you talk about the disabled? You could just as easily ask what difficulties do the people of Cambridge have. I also wanted to say that there are many disabled people who claim DLA who do work and do not claim other benefits. This consultation exercise come across as a cost saving exercise and I resent the implication of it being a benefit that encourages worklessness and benefit dependency.</p>
EM463	11-Feb-11	<p>Dear Sirs, Please find attached my comments on some of the questions on DLA reform. I have answered those questions that I felt were aimed at the general public rather than health professionals. Regards,*</p> <p>*</p> <p>1. Your response: The major barrier preventing disabled people participating in society and leading independent, full and active lives is lack of income. Although some disabled people do manage to work, they</p>

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		<p>are almost always limited in the type of work they can do by their disability, thus their earning capacity is also limited, usually in a very big way. Even those, like myself, who manage to do some paid work are seldom able to continue working until normal retirement age and their earnings limitations means they are unable to save for a pension. *</p> <p>The other major barrier is in being able to get around independently in a society where daily living evolves around the use of a car and where public transport is extremely limited in many areas, if it exists at all. In my area over the last decade it has become necessary to access out of town stores and retail areas to buy even the simplest and most basic everyday items and essentials. *</p> <p>As a blind person I feel more and more isolated from society due to my inability to drive or to get around on my own and the difficulty I have in assessing modern technology which is taken for granted by most people. Local buses have reduced and are facing further cuts and taxi fares are very high. The DLA helps but in no way covers all the extra costs of being disabled.*</p> <p>2.Your response: The above points are all a vital part of the benefit and I hope the promise will be kept to keep the new benefit non taxable and non means-tested. It should certainly never be means-tested for anyone who has paid National Insurance or whose spouse has paid NI. The special circumstances for people with a terminal illness should be kept without question.I am very concerned that it may not continue for people after the age of 65. This was an important part of DLA in that it recognised that a disabled person, through no fault of their own, had severe limitations with regard to job prospects and earning capability, and therefore their ability to save for retirement. Although I managed to work for several years with my disability, I was unable to do the kind of job I would otherwise have done and as my health worsened I had to retire early just at the time of life, as my children became independent, when I would have been saving hard for my retirement. The only consolation I had was that I would receive DLA after 65 and I am just terrified at the thought that it might be taken away from me when I will need it even more than ever. I also feel that a lot of money is going to be spent on unnecessary reassessments. Surely the people who know best the problems the recipient has are his carers and doctors. Certain conditions that are permanent or even degenerative, should be exempt from continual reassessments which would cause added stress. There may be some disabilities that might improve or be treated successfully but even then consideration should be given to the fact that the person's earning capacity would have been severely restricted during the time they were disabled. *</p> <p>3.Your response: The extra costs faced are many and various and will differ with each disabled person. However, what is universal is that disabled people face the same costs as other people for everyday survival and their ability to earn money to cover these costs is hugely restricted by their disability. I would guess that the majority of people receiving DLA have to use it replace the loss of earnings due to their disability. The new proposals seem to completely ignore the fact that disabled people have the same needs as others, eg housing, food, heating, etc but do not have the opportunity or ability to work to pay for these. It is easy to say that it is easier to find work in modern day but this is simply not true. The barriers to disabled people in the workplace are enormous in spite of rules about access and equality. This is the age of targets and cost cutting. Why should an employer take on someone who is going to need more support, most probably have more time off and not be able to achieve the same as a fully abled person? Even if a job can be found, it is highly unlikely to be as good or well paid as that person would otherwise be capable of doing. There is also the problem of accessing the workplace and the huge cost of taxis where public transport is unavailable for those who are not able to drive. In terms of</p>

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		<p>extra costs for daily living these can include wheelchairs, all sorts of physical aids, special software for computers, special vision aids such as CCTV and digital magnifiers (all of which are extremely expensive) extra heating and lighting, special diets, taxis, and most of all, care and assistance from other people. Anyone with a serious disability will be dependent on other people for most of the things that other people take for granted.*</p> <p>4.Your response: I think that the existing rating system is easy to understand and takes into account people's change in needs as their disability worsens or changes. Three rates of care are needed as there is a huge variation in people's needs and it is very important to take into account a person's need to be supervised to prevent accidents and injury. A person may physically be able to walk but may not be able to do so safely, either for them or people around them. *</p> <p>The current system of rating for needing care in the daytime and/or at night seems very relevant as disability is with you 24/7 but not everyone will need night time supervision or help. I do feel it is unnecessary to ask people to fill in all the forms again if their condition has worsened. Surely it should be enough for their change in condition to be reported.*</p> <p>5.Your response: In order to save wasted costs of assessing people with permanent and recognisable disabilities I believe that certain conditions, including the ones listed in Annex 1 plus a few others, should have automatic entitlement. It will not be an easy task to assess some other health problems and efforts should be concentrated on doing these more difficult assessments properly. In a civilised society it should be the disability rather than the impact that has which is recognised. The impact may vary from day to day, even hour to hour, and from person to person at different times in their life but they will always face the barriers and difficulties of their disability. I cannot imagine how a fair and true assessment of impact can be made. There will no doubt also be many appeals which will cost further time and money to the system. Someone who has lost a limb or their sight or hearing will always be disabled no matter how many artificial limbs or hearing aids they have. They may be able to do some things on a good day but it will always be difficult for them and they will always have barriers. There is no way of giving someone artificial sight and therefore I believe blindness should also give automatic entitlement. A guide dog or a white cane are no replacement for eyesight. If you disagree just try spending a day, or even an hour, with a blindfold!*</p> <p>6.Your response: There are obvious ones including getting washed and dressed, keeping clothes clean, cooking, keeping home clean (which is not part of current assessment but should be, as it is as important as keeping oneself clean. I don't see how the two can be separated), keeping safe in the home (ie avoiding falls and other accidents and injury), keeping safe outside the home, crossing the road, getting about generally, being able to get to shops, doctors, hospital, dentist, library, bank, etc., being able to read and respond to correspondence, being able to use the internet is fast becoming an essential part of everyday life (which is largely being forced upon us), being able to read books and watch or hear TV and radio, having social contacts and being able to go out to meet friends and family, being able to work and to get to work, visit cinema and theatre, museums, galleries, cafes and restaurants, etc, and to attend courses and classes, pursue interests and hobbies, participate in sports and taking exercise in order to maintain the best health and wellbeing possible in spite of disability. *</p> <p>7.Your response: I appreciate that this can be difficult in some cases but the carer and doctor would be the best people to assess these cases rather than someone who does not know the person or their history. I feel these are some of the people who will suffer most under the new system. The whole reason for changing the system is to save money and the aim is to reduce the number of claimants. I stress again that I can</p>

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		<p>see just as much money being spent, possibly more, except that the money will be going to agencies and assessors and on administration instead of to the disabled people who need and deserve it. Will we ever be told these figures and given an analysis of expenditure? I guess not! *</p> <p>How much of the money taken away from the disabled will be spent on administration and agencies doing these extra assessments? The amount of DLA an individual receives is very small compared with what these new reforms will cost.*</p> <p>8. Your response: By definition anyone who needs to use wheelchair, crutches, artificial limb, guide dog, hearing aids, CCTV, digital magnifier, or any type of aid not required by a non disabled person, is 'Disabled' and therefore requires the support supplied currently by DLA and, hopefully, by PIPs. None of these aids replace the ability that has been lost. They simply make life a little more bearable and it would be wrong to penalise someone because they are able to use an aid. *</p> <p>It should be remembered that we are talking about a small amount of money here that is a contribution only to the extra needs a disabled person has. It has never been assumed that the money from DLA is sufficient to provide the care that is needed as the criteria for getting the benefit. Under the new reforms it sounds as though someone with a prosthetic limb will no longer be considered disabled! This is outrageous and unbelievable in a civilised society.*</p> <p>9. Your response: I personally think that the current information on DLA is perfectly clear about its aims and who is eligible. I really do not understand why it is being changed except that it is 'change for change sake'. At the end of the process I do not believe any money will have been saved but I do believe that many disabled people will suffer hugely. *</p> <p>The forms are difficult to fill in for some people because they expect the claimant to have exactly the same problems every day and the same number of times a day. Disability does not always work like that as the problems faced are so numerous, complex and variable. The forms do not take into account the variation that some people have in their condition.*</p> <p>10. Your response: I believe that the GP and hospital consultant or other healthcare professional who knows the person and their problems are the best people to make the assessment in conjunction with the carer and the claimant. It should be understood that the vast majority of disabled people can only cope with their disability by being as positive as possible and by concentrating on what they can do, however little, rather than what they cannot do. *</p> <p>11. Your response: This would be appropriate providing it is done on a fair basis and the claimant is not put at an unfair disadvantage. The claimant should be given sufficient information about what the meeting will involve and what questions will be asked and what discussed so that they can give proper considered answers. They will be under considerable stress as the outcome could be devastating for them. We are all familiar with the syndrome where on a visit to the doctor or hospital it is only afterwards that you remember significant information or questions.*</p> <p>I do feel this could be incredibly stressful for some claimants, especially the elderly and those with learning difficulties. It would, for some, be a barrier to actually claiming. For many claimants DLA is the only benefit they have ever received and they will already be sensitive about being considered as 'scroungers'.*</p> <p>12. Your response: The type of disability should be the criteria for frequency or reviews. Many people have disabilities which are permanent and which can only become more difficult with age. Such conditions should not need to be reviewed as this would be a waste of resources. For other disabilities the frequency of reviews would have to be decided on an individual basis but always with careful consideration. A non disabled person cannot possibly understand the importance of this</p>

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		<p>benefit.*</p> <p>13. Your response: If a person is knowingly receiving the benefit when they are not entitled then this is fraud and should be treated as any benefit fraud but there is often a fine line between being eligible and not and cases should only be pursued when there is definite evidence of fraud.*</p> <p>14. Your response: The person's health professional would be the one to provide this information and advice and is probably already doing so. They would know the person's needs and also the local agencies who could offer help. Such help and support differs enormously on a regional basis and is likely to be greatly reduced as a result of government cuts by the time the new benefit is rolled out. A lot of money could be wasted here with too many people trying to do the same job with very little actual result for the disabled person.*</p> <p>15. Your response: So often disabled people are sent on a wild goose chase with offers of support that just do not materialise due to lack of co-ordination, lack of funds or staff, or just simply because the actual individual needs of the disabled person are not fully understood. The problem is that most people genuinely want to provide advice and support but, at the end of the day, it is just not available and the disabled person is left to research their own supply of aids or support. Money is therefore wasted on good intentions when it would be better given directly to the disabled person who knows their needs better than anyone.*</p> <p>I am blind and also have ME, fibromyalgia and an auto-immune disease which flares up occasionally with very serious effects on my health. As a result of one flare up I have lost all balance function in both my ears leaving me with permanent and serious mobility problems. This combination of permanent disabilities is very rare and very well intentioned people sent me to various experts in the hope of getting help for me. In the end, I got a huge amount of sympathy but no actual help and I was left to make my own walking aids with my husband's help. There must be many other disabled people out there with an equally difficult combination of problems.</p>
EM464	11-Feb-11	<p>I am a member of the national autistic society, commenting in my personal capacity as a recipient of the current DLA. I have a number of impairments including autism, dyslexia, and hypermobility syndrome. The impact of this and the failings of society often mean I am also suffering from additional mental health difficulties most notably depression and obsessive compulsive disorder.*</p> <p>I will not be answering the specific questions asked in the document as I consider that they are very leading questions, based on a very poor set of proposals that betray a lack of understanding of what the current benefits are for and how they work.*</p> <p>I consider this consultation to be extremely flawed particularly since the Government is demonstrating very bad faith in publishing a bill before the consultation has even been completed. That does not inspire confidence in either the fairness of the process nor that any of those who will point out the proposals manifest faults will receive any kind of hearing whatever.*</p> <p>Above all, as I shall set out the process appears to coming out not on any real basis of there being a need to reform current DLA, but appears to be based on two things, namely the desire to reduce expenditure on the welfare budget, and even worse an ill founded ideological assumption that the current benefits are over generous and encourage fraud, neither of which is the case, as I am sure the many charities who will respond to this bill will point out without my needing to do so.*</p> <p>There is an old saying "if it ain't broke don't fix it", I can recall that when DLA was introduced, it was as a reform of the previous legislation, bringing two former benefits into line with each other and creating additional much needed benefits payable at lower rates for which there was and continues to be much social need. DLA was also revolutionary</p>

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		<p>at the time in the introduction of a tripartite appeals panel consisting not only of a medical expert and a legal expert but a lay member of the tribunal, expected to be a disabled person with experience of the living experience of disability. My mother was one such member and I can well recall the additional degree of fairness to the appeals procedure that this added.*</p> <p>Where the previous benefit has been at fault is in several things, not properly addressed or amended in this proposed replacement.*</p> <p>Firstly the benefit rates are not especially generous with increases being paid in line with general inflation, not with any real relationship to an index of the real costs of paying for care, additional expenses and above all transport which have risen out of all proportion to any datum of when the benefit was first conceived.*</p> <p>Secondly that there remains inbuilt age discrimination in the benefit, regarding the mobility component and people over the age of 65, a category most likely to be in need of it.*</p> <p>Thirdly the application process which has been complex, hard to follow, and particularly discriminatory in not giving any meaningful provision to complex needs arising out of mental health conditions, and particularly ill suited to the needs of people with autistic spectrum disorders.*</p> <p>These may not have been adequately understood at the time the original legislation was framed or the basis of the forms drawn up. There is no such excuse now, and yet in the short consultation period I see no evidence of pro active consultation with the major charitable organisations in the field, one of whom I have assisted in drawing up their particular response.*</p> <p>The current proposals make no attempt to deal with any of these shortcomings of the current benefit and so cannot be welcomed as an improvement on them.*</p> <p>There are many additional faults with the new system. The proposals are unclear about the situation of children and people over the retirement age, and the proposals are based on an overly medical approach to the phenomenon of disability in society, governed toward a simplistic approach which serves the agenda of a privatised assessment system, that fails to understand much about disability as it affects daily life and with somewhat contradictory agenda. I shall refer more to this in relation to something that has been come to be known amongst many disabled people, particular those with less visible or medically obvious conditions as "spoon theory"*</p> <p>There is no clarity on the appeals procedure or to what extent current innovatory procedures and the whole wealth of precedent based upon current practice and commissioners decisions will be taken into account in future, with the inevitable result that for some time there are bound to be inevitable miscarriages of natural justice and many mistakes as the new system finds its feet.*</p> <p>There is no consideration of the real costs of care, based upon a scarcity of resources and a decline in social services provision year on year.*</p> <p>Finally there is no real consideration of the interrelationship of the current system with the validation of a lot else, and without any meaningful substitute or "joined up thinking" a stricter set of criteria aimed at a targeted reduction in number of claimants, will leave many people a lot worse off than the loss of the current DLA because of the benefits passing effects.*</p> <p>These people will not cease to be disabled in any meaningful way simply because they do not meet a stricter set of criteria, they will simply be people who do not meet a more rigid and restrictive set of criteria, there real social needs will remain the same and the reality for these people will be a lot worse than poverty and debt, it will mean an inability to provide care for themselves, further negating any drive to assist disabled people into employment wherever possible, and will no doubt result in a greater long term cost due to an increased number of hospital admissions, longer</p>

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		<p>stays in hospital earlier recourse to institutional care, and beyond that I am certain an increase in excess mortality amongst that population.*</p> <p>Note on Spoon theory. In essence this is a way of explaining the limited resources of a disabled person to carry out the same task on a regular basis even though they appear to be able to carry it out at another time. The full text is available here</p> <p>http://www.butyoudontlook sick.com/articles/written-by-christine/the-spoon-theory-written-by-christine-miserandino/ The assessment process as intended will no doubt act with extreme prejudice against people with variable and less obvious conditions as is currently the case with the appalling track record of ESA assessment as has been widely reported.*</p> <p>I enclose a PDF of the article regarding spoon theory</p>
EM465	11-Feb-11	<p>1.: I respond only from my experience of our son, [REDACTED] who is severely learning disabled. [REDACTED] does not have the mental capacity to support and maintain his own life. He is fully dependent on support from others.*</p> <p>2.: The allowance is important in terms of the amount of financial support and however it is wrapped up is to a certain extent irrelevant. The monetary value is key.*</p> <p>3.: In [REDACTED] case it is substantial support costs covering 24 hours per day.*</p> <p>4.:Daily Living-Two rates seem appropriate from our experience. Should make it easier. Mobility-This has always been contentious for [REDACTED].He is able to walk BUT he requires someone to be with him at all times for his personal safety.This is not taken into account under the present system.[REDACTED] has to find travel costs for both himself and his support provider.*</p> <p>5.:Short answer YES.In cases where it is known from a very early age that an impairment is for life then any award should be given,supported by GP/Hospital/School/SocialServices for life.*</p> <p>6.:First identify:Anyone in the critical banding [Social Services] should be prioritised.Social interaction is key to a fulfilling life.*</p> <p>7.:Through self assessment with variation or fluctuation being initially referred locally to Social Services.*</p> <p>8.:For personal independence any aid or adaptation must be included on the definition of would that independence fail without it. What is defined as an aid or adaptation ? An object ? [REDACTED] needs the assistance of a fellow human being to live in a safe manner.Is that human being classed as an aid? *</p> <p>9.:I have long since held the view that there are too many layers of departments dealing with benefits.The responsibility for signing off any claim must be local.[REDACTED] is known locally through his G.P/Hospital/School/Adult Services.There is a clear audit trail of his disability.I would suggest any claim begins locally and must involve at least two independent bodies who must sign off the claim. The claim form should be simply I wish to claim.....x benefit.The process then begins locally either to sign it off as an entitlement or to decline with explanations.*</p> <p>10.:Medical evidence provided through the persons GP and supported by a hospital consultant and/or Social Services.*</p> <p>11.:Most if not all people will registered with a G.P who should have a medical record for that person. The G.P should be the first port of call without any issues. Fraudulant claims may present difficulties for a G.P.*</p> <p>12.: Life time impairment-no review necessary or required. Temporary impairment-6 months.*</p> <p>Reviews should be different i.e Physical impairment compared to mental health issues. *</p> <p>13.:Through local consultation.[REDACTED] has an annual review where all aspects of his support needs are discussed.*</p> <p>14.:Who Qualifies written in plain English with examples.Useful to have a local contact for advice.*</p> <p>15.:No the system should be voluntary or GP led.*</p>

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		<p>16.:No.Aids & adaptations should be accessed through the Health Service with any chargeable costs being addressed at the point of supply.*</p> <p>17.:Unless a life time impairment then reviews should be signed off by the educational authority as well as other services.*</p> <p>18.:In [REDACTED] case entitlement to the higher rate of the DLA care component has enabled access to other support funding such as ILF.This has made a big difference to [REDACTED] life.*</p> <p>I believe certain categories of severe disability should be targeted at an early stage enabling/passporting access to all entitled benefits without the need for separate claims.*</p> <p>19.:There would be every likelihood that support systems would suffer.*</p> <p>20.:Please set up a clear audit trail for the disabled person</p> <p>LOCALLY[NOT NATIONAL] Once a disabled profile of the person is known[birth/school/G.P/Hospital/Social Services] issue a disability passport which should be placed on a National register and clearly show all entitlements applicable from the benefits system.*</p> <p>21.Your response: No access to page 28*</p> <p>22.:Proposals should in the main have emphasis Locally thereby removing duplication from the system</p>
EM466	11-Feb-11	<p>Hi I have an incurable progressive condition MS. Life will only get harder for me. Being awarded DLA 'indefinitely' gave me peace of mind. This current review is causing stress through uncertainty which makes my condition worse. Regards</p>
EM467	11-Feb-11	<p>1.Despite legislation to give disabled people rights with regard to access to goods and services, employment and education, barriers still exist. There appears to be no external monitoring and limited funding to aid business in meeting their requirements, particularly regarding access to goods and services. The phrase "reasonable adjustments" often means that if the adjustments are beyond the financial means of the business, they do not happen because there appears to be no central, sufficient funding for adjustments, or because people do not know how to access funds. Therefore, the service and premises remain inaccessible.*</p> <p>There also appears to be no robust central monitoring to ensure that businesses are actually investigating their legal duty, or behaving in a way that is acceptable to disabled people (eg workmen blocking pavements and not providing a ramped and safe route around their work). Therefore, it is left to disabled people to bring about ad hoc legal action to ensure that Equality legislation is enforced in this area. Clearly this is unfairly onerous on disabled people, who often have limited energy and do not want to spend every outing that they engage in as disability monitors, ultimately resulting in legal action against service providers and businesses. Other barriers that exist are the cost of services, equipment and maintenance of equipment, where this cannot be provided through social services or the NHS.*</p> <p>2.The reassessment of everyone, periodically, is proposed. But many conditions and disabilities are congenital or incurable and relatively stable. It would appear to be unnecessarily bureaucratic and expensive to reassess people in this situation.*</p> <p>3.One of the main problems for disabled people in terms of cost is that they do not have the choice of services that other people have, so may not be able to access the cheapest services, as they are inaccessible. For example, when holidaying, the most affordable accommodation is often inaccessible, or the most accessible local taxi company is an expensive one.*</p> <p>Also, it is not practical for people with mobility impairments to live too far away from work and services, which means that they will need to live close to town centres, which will be more expensive in terms of rent and mortgages. Taxi fares through Access to Work can only partly address this, as people with mobility impairments often experience continence</p>

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		<p>problems as well, which will make regular car journeys at rush hour in congested traffic, extremely difficult for them.*</p> <p>There are some services that are much more important to disabled people than non-disabled people, for example, taxis, equipment and aids and associated maintenance costs, someone to help with cooking, cleaning, changing bedclothes, ironing, general housework, shopping, computer services (the internet can be a lifeline for people with some disabilities) childcare and accessing children's groups and activities.* Disabled people can be unable to work full time and this, together with their extra living costs, can be problematic. DLA can provide valuable assistance with this.*</p> <p>4.The question of whether people will understand the system better if there are 4 rates of pay rather than 5, seems rather redundant. Care must be taken to ensure that those on the middle rate care allowance are not suddenly moved to a lower rate and find that they do not have enough money to cover the costs of their care. Any resulting system must meet the needs of disabled people and not be changed purely to make it easier for administration purposes.*</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 applying?*</p> <p>Generally, it is best to make sure that an individual's needs are met, as people's needs will differ, depending on their individual circumstances. However, if the results of a particular disability are reasonably universal, it may be appropriate to have automatic benefits for these. *</p> <p>6.Throughout the consultation document, reference is made to those in "greatest need". However, how this is identified and weighted is not stated. Care must be taken to ensure that arbitrary decisions are not made by those who think that some disabilities result in greater need than others. For instance, mental health conditions have long been a "poor relative" in terms of being understood as a disability, but the results of living with a mental health condition can be just as difficult as with a physical disability, if not more so.*</p> <p>Also, care needs to be taken that not only those with the "greatest need" receive a payment. There are different levels of need and all of these should be taken into consideration.*</p> <p>The activities essential for daily life, apart from those essential to staying alive will depend on the individual and will include their access to work, study, social activities, medical care, and looking after their home, self and families.*</p> <p>7.It is important that, apart from taking into consideration how the condition affects someone from day to day, that the overall effect of a fluctuating condition is considered. If a person is deemed to be unreliable because their unpredictable and fluctuating health makes sustained work difficult, they will struggle to hold down a job or maintain a level of study, make regular appointments, etc. How disruptive is their condition to their lives overall?*</p> <p>8.The fundamental difficulty with this premise is that while aids and adaptations may improve the life of a disabled person, they will never remove all the barriers that exist and make their lives as they would be if there was no disability. A wheelchair will certainly improve mobility for a person with limited walking capacity, but that person will still depend on all businesses and services making adaptations to their property and services to enable the disabled person to use them. Using trains will always be difficult until all of the stations are made accessible and the trains are all ramped. Using taxis will always be difficult until taxi drivers will not refuse to pick someone up who has declared that they are a wheelchair user. Adaptations and aids may remove some barriers, but will never be able to remove the ones that are dependant on the behaviour of other people changing.*</p> <p>Therefore, the premise that DLA should take into account any</p>

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		<p>adaptations and aids that a person has is fundamentally flawed and unnecessarily bureaucratic.*</p> <p>A person's DLA should not be dependent on whether a person accesses the help and adaptations that might be available. They should be made aware of what these are, but it should be their personal choice whether they access these things or not. Personal will and individual freedom to make one's own choices should not be related to whether a person has a disability or not. It should be respected as an individual's human right. After all, the new name for DLA will be a "Personal Independence Payment". Therefore, it should promote personal independence.*</p> <p>9. The questions could be designed so that the claimant does not have to keep repeating themselves. At the moment, the form appears to have been structured for the benefit of the assessor only.*</p> <p>Improve information available at all GP surgeries and hospitals, CABs, disability organisations, HE disability offices and schools, for example – a short leaflet, well distributed.*</p> <p>10. Medical professionals involved with the person's care and treatment, other non-medical professionals involved with the person regularly, people who live with them or see them regularly, such as family and friends.*</p> <p>11. This can be a very intrusive and upsetting experience. Any assessors must be well trained and sensitive. They need to be aware that some people may not fully realise how their lives have changed over time and may "play down" any difficulties as a result. There is also the problem of the disabled person being unable to fully articulate the problems that they experience on the day of the assessment, eg because they have a fluctuating fatigue condition such as ME or a mental health condition, such as bi-polar disorder.*</p> <p>Are there any location? This currently happens in a great deal of cases. It might be inappropriate for those who experience great anxiety with formal situations, such as people on the autistic spectrum or those with mental health disabilities.*</p> <p>12. Evidence and guidance should come from medical and other professionals who know the person and see them regularly (GP, specialist, social services, carer organisations). Guidance will need to be given to these people, to prevent them being unnecessarily burdened and so that they are clear on what any trigger points are, in terms of activating the need for a review.*</p> <p>An increase in reviews will cost more to administer, as will any resulting appeals, which will most likely increase. Figures on this should be kept and compared with any amounts of money previously lost either because people didn't think to notify anyone of changes, or because there was any fraud. Otherwise, there will be no data on whether the changes to the process justify the cost of implementing them.*</p> <p>Should there be different ...condition? Perhaps assessments could be offered by telephone, email or Skype.*</p> <p>13. Annual prompts by email or letter would help with this. There is no evidence in this paper that the system will be easier to understand, but if it is, that will be positive.*</p> <p>Are figures available on the instance of fraud? If it is not common, the provision to financially penalise people for not informing the government of a change in circumstances could be costing more than before for no conceivable benefit and could lead to some unjustified difficulties to vulnerable people, leading to an increase in the cost of dealing with these mistakes and causing unnecessary distress to disabled people. The consultation paper itself, recognises that people often don't recognise gradual changes that are taking place.*</p> <p>14. Helpful information would be: *</p> <ul style="list-style-type: none"> • where to access further assistance through health services and local support and national disability organisations, such as RADAR. * • Advice on how to alert people about any legal miscarriages, failure by

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		<p>businesses to fulfil their legal obligations around access to goods and services, employment and education, where to find standard letters addressing some of this. *</p> <ul style="list-style-type: none"> • Information on other benefits.* <p>15. People may not access advice and support because of their disability. For example, a fatigue condition, mental health disability or being on the autistic spectrum may present barriers to them doing this. They may also be working full time, have children and just be very busy. This goes back to the point raised in response to q8. While information should be made available to people, it is their fundamental human right to make a decision on whether or not they access that support. Some people may have a very good reason for not accessing the support, some may be prevented from doing so because of their disability or personal circumstances, and it is important that they are not penalised for this. Advice and support should be offered but not insisted upon.*</p> <p>If the advice and support given recommends the purchase of goods and services, then the danger is that the government is channelling a person's individual finances in a way that suits the government best. They could be giving the impression of freedom by providing financial support, but actually attempting to control where that money is spent. This would limit an individual's personal choice and independence.*</p> <p>16. This could be helpful, if a large purchase, such as a powered chair is needed.*</p> <p>17. Children might "show off" at assessment, so it is important that this be recognised as not typical of their abilities and daily life. Remember that disabled parents have extra needs too, particularly if they have disabled children.*</p> <p>18. Passporting to the blue badge, parking permits for carers, access to grants for insulation and warm front grants are vital for some people. The motability scheme is often a lifeline.*</p> <p>19. See answer to question 18. Without the blue badge scheme and motability, mobility would be very difficult for people with problems in that area. Without carers' parking permits for regular visitors (where evidence of DLA can be requested by local councils), it is very difficult to get enough parking permits when you live in an area of restricted parking.*</p> <p>20. More sharing of details such as medical information and personal details between necessary depts would cut down on the need for the disabled person to repeatedly fill in forms with the same information. Consent to share should be sought from the person, before this is done, so that they know who has their personal information.*</p> <p>21. People whose first language is not English may struggle with an overly bureaucratic process and with expressing themselves at a face to face assessment. Care must be taken not to alienate ethnic minorities throughout the process.*</p> <p>22. The main points of concern about this document are firstly, the proposal that British society has changed sufficiently to include aids and adaptations and the difference these make to people's lives when assessing a person for DLA. DLA is a payment that is made to people to take into account the extra expense they must meet because they are disabled. Having equipment such as a wheelchair does not remove the expense of this. There are maintenance costs associated with much of this equipment. Also, disabled wheelchair users will still not be able to access goods and services to the extent that non-disabled people do and hence be able to make choices based on cost to the same extent.*</p> <p>Although the law has changed, the majority of small suppliers of goods and services have not made themselves accessible. More monitoring of this and funding for businesses who cannot afford to make changes should be made available.*</p> <p>Secondly, the repeated reference to getting funding to those with "greatest need". Other people may have need, but not the "greatest". Will these people be penalised? What criteria are used to assess "greatest</p>

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		<p>need"?*</p> <p>Thirdly, the reference to fraudulent claimants and the idea that people who don't inform the government of any changes should be penalised. In this very document, it is stated that people often don't recognise gradual changes that happen to them and so don't inform the government. How will this be assessed? Also, there is no information on how much fraud is actually costing the government with regard to DLA and how this is balanced against the proposed costs of changing the process to prevent this.*</p> <p>Fourthly, the proposal to have regular reassessments for all claimants, regardless of whether their condition is a life long, stable one or not. It is to be questioned whether the cost of introducing this will be outweighed by the benefits. It may cause unnecessary anxiety for vulnerable people, particularly those with conditions that are prone to debilitating anxiety. There will probably be an increase in appeals against decisions, which will be costly to administer and cause further anxiety. This will need to be monitored closely, along with all changes, and assessed for fairness toward disabled people. We look forward to seeing regular reports on this.*</p> <p>██████ ██████.</p>
EM468	11-Feb-11	<p>Hi, I can't see which question these comments would be applicable to, but thought they were important.*</p> <p>I think there is an important distinction between mental and physical health problems. I have the misfortune to suffer both (depression and multiple sclerosis) and receive care and mobility components of DLA. the payments are invaluable in helping me manage and limit the effects of the MS but have no impact on the depression. If there is a need to reduce the overall cost of disability payments then surely it would be most effective if physical impairments had priority over mental ones. *</p> <p>I have spent time attending a mental health day centre and almost without exception everyone received high rate care DLA - the justification being that there was a need for constant supervision. The reality was that the money was usually spent on alcohol, cigarettes, and drugs. If someone really needed constant supervision they are unlikely to be living independently. *</p> <p>I am very unhappy that people with physical conditions might lose vital financial support that makes a real difference to their lives when it would be easier and more justified to cut payments to those who have no real need of the support. I need convincing that you can attribute significant extra costs to living with mental ill health. I hope that somebody takes the time to look into this.</p>
EM469	11-Feb-11	<p>I have been disabled since birth with Spina Bifida. After attending government-run special schools until the age of 16 I was then provided with an invalid carriage. As time passed this was exchanged for Private Car Allowance, which became Mobility Allowance, then DLA. My letter of entitlement to DLA says that it has been awarded for life. My disability is such that it will never improve and will, indeed it has already, become worse as I get older. The consultation document, as far as I can see, doesn't make it clear what will happen to those recipients, like myself, who are currently in receipt of DLA for life and will be over 64 when they have to apply for PIP. This concerns me as I will probably be over 64 when I am invited to apply and fear that I will automatically be rejected on age grounds. DLA is currently a passport to other essential benefits, ie free road fund licence and, because I am a wheelchair user and need hand controls, VAT exemption on the purchase of a new car. I think the legislation for PIP should include a clause that for DLA recipients who a) have been awarded DLA for life and b) will be over 64 when they have to apply for PIP the age restriction and qualifying periods will not apply.</p>
EM470	11-Feb-11	<p>1. First and foremost it is not possible to lump all disabled people together; my particular concern is with people affected by multiple</p>

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		<p>sclerosis. There are many different symptoms of this disease, and its fluctuating nature means it is often hard to predict how some-one with MS will be on any particular day, or indeed part of a day. It is sometimes possible to participate in mainstream activities, sometimes not. Those with obvious problems with mobility will have the usual difficulties regarding access and public transport, but those with more hidden symptoms will be equally disadvantaged. Despite the Disability Discrimination Act employers are loth to employ some-one with a diagnosis of MS – even though many of us might be capable of working at least part-time. Work has, however, had to be abandoned by many more. Fatigue which almost closes down ones cognitive function at the drop of a hat, and can make it impossible at times to complete a task one has started, is one of the hidden symptoms which can devastate peoples' lives. Pain, as well, is a major factor for about 40% of people with MS. Incontinence is common, often meaning people are uneasy about going far from access to a toilet. Tremor can mean frustration and humiliation for people trying to eat and drink, meaning eating and drinking in company is too humiliating to contemplate. Memory problems can make word-finding difficult – often causing great impatience and frustration in the person with MS and a listener. Clumsiness and poor balance erode confidence and make it hard to manage in unfamiliar environments. Stumbling and falling can happen anywhere. In other words, with MS the very condition itself can act as a barrier to participating fully in society*</p> <p>2. I feel it is essential that the application for DLA should remain flexible enough to enable people with MS to explain how their symptoms affect their day to day life. Again the very fact of being diagnosed with MS does not mean we are all affected exactly the same, and generic questions must give the opportunity to explain the problems peculiar to them. The ESA questionnaire has been found to be inadequate in many cases for people affected by MS, and there is huge concern that this might be the case as well with DLA*</p> <p>3. People with MS may have extra costs re: transport. Fatigue means that even those who apparently have little problem walking cannot walk far, and certainly can't carry out any tasks after walking. Any grants for extra adaptations in the home will have to be means-tested, and savings can be decimated paying for these and for mobility aids. Accessible accommodation is often more expensive than that in the mainstream. For those with problems of incontinence the appropriate pads have to be bought. Heating costs in the home can be much higher for people unable to keep warm through normal exercise; if household tasks and household maintenance can't be managed these have to be paid for. Frequently extra aids are necessary – rails in the bathroom or outside; a mobility scooter or wheelchair or walking aid; a car to enable some-one to leave the house; special cups and straws to allow drinking without spilling; stairlifts when balance can permit transfer on and off – and all these cost money. DLA as currently administered has helped with these costs and has been a vital lifeline to people with MS. *</p> <p>4. The fact of having different levels of DLA - two for mobility and three for care -has always been quite complicated, with certain abilities or factors triggering a certain level. I don't see this changing. People applying for DLA are advised to seek the help of a specially trained benefits advisor and are currently overwhelmed by the way questions are worded. I cannot see this being different in the future. However the questions are worded and whatever the evidence sought, people with MS will require outside assistance to truly convey the nature of their condition and the problems it causes in their day to day life. My experience is that people tend to minimise rather than be realistic about their difficulties, and need support to describe things as they really are. I fear that there could be a risk that a new type of application may lead to an inaccurate description of the effect of MS, with people missing out on vital financial support as a result. *</p>

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		<p>5. With the appropriate consultant neurologist confirmation that a person has a diagnosis of MS I feel that this should trigger an automatic entitlement to the benefit. I hope I have demonstrated above how many areas of the life of a person with MS are affected, even when symptoms are not always apparent. This is a progressive, lifelong condition, and everyone affected will have some symptoms with which they are struggling, and which may mean they are incurring extra costs. *</p> <p>6. This question seems to indicate that there may be a desire on the part of the government to remove support from those who seemingly are not badly affected in their daily life. If we look at the social model of disability questions regarding physical access to transport, buildings and outdoor facilities are extremely important, and there is work in progress as a result of the Disability Discrimination Act. If we look at Maslow's Hierarchy of Needs there is no difference in the needs and aspirations of people with disabilities and those without – in other words one starts with basic physical needs such as warmth, food and shelter and then moves towards the possibility of each individual choosing a way of life over which he/she has control. The ability to participate in work is important for stimulation, self esteem, social interaction and finance – but some people affected by MS simply are not able to commit to a regular work pattern, or paid employment in any way. As a former chairman of a large branch of the MS society I have had occasion to speak to many who have had to give up paid employment, and I've not met one who would not want to be working if their condition allowed it. *</p> <p>7. MS falls into this category. People affected by MS cannot predict the days and times when their symptoms will be worse than at other times – but we have found it helpful to keep a diary, logging exactly what our symptoms are at any given time. I am concerned that a medical assessment will not be able to take into account the anxiety and stress caused by the uncertainty of a fluctuating condition, particularly as everyone affected by MS is affected differently. *</p> <p>8. If people have aids and adaptations these are there to facilitate some aspects of daily living, but do not take away the problems caused by having an impairment in the first place. These aids also have to be paid for, and depending on the progress of their condition may not be appropriate permanently. I feel strongly that the fact of having aids or adaptations should not replace eligibility for DLA. *</p> <p>9. The claim form could be more appropriate if there were more open questions rather than the type of questions which exist at present. For example a section might ask 'how is your walking affected?' rather than 'How long is it before you suffer severe discomfort?' I cannot see that completing a form to claim disability benefits could ever be a positive experience – as a person with MS and as a CAB adviser who has helped many people my experience is that completing the form makes people confront the problems caused by their condition, and can be very distressing. The fact of being able to claim DLA, however, at least makes people feel that society recognises the fact that disabling conditions bring with them extra expenses. *</p> <p>10. Frequently GPs are not aware of the day to day difficulties people with disabling conditions such as MS experience. Applicants should have the choice of who is contacted; in the case of MS a specialist nurse, consultant or physiotherapist might be appropriate. Patients will however have had contact with different people in different areas, and there must be flexibility in who is approached. I am very concerned that it is suggested a DWP medical assessment should be carried out in all cases. My experience is that a generalist medical assessment will not be appropriate for people affected by MS since the potential questions may not tease out the particular difficulties experienced by individual patients.*</p> <p>11. A healthcare professional covering all types of DLA application cannot possibly have the in-depth knowledge and understanding of every condition. GPs may see very few patients with MS and this could be the</p>

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		<p>case with a doctor employed by the DWP. If appropriate medical evidence can be provided by specialist healthcare professionals involved in a patient's care there should be no need for a separate medical interview carried out by some-one who is not expert in that condition. *</p> <p>12. It should be recognised that MS is a lifelong condition. People are likely to get worse, not better, and the distress and stress caused by carrying out reviews intended to see if some-one's eligibility for DLA has ceased is enormous. It is already a big enough burden to be diagnosed with MS; people affected by MS can do without having to prove again and again over the years that they need their DLA *</p> <p>13. Again with a fluctuating condition such as MS one never knows how the disabling effects will manifest themselves on any given day. If some-one has a good period and contacts the DWP to report it the very next day he/she could be in bed suffering a major relapse.*</p> <p>14. Claiming disability benefits has in the past proved complicated and time-consuming. In my opinion specialist help and advice through organisations such as CAB will continue to be vital.*</p> <p>15. This question is not clear. I don't know whether you are referring to claimants who don't report a change of circumstances or potential claimants who are deterred from claiming in the first place.*</p> <p>16. There is no one answer to this. Those with savings above a certain amount will have to fund their own aids and adaptations – and Disabled Facility Grants are means tested. Some aids, but very few, may still be provided by the NHS or Local Authority. If DLA mobility is intended to help with getting out of the house, and DLA care is to help with extra expenses with personal care it seems unreasonable that there should be a definite expectation that it should be used towards aids and adaptations. One of the advantages of the current system, however, is that claimants have choice and control over how their DLA is spent, and it can therefore meet the aims of the personalisation agenda.*</p> <p>17. I feel the key differences to take into account should be the differing levels of development and need for supervision in a child with a disability.*</p> <p>18. The passported benefits are helpful for people receiving DLA – but if DLA is removed for any reason the effect of removal of other benefits and services can be disastrous, slashing a claimant's income by far more than the DLA itself.*</p> <p>19. Income for people with disabilities needs to be the equivalent of a living wage. If that can be achieved it doesn't matter how it is made up.*</p> <p>20. The ability to work and the effect on ones life of having a condition such as MS are quite separate, and should not be confused. *</p> <p>21. I don't see that the proposals have a particular impact on the different equality groups.*</p> <p>22. No</p>
EM471	11-Feb-11	<p>Dear Sir/Madam, I cannot reply because I do not have PDF on my computer, however I would like to say that people over the age of 65 should not be subject to assement, Situations vary and Ive only just found out about this consultation period through Mobilise a charity organisation working for the disabled. When the age of retirement goes up in 2018 I,ll personally be 72, Im disabled as it is and my wifes carers money was taken away when she retired because her pension was higher than the carers allowance yet she is sttill supposed to look after me 24/7 I feel that the government or whoever is responsible for this consultation should have sent out forms to all the disabled but they didn't?</p>
EM472	11-Feb-11	<p>Dear Sir, I would like to add my voice to the protesters who are outraged at proposed cuts for those genuine people who are already disadvantaged by their medical conditions. One only needs to witness them on TV to realise their authenticity. Cuts need to be made in other departments before this! Yours sympathetically,</p>

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EM473	11-Feb-11	To whom it may concern, I wish to register my dismay at the Governments proposal to abolish DLA and replace it with means tested PIP. Although I'm sure the present system is abused by some, it is surely unnecessary to assess annually those suffering from untreatable progressive conditions, proposed under PIP I understand. These people have enough to put up with just trying to live without the insulting requirement to fill in forms to justify their need. People unfortunate enough to suffer in this way are surely entitled to on-going support at present provided by DLA on a permanent basis.
EM474	11-Feb-11	<p>I have filled in what I can but as an individual some of the questions are beyond knowledge.*</p> <p>1.Your response: Mainly Mobility, and the cost to the individual.*</p> <p>2.Your response: All of it, but made simple to understand, as at present, you get it as long as you tick the right boxes in the right language.*</p> <p>3.Your response: Personally I have a powered wheelchair, a manual wheelchair, a triwalker, a stair lift and a Motability car. *</p> <p>4.Your response: you have 5 rates at the moment, so losing one will not make a lot of difference. Making the application easier would be a help.*</p> <p>5.Your response: All claims should be based on individual needs.*</p> <p>6.Your response: Being able to do anything that a non disabled person can do is the most important thing, being able get to sporting arenas, pop concerts, visiting relatives, or even getting to work.*</p> <p>7.Your response: occasional re assessment if needed.*</p> <p>8.Your response: No*</p> <p>9.Your response: I am only an individual person, Having gone through the process myself, some of the questions asked were to be quite were downright stupid. Why not have an interview panel with the disabled person and their medical history so that they or a representative can answer any questions there and then.*</p> <p>10.Your response :Medical assessment taking into account Medical History and not just one Dr's opinion that can be told how many to allow in any one period.*</p> <p>11. Your response: Please read answer to Question 10.*</p> <p>12.Your response: Not suitably qualified to comment on this question.*</p> <p>13.Your response: could you not make enquiries on a regular basis, say once every one or two years from the patients GP ?*</p> <p>14.Your response: Lots, personally I have used Age UK.*</p> <p>15.Your response: Did not understand the Question*</p> <p>16.Your response: When I was working I paid for all adaption out of my wages now I am retired I cannot afford to buy anything, the main cost that I have or should I say benefit, is my Motability Car which is my essential lifeline to the outside world.*</p> <p>17.Your response: Not suitably qualified to comment on this question.*</p> <p>18.Your response: Not suitably qualified to comment on this question.*</p> <p>19.Your response: Not suitably qualified to comment on this question.*</p> <p>20.Your response: I personally have no problem with my details being shared by suitable agencies.*</p> <p>21.Your response: Not suitably qualified to comment on this question.*</p> <p>22. Your response: Now we come down to the nitty gritty of how I feel that these changes will affect me as a disabled person. I have had DLA with the higher rate mobility allowance for about 10 years now, and which is used to obtain a mobility vehicle, and the lower rate for home care for about 2 years. If I were to be re asessed and because of financial restraints I lost that Mobility car I would be constrained to stay at home and never go beyond my local shops. I could not afford to buy a vehicle on my pension and the loss would also mean that I would be restricted in seeing my grand children as often as I would like, even though they only live 13 miles away.*</p> <p>*</p> <p>The only problem with DLA as it stands is enforcement. Or lack of it, on abuse of the system. Time and time again I read that someone has been</p>

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		falsely claiming the allowance and they get their wrists slapped. There must be thousands of disabled people who see this happening every day and living in despair as to what this country is coming to.
EM475	11-Feb-11	<p>Dear Madam/Sir, My comments on the Benefits Reform paper are as follows: *</p> <p>1) I appreciate that something has to be done to reform the benefit system. Can I say, though, that those who are going to be hit the hardest are disabled persons, many of whom have a low income as it is. So if you take away the majority of what disabled persons receive via their Mobility and Care components of the DLA benefit, many disabled persons will find themselves with virtually no income at all. *</p> <p>2) One of the reasons for the above is that a great majority of those who receive the Care component of DLA and have now to apply to already over-stretched Local Authorities for a personal care budget, will decide not to do so. The reason being is that this DLA Care component has been given to their carers and those Carers, in my case my wife, have known exactly what to spend the money on to help me. Further the Disabled persons have been used to waiting no time at all for those essential care requirements. Disabled persons and their carers without meaning to be, are proud people who actually don't like to complain. So rather than applying for a Local Authority Care Plan, they will stay completely quiet and simply not apply for a LA personal care budget at all. *</p> <p>3) Visually impaired persons are soon, after a long campaign, to be able to apply for the DLA Higher Mobility rate. However this Higher rate is only going to reach them, and within a very short time, if the present plans go ahead, Blind persons will either have this DLA Higher Mobility component completely removed, or it will be substantially reduced.*</p> <p>4) I therefore suggest that the plans to change the DLA benefits as they now apply, should be more gradually phased in by the Government, so that disabled recipients might be given the chance to have what exactly is proposed in the way of substantial cuts to their incomes, fully explained to them and why exactly their benefits are being greatly cut or in some cases, completely removed from them. It always fills me with real satisfaction that it was a Conservative Government who introduced DLA in 1992. And as someone who has appreciated the compassionate nature of this benefit, I find it hard to understand why, it is now to be removed.*</p> <p>5) I am also one who appreciates everything that Ian Duncan Smith has done over recent years and therefore feel persons who have been long-term unemployed should form the Government's main thrust of the Benefits Reform agenda. As one who left school as a 17 year old in [REDACTED] and worked hard and long hours to keep up with my fully sighted colleagues, after losing my sight when 19 years old, then continuing in work for a 38 year total, unemployment is the area I feel should form the first phase of Benefit Reform. *</p> <p>6) As said above, I applaud Ian Duncan Smith's work amongst those within deprived areas in our country where there are thousands of unemployed. So, as one who can say work motivates, satisfies, and pays many unseen 'dividends', long-term unemployment is the first area the coalition Government should devote their main efforts towards, within their Benefits Reform programme. *</p> <p>7) I therefore respectfully ask that the long-term unemployed be given every bit of encouragement possible to gain work, as I know this will greatly raise their self-esteem and at the same time, it will make a substantial contribution to lowering our ever-growing serious drugs culture. This is because many who are long-term unemployed in our country have, for many years, been unable to engage in any form of employment because of their long-term drugs dependency.*</p> <p>This is all I would wish to say regarding the Government's Benefits Reform programme and would respectfully ask that you seriously</p>

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		consider the points I make above. Thank you. Yours truly,
EM476	11-Feb-11	<p>1. Your response: Educating people (Joe public) to understand the difficulties faced with Autism*</p> <p>2. Your response: We do not want changes*</p> <p>3. Your response: Child care, respbite care and short breaks*</p> <p>4. Your response: Confusion?*</p> <p>5. Your response: Yes Autism is a life long disability, the Autism will never go away. it is very complex and full training is needed to understand this.*</p> <p>6. Your response: inclusion*</p> <p>7. Your response: Please see comments below*</p> <p>8. Your response:*</p> <p>9. Your response: Please see comments below*</p> <p>10. Your response: Consultant report*</p> <p>11. Your response: Please see comments below*</p> <p>12. Your response: No reviews needed when you have a life long disability*</p> <p>13. Your response: 14. Your response:*</p> <p>15. Your response: yes*</p> <p>16. Your response: We have to apply for charity funding or do without*</p> <p>17. Your response: Please see below*</p> <p>18. Your response: 19. Your response: 20. Your response:*</p> <p>21. Your response: Please see below*</p> <p>22. Our response: *</p> <p>I run a support group containing 65+ families, for Adults/ children living with Autism/Aspergers syndrome.*</p> <p>Their responses to the proposed changes to DLA are as follows;*</p> <ul style="list-style-type: none"> • Forms are repetitive and take a long time to fill in.* • They do not give a clear picture of the Adult/ childs condition.* • DLA does not take into account the effects of the childs disability on the parents and siblings, more funding is needed to support siblings.* • The home assessment would not give a clear true picture for this disability as our children have particular difficulties (social interaction, sensory difficulties and behaviour problems, they behave very differently in different settings.* • The changes that are being made are unrealistic. You cant judge a child with Autism/Aspergers for a short period of time and expect to be an expert. What sort of experience in this disability will the assessors have?* • The whole situation and changes that are being made are absolutely ridiculous and totally unfair, we have been through enough with all the form filling and now you are putting more stress on an already stressful life, those which are already claiming DLA should be left alone. Why cant you start these changes to new claimants?* • The forms to claim disability allowance don't take into account the mental incapacities of the children and their inability to find employment as an adult.
EM477	11-Feb-11	<p>1.Your response: Too many barriers are subtle, so for example our son couldn't go to after school clubs as they didn't have the extra support he needed. *</p> <p>2.Your response: As it's difficult for any ordinary person to understand how and why they receive DLA, it is hard to say whether or not anything should stay the same. I have applied twice for DLA and a simpler form and a rate which reflected the actual difference in cost would be helpful. *</p> <p>3.Your response: I'm only going on our own experience with our son, but extra costs for us include:*</p> <p>Paying extra for 1 to 1 sports lessons so he can take in the rules of play which he struggles to do in a group setting*</p> <p>Damage to the house, all our belongings, all his belongings*</p>

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		<p>Finding suitable activities to entertain him as he struggles to entertain himself for more than 15/20 minutes*</p> <p>Electronic games/remote controls need to be sturdy, as can be easily broken, so additional protection and frequent repair bills can add to costs*</p> <p>Finding NHS therapy is like finding Hen's teeth and the demands made upon the family by NHS staff are often unreasonable, so we've resorted to getting private therapy from a qualified NHS children's clinical psychologist who helped write the NICE guidelines which our local child psychology team wouldn't follow. This is £135 a session plus transport costs, and is needed at least twice a month and this is really galling as we should get this provision free, but it is the cost we pay for having a child whose 'disabilities' don't fit neatly into our local NHS trust's policies.*</p> <p>4.Your response: Our fear is that this could penalize children whose needs are not being provided by NHS and that the lower rate will be applied more often due to budget requirements and as the rates are pitifully low at the moment and don't cover the extra costs of having a child with disabilities, this is of great concern.*</p> <p>5.Your response: Whilst all claims should be based on the needs of the claimant, there should be a basic and transparent level of disability that means, as long as it is backed up by medical expertise, people with disabilities can get an automatic entitlement as it helps cover extra costs. So a person with a disability should not be worse off due their disability costing them much more.*</p> <p>6. Your response: This question suggests you don't want to pay for support for all people with disabilities. It is not about prioritising, it is about providing adequate support for those in need. A range of activities are always necessary and though things like trips, support in sport may be seen as luxuries, these activities support the person as a whole and without them there would be more need of expensive drugs to combat social isolation.*</p> <p>7.Your response: By getting appropriate advice from professionals with expertise in those areas. *</p> <p>8.Your response: Aids and adaptations are expensive and often need replacing/updating and with recent cuts in services these may be difficult to get hold of, so provision should be made for DLA to cover the costs of these aids. Anyone who thinks these aids are easily obtainable clearly doesn't use these services.*</p> <p>9.Your response: Information about previous claims could be stored and sections which don't apply could be listed at the end of the form. Claimants could then be asked to note any changes, rather than completing a new form with many of the same details. One way of improving information is to actually publish the criteria for it. *</p> <p>10.Your response: Consultants and Social Service staff and Parents/family*</p> <p>11.Your response: Whilst for benefit cheats, an interview where they can 'blag' their way into benefits may not be too much of a hurdle, for many self-deprecating, self-deluded people, they will say 'there's nothing wrong that I can't sort out' . So genuine people with disabilities, particularly those with mental health issues will not get the support that is necessary for them to live their life and will end up getting into debt. For these people a meeting should be arranged with their own healthcare professional as well as the Benefits healthcare professional.*</p> <p>12.Your response: If the condition is a lifelong one, then reviews should be kept as simple as possible and involve the professional involved in the care of the person with disabilities*</p> <p>13.Your response: By making it easier and not reducing the benefit drastically for a slight improvement. Or by setting a specific time frame, so that each year claimants notify you of any changes rather than every single time something minute happens in their lives – it's difficult enough living with a child with disabilities without worrying each time your circumstances change slightly you could be in breach of the new benefit</p>

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		<p>rules*</p> <p>14.Your response: People need to be aware of how and why the benefit is paid*</p> <p>15.Your response: The requirement to access advice and support is more likely to put people off, but it should be provided for those who wish to use it and having locally based staff who can help in welfare benefits centres and other places like hospitals or libraries might help*</p> <p>16.Your response: The problem with one off costs is that they are not 'one offs. Aids and adaptations are continually changing and need updating and so those people who need aids and adaptations will need more than a one-off payment to cover this.*</p> <p>17.Your response: children do not perform well in front of strangers and so a 1 to 1 assessment is not likely to give accurate results*</p> <p>Teenagers want to be the same as everyone else and so will deny that they have any issues and so not get the support they need to help them enjoy life like other teenagers.*</p> <p>18.Your response: No information was given to us about the other services available for our son, so it has mainly been by talking to other parents and sometimes a professional that we have gained additional services. A list of local services provided by the NHs would be helpful, but our local trust responded to my request made in October 2009 by referring me to various individuals but not providing a list of services as requested.*</p> <p>Other services like Free transport, support with council tax, information on Disability discrimination and offers for people with disabilities at leisure attractions eg:cinema, Alton Towers would also have been useful.*</p> <p>19.Your response: As we currently find we have had to explain each time we use a different service, the most useful identification has been the Goldcard transport card as it has identification and is wallet sized. So assuming this was still the case the Goldcard would be our main means of identification and if necessary backed up by official letter.*</p> <p>20.Your response: Social services, Mental health services and DLA could be linked *</p> <p>21.Your response:*</p> <p>22.Your response: Our main concern is that mental health provision is already patchy around the country and this new benefit could be seen as a way of getting people with disabilities to pay for their own therapy and their own aids/adaptations and social services prioritise those most in need so rather than providing the services required by people with disabilities as part of their budget, they will charge people with disabilities for any services they use, claiming that individuals now have control over their own budgets and so must pay for services that were previously free.</p>
EM478	11-Feb-11	<p>1. Those disabled people who do work generally occupy low paid employment. They experience prejudice when applying for either promotion or higher paid posts. There are individual exceptions to this but they do not reflect the experience of the majority. Low income is a barrier in itself and limits the opportunity of the disabled to participate in society and lead independent lives. Even those currently in receipt of DLA cannot do this where they are either unemployed or on low pay or considered unemployable by industry. This is all identified in the social model of disability.*</p> <p>2. The recognition of the fact that all disabled people face challenges in their lives.*</p> <p>3. Disabled people spend more time at home and suffer many conditions that make them susceptible to the cold. Home heating costs have become a major spend and the trend is for this to continue. Multi-item repeat prescription medicines are a regular expense. The NHS offers aids that are basic and frequently the cheapest option. Improved aids are expensive but often prove to be a better investment with regards to improving the quality of life experienced. Disabled people can also be compelled by their conditions to follow strict diets that require them to buy</p>

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		<p>foods that are more expensive than everyday products.*</p> <p>Public transport is free in some instances but bus stops are not always convenient for either the beginning or the end of a journey. In icy weather the bust stop at the end of the street becomes unreachable for me. Taxis have to be relied upon in bad weather or where public transport does not offer a drop off point close to the destination but their costs are being driven up due to fuel prices.*</p> <p>4. Clearly limiting the benefit to two components of two rates will make it easier to understand and cheaper to administer, although claiming that it will ensure appropriate levels of support is supposition as the rates have not yet been identified. The proposals claim that people will be dealt with on an individual basis but for those found eligible actual support will be delivered in a strictly uniform manner limited to the two components and two rates mechanism. This does not reflect the unique and individual circumstances of the disabled person. The proposal is more concerned with making the benefit easier and cheaper to administer than with actually meeting the needs of the disabled. The diversity of the disabled is acknowledged in the assessment process but not in the delivery of the benefit where two sizes are seen to fit all cases.*</p> <p>5. There are some health conditions that are known to be either incurable or have only limited treatment available. Where health professionals establish that such conditions are always likely to qualify for the PIP then it seems pointless duplication to insist that everyone suffering from such conditions goes through the same full assessment procedure when the end result is predictable. Accepting that some conditions will result logically in eligibility will save time, money and workload. It should not be seen as an easy option but the application of commonsense.*</p> <p>6. Is the benefit aimed at disabled people or only a section of the disabled community? In the preamble a particular group referred to as 'disabled people' is talked about but this changes to another group referred to as 'least able' or 'most challenged', and then back to 'disabled people' again. Are they one and the same? Some clarity in definition would be appreciated.*</p> <p>If the proposal is accepted as stated then it is supposedly able to identify which applicants need the most help, even if this help is limited to one of two rates from one or both components. Clearly the criterion for eligibility is going to have to be broad as the diverse nature of disability has already been acknowledged, however, the limited structure of the benefit itself would seem to work against a system of prioritisation as it is so inflexible. If the criterion for eligibility was set to reflect only the needs of the 'most challenged' then this would answer the question, but it would also exclude all those disabled people who are still challenged by everyday life and still less able than able-bodied people. Their fate would be one of social abandonment.*</p> <p>What is everyday life? This is thrown out as a vague concept with an assumed definition. The proposal accepts the individual nature of disabled people's experience of life. For someone with impaired mobility everyday life might be not moving around very much. This does not reflect a desire not to get about but rather a conscious acknowledgement of all the physical problems and dangers associated with moving. Social activities are essential to human well-being, whether they are recreational or vocational, which means getting out of the house. An ability to participate in society would therefore be an essential activity which will prove challenging to disabled people to varying degrees depending on the nature of their disability.*</p> <p>*</p> <p>Would severely disabled people be expected to undertake everyday life activities? Those most capable of doing so would be those most expected to desire to do so and, consequently, perhaps these should be the people offered most help as they will offer a return on the investment made in them through the PIP benefit.*</p>

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		<p>7. The assessor must have either the appropriate knowledge of the disabled person's condition or access to expert medical advice from an appropriate healthcare professional. Evidence based practice must form the foundation of all assessments of variable conditions and this can only be verified through the use of clinical experience.*</p> <p>I have previously been assessed by GP's who had no knowledge or experience of my condition as it is very rare. Their assessments were made in ignorance of scientific facts concerning my medical problems and consequently my applications failed. It was only when I presented accurate information from my own medical files that my application was accepted. Accurate information collected by those qualified and trained to interpret it correctly is the only basis for a fair evaluation in all cases, not just those of a variable nature.*</p> <p>8. Not all the aids that exist are necessarily available to a disabled person and not all disabled people want to use the aids that are available to them. As stated previously some aids are very expensive and not offered by the NHS; will the existence of such aids be considered during the PIP assessment?*</p> <p>The presence of an aid does not necessarily mean that a problem is overcome or that they are more able as a result of using it. In some cases the use of an aid, such as a wheelchair, also involves encountering many other problems. Although a wheelchair might suggest greater mobility for the user this can be illusionary, a wheelchair is easily stopped by the presence of a kerb only a couple of inches tall which makes the disabled person dependent on the intervention of someone else to get them up or down the kerb. Many aids have only a short-term beneficial effect and become redundant as the condition progresses.*</p> <p>If aids and adaptations are to be considered then they should be in a holistic sense, that is, what benefit they provide, what further problems they might give rise to, the span of their beneficial life in terms of the progression of the disabled person's condition; no conditions exist in a steady state, they are all subject to change even if only through the aging process.*</p> <p>As all conditions have a medical origin it is to be hoped that disabled people have been educated by exposure to the NHS, or through referral by the NHS to Social Services, as to what aids are available to them. It would be a failing of the system if such help was offered only when the disabled person applied for a benefit!*</p> <p>There are many problems encountered by disabled people that cannot be rectified by a physical aid alone, they need to employ coping strategies too. As the successful employment of coping strategies can make the disabled people seem more able this might be interpreted as them being less in need of support. In truth all coping strategies are highly individual and are often the result of trial and error. As conditions progress they often need to be modified or even abandoned. When disabled people are being assessed a thorough review of their use of aids and adaptations should be made in a manner that does not negate their status as disabled people; their success in meeting challenges in their lives should not be turned into grounds for withdrawal of support. Such an action would only encourage disabled people to become totally dependent and goes against the declared intent of allowing them to lead active and independent lives.*</p> <p>9. Applying for a benefit is never going to be a positive experience in the first instance and the government do not help here by suggesting that only scroungers and the work-shy receive benefits!*</p> <p>A clear criteria for qualification needs to exist for consideration prior to application. Stating that a condition must exist for at least six months prior and six months after making an application is a good start but without further criteria to support it the status of eligibility even to apply remains vague.*</p> <p>What is the benefit really supposed to achieve? Leaving behind all the</p>

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		<p>rhetoric how is the benefit supposed to contribute to the lives of the disabled? Is it meant for consideration by all disabled people or just those in most need or facing the greatest challenges? How do you define 'most' or 'greatest'? Even in the proposal you do not make this clear! Clarity of purpose must come first, followed by honesty in terms of eligibility – you want recipients to be honest with you about changes to their circumstances then you must be honest with them when offering the benefit!*</p> <p>Ask for clinical evidence to support subjective accounts of a condition's impact and make it a statutory requirement that health professionals must provide such evidence, honestly and accurately, when requested. Allow the claimant to see the evidence if they so wish, especially where a claim has failed. It was the weakness of the clinical evidence provided by my healthcare team that led to my several claims failing but no one told me that! Once I provided the clinical evidence to support my own statements my claim was approved.*</p> <p>Disabilities are diverse in both cause and effect, do not constrain evidence by the application of an arbitrary scale, such as how far can you walk in good weather over a level, non-slip surface; these ideals seldom exist in everyday life. They do not represent the challenges that face disabled people. If you want to truly know the manner of the problems faced by each individual then treat the evidence on that basis accordingly.*</p> <p>10. Clinical evidence must be considered crucial. All disabilities arise from a physical cause, therefore, healthcare professionals must be included. Other sources where appropriate to the individual, such as; social services, carer and/or family members. Finally, the subjective experience of the disabled person themselves which would be expected to agree with the supporting evidence.*</p> <p>11. If the healthcare professional is knowledgeable as to the disabled person's condition then this will inspire a degree of trust, otherwise the disabled person can spend a large part of the interview either educating the other person as to the nature of their condition, as I have done many times, or dispelling commonly held misconceptions about their condition. The ability to talk to someone who knows what you are talking about is fundamental to establishing a positive relationship and, by extension, a positive experience. Ignorance quickly reveals itself and can leave the disabled person with a very negative experience and, consequently, no faith in the system. A series of successful appeals based on challenges to assessments made in ignorance benefits no one and will only cost more time and money.*</p> <p>A choice should be offered where possible as to where the interview takes place. I personally do not like conducting them in my own home but other people might prefer it.*</p> <p>12. Reviews should be carried out as when necessary in consideration of the complaint suffered by the disabled person. Some complaints are slow to change and should not be reviewed needlessly merely because an arbitrary number of months have passed. This would save time and money. The process should not be carried out as if just checking up on the claimant, as if doubting the veracity of their previous assessment, suspicion does not instil any faith in the system where there's no reason for it arise. Medical guidance can be sought as to the progression of most conditions and key points flagged accordingly. There can be no objection to reviews taking place when it is understood by both parties that they are a routine part of the system designed to ascertain that the disabled person's situation has not changed significantly, but that if it has to their detriment then further help will be available. If the reviews are applied with commonsense and not simply to a uniform set of intervals irrespective of the condition suffered by the individual then they will be seen as less intrusive and inspire a better compliance.*</p> <p>13. Make the instance of when a change must be reported easy to</p>

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		<p>understand. Clearly identify when this instance might occur and encourage recipients to discuss any changes with a member of staff no matter how trivial it may seem. Make communication between the department and the recipient a normal event and not something that the disabled person should worry about. Stress the positive aspects of reporting a change first and ensure that threats to punishment and/or legal action are secondary, reserved for those who knowingly seek to withhold important information. Stop making benefit recipients feel as if they will always have something to answer for.*</p> <p>14. What is the criterion for eligibility to apply and will the benefit help them. *</p> <p>15. No. Forcing people to do anything only breeds resentment. As stated previously, all impairments have a physical origin and if they are serious enough to present a physical manifestation then the individual will have been referred to a healthcare professional. It is within the clinical setting that the person, as a patient, can be referred further to receive advice and support. The NHS is already very good at this so why duplicate the effort? Tying it to the benefit is simply a crude act of coercion and is contrary to the declared objective of making disabled people independent and capable of making their own decisions.*</p> <p>16. How I spend my DLA appears to be up to me, which I agree with because ultimately I am the expert on what I do or do not need to cope with my condition! I have used it to buy various aids as and when I discovered something that might benefit me. However, if there was an aid that was of a significant cost then perhaps the ability to draw on future payments of the PIP benefit so as to be able to afford that item immediately without following expensive credit paths might prove useful. There are aids that I could use that are too expensive for the NHS to supply and, by extension, far too expensive for me to buy from my limited funds.*</p> <p>17. They have parents who are intrinsically involved with the child. Listen and value their experience and opinions; they often possess the most expert knowledge.*</p> <p>18. DLA should be important in this respect but it has not given me access to any other service or entitlement that I can think of. I had both a bus pass for a disabled person and a Blue Badge for disabled parking long before I was awarded DLA. Local council and social services recognised both my disability and the degree to which it impairs my mobility much quicker than the DWP, not the other way around.*</p> <p>19. As stated above, DLA has never worked in this fashion for me therefore I see no adverse implication for PIP. However, I think that DLA/PIP should work in the suggested fashion as not all support, benefits or life enhancing opportunities are connected. Many individuals merely stumbled across them rather than as a result of being directed. If the award of, or even just the application for, PIP initiated the move to an umbrella type process where people could be made aware of what else existed out there for them this could be of great benefit and improve the efficiency of such support schemes.*</p> <p>20. How about establishing a person's status as being disabled once and using that for all other considerations for eligibility? Obviously the degree of disability would impact on decisions concerning some benefits and services but on the whole the award of the status should make future assessments pertinent to what level of support they need and not as to their status as disabled. Reviews could also be used to reflect the person's changing degree of disability.*</p> <p>21. I will only answer in respect of disabled people because that is what I am. The preamble jumps from disabled people as a collective to the use of terms such as 'greater challenged', 'most needy', and 'less likely' to vaguely identify a possible specific sub-group within the greater body of the disabled. This is clearly misleading. If the aim of the proposal is to target only a small percentage of the disabled then say so from page one!</p>

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		<p>All those disabled people currently in receipt of DLA who fail the proposed review will remain disabled but their support will be removed. They will continue to face challenges to remain independent, live active lives and participate in society but their situation will no longer be acknowledged. Thought must be given to this group of people who will form a significant minority within society. They will fall between those with the greatest need, many of whom already receive the greatest help, and those who need little or no help to overcome their impairment and, consequently, are in danger of becoming forgotten about by the state. They will prove the measure of failure of the system.*</p> <p>Disability affects by degrees, those in greatest need of medical intervention are not always those in the greatest need of support to live everyday lives; their very condition makes that aspiration impractical. A person who needs 24 hour care cannot be expected to ever participate in 'everyday life'; they are too restricted by their condition. However, someone who can be more active will have not only a greater chance of such participation but also a more practical desire because fulfilment will be within their reach. Those in need of 24 hour personal and medical care cannot be expected to take up employment but those who suffer less severe disabilities have every chance of becoming active, independent and employable with the right kind of support. The potential to participate more fully in society of the disabled person applying for PIP should also be assessed alongside their disability.*</p> <p>22. I am concerned about the lack of clarity concerning the target group for these proposals. As mentioned in the answers provided above the target group is first identified as 'disabled people', which seems pretty inclusive, but then it becomes fragmented by reference to 'the most needy', those facing the greatest challenges', 'the most vulnerable' etc., which is it?*</p> <p>PIP, like DLA before it, will not herald in some new age of dynamism nor will it make society more responsive to the needs of the disabled. Please do not make these spurious claims. The amount of money being spent is not large in comparison to other public expenditures and its' impact on the larger society will be reflected accordingly. The only real impact will be on disabled people and their families.*</p> <p>Disabled people do not live in an ideal world and they should not be assessed against a set of objective criteria derived from such a concept accordingly. Basic activities like walking down the street and crossing a road are fraught with problems, dangers and challenges that the able-bodied never stop to consider. This is everyday life to me.*</p> <p>We want to work! I am disabled and I have worked most of my adult life. However, employment has always been at the lower end of the pay scale, after 20 years with my current employer my career amounts to 2 promotions, 1 suitability to further promotion that has led to nothing, and a salary of just over £20,000. I also have a successful finding of discrimination on the grounds of disability against them. DLA has not altered this culture in the workplace, PIP will not either.</p>
EM479	11-Feb-11	<p>Having read the DLA reform document, I have the following comments:-*</p> <p>Question 11 - face-to-face discussion with healthcare professional - it is ESSENTIAL that this healthcare professional is fully trained in the specific area of disability of the person they are meeting - otherwise assessments are at the risk of not being made fairly as opinions will be subjective, like some made by the current decision makers and claimants will be at the risk of not being treated equally. It could be seen as inappropriate (and confusing) for a child with certain disabilities (for example autism) to have to be seen by a healthcare professional when they are highly unlikely to be able to contribute and this will put unnecessary pressure on the parent/carer.*</p> <p>Question 12 - surely the frequency of review will have to vary depending on the needs of the individual and their impairment/condition. A child with a lifelong disability (eg autism) is not going to get better.*</p>

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		Question 17 - differences to take into account when assessing children - depending on the nature of their disability and their age, it may often be unlikely that they can contribute (or sometimes even understand) what this stranger is doing in their house and could be extremely upsetting and stressful for both them and their parent/carer. These views are the personal views of a parent of a child with autism and a young person with Aspergers Syndrome.
EM480	11-Feb-11	I think we are all aware the Country owes a lot of money. <u>One way to pay it off is do what the ConDems are doing; try to pay it off now and quickly with all the social upheaval this brings. The second way is to half the deficit in 4 years as the Labour Party profess with far less disruption all in one or two years. The Third way combines getting rid of the deficit in one year. This way does not affect 99.9% of the population so therefore would not have to stop DLA payments to care home patients? See http://robinhoodtax.org/</u>
EM481	11-Feb-11	<p>1. Your response: Too much of their limited time and energy is wasted on endlessly filling in forms, answering the same questions over and over again, being expected to perform like a trained monkey for anyone the DWP says they should and just when you've learned to do your limping best to get through the hoops they alter the assault course. *</p> <p>2. Your response: All of it. *</p> <p>3. Your response: Fighting the same old battles on constantly changing terrain. *</p> <p>4. Your response: Instead of making my partner fight once you remove the mid-level care component she receives at the moment, add a mid-level to the mobility allowance as the two tier system already in use has never worked. *</p> <p>5. Your response: Anyone who has paid national insurance contributions should be entitled to an equal level of benefits. *</p> <p>6. Your response: As only the individual can say what to them would constitute a full and active a life, try asking them and then actually listen to the answer. *</p> <p>7. Your response: Other than asking a panel of the relevant medical experts (making it a large one – ask three doctors get three different opinions) stop making people feel they have to act ten times worse than they are to get the DWP to admit they're half as bad as they are. *</p> <p>8. Your response: No – aids and adaptations are only any use if it is guaranteed they, and if necessary an exact replacement, will be readily available anywhere the disabled person goes; and speaking from personal experience, my partner was eligible for numerous aids and adaptations when she left hospital following her stroke, most of which proved unsuitable for either her, our home or both and have long since been returned. *</p> <p>9. Your response: Stop requiring people to write down exactly the same dates, facts and figures over and over again when these have already been supplied to the DWP, and usually several other government departments, repeatedly and are available at the click of a button; and, if you really want to improve clarity, stop totally overhauling the system every few years plus every time the government changes. *</p> <p>10. Your response: The persons' GP (who should know them best, and given the zero tolerance "it's not on" campaign I do not accept they might feel pressurised into lying and if they are found to do so should be struck off immediately) together with any other professional that has had a hand in their diagnosis or treatment, plus anyone else who has day to day experience of the persons abilities and limitations and is prepared to give a statement of the facts in writing once they have been warned of the consequences of giving false testimony. *</p> <p>11. Your response: Most disabled people have had numerous face-to-face meetings with healthcare professionals who are experts in their fields with years of experience, so I've never seen the validity of sending</p>

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		<p>them to see someone who has taken a DWP training course to make them an "expert" (I got an obstetrician once to examine my very male bad back, joints and other problems!) and who is just in it to make extra money. Plus when you are required to attend a DWP medical you are given dire warnings of the consequences if you fail to attend, so you do your best to look after yourself so you are fit to get there and then they find "you're nowhere near as bad as you made out you are in your day to day life"! *</p> <p>12. Your response: Again, a (large – see above) panel of relevant medical experts together with the persons own GP, etc, regarding whether theirs is a condition that is liable to improve, remain the same or worsen with time. *</p> <p>13. Your response: Accept the news their condition has worsened as readily as *</p> <p>you do that it has improved. *</p> <p>14. Your response: Ensure that "expert" advice actually is e.g. after my partners stroke her benefits were messed up first by the local social services (DHSS, DSS, whatever else it's changed its name to, I forget?), then by a local disabilities advice centre (D.I.A.L.) where (like the C.A.B.) the quality of the advice you get depends on the advisor you get, until finally being sorted out by the advocate at our local carers support centre (P.C.V.S.), then when I recently claimed Industrial Injuries Benefit (I.I.B.), between myself, my entire GPs surgery, the local DWP office and the PCVS we struggled to decide who was blind and who should lead, and it wasn't until I was awarded IIB that I and most of those involved found out it is deducted penny for penny from our Income Support (I.S.); so yes, the system is C.O.M.P.L.I.C.A.T.E.D. and people need advice that is worth having, but you could only include it in the claim process if you could convince them that it was genuinely impartial and that you are not using the P.I.P. and a stated desire to simplify things to hide an intent to make C.U.T.S. *</p> <p>15. Your response: See above. *</p> <p>16. Your response: No, because thinking you can foretell the future is how we got in this mess on the first place. *</p> <p>17. Your response: That as soon as a disability is diagnosed the parents begin to experience increased problems and expenses irrespective of the child's age, and the parents usually want and often need to equally share the caring role. Plus a child is even less able to deal with a DWP appointed medical "expert". *</p> <p>18. Your response: Unless you qualify for full mobility allowance, and then only if you are a driving licence holder or married to the person who is, we have not found DLA as much of a "passport" to anything; Income Support is the passport to services - for anyone who receives it - and without it DLA counts for nothing. *</p> <p>19. Your response: See above. *</p> <p>20. Your response: See the answer to 9 above, and I would have no problem with any of my personal information being shared between any departments that had a genuine reason for needing it apart from governments' laughable record for keeping it secure. *</p> <p>21. Your response: The introduction of yet another type of postcode lottery is something we could do without. *</p> <p>22. Your response: I've had about a dozen (tax-payer funded) medicals in the last 14 years and having appealed the few I failed I've won all but one. I recently found out that ever since I became my partners official carer in 2003 all the forms I've filled in and medicals I've attended have been a complete waste of time because as my partner is even more severely disabled than I am even if I fail the tests it will make no difference whatsoever to the benefits we receive, and when I pointed this out to our local DWP office and asked what was the point the only answer they could come up with was they would stop our money if I didn't do as I was told. How will changing the system yet again and yet another round</p>

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		<p>of tests save any money or improve our lot, and if it turns out I * am suddenly fit for work again and can fit another job in around the minimum 35 hours a week (I wish – often feels like I've done a 35 hour day!) I need to qualify for the £1.54 per hour maximum Carers Allowance I receive, what will the ConDem alliance do next - walk on the water?</p>
EM482	11-Feb-11	<p>1. THERE ARE MANY PHYSICAL BARRIERS THAT STOP A DISABLED PERSON FROM LEADING A FULLY INDEPENDENT LIFE, FROM HAVING TO RELY ON BEING ASSISTED WHEN OUT WHETHER THAT IS BECAUSE OF NEEDING HELP TO BE 'PUSHED' TO PERHAPS NEEDING GUIDANCE AND SUPERVISION. MANY AREAS ARE STILL INACCESSABLE TO WHEELCHAIR USERS THEREFORE HELP IS STILL REQUIRED. HELP MAY BE NEEDED TO ATTEND TO PERSONAL BODILY FUNCTIONS E.G. ASSISTANCE WHEN USING PUBLIC TOILETS, FEEDING COMMUNICATION ETC. THERE ARE ALSO THE HIDDEN BARRIERS - PUBLIC ATTITUDE, THERE IS DICRIMINATION, HARASSMENT AND IGNORANCE NONE OF WHICH HAS BEEN MADE ANY EASIER BECAUSE OF THE CONCERTED EFFORT BY THE GOVERNMENT TO DEMONISE DISABILITY BY THE CONSTANT RETORIC ABOUT THE COST OF DISABILITY TO THE TAX PAYER (MANY OF WHOM ARE DISABLED) TO THE 'SCROUNGERS' CONNING THE SYSTEM. EVEN THOUGH THE PERCENTAGE OF DLA BENEFIT CHEATS IS FAR LESS THAN THE HOUSING BENEFIT AND JSA CHEATS. *</p> <p>2. DLA SHOULD REMAIN GENERALLY THE SAME WITH A MOBILITY COMPONENT, WHICH SHOULD BE AVAILABLE TO ALL THAT MEET THE CURRENT CRITERIA INCLUDING THE PEOPLE WHO LIVE IN RESIDENTIAL HOMES. THEY HAVE THE RIGHT TO LIVE AN INDEPENDENT LIFE WITH THE MEANS TO ACCESS THE OUTSIDE WORLD WHENEVER THEY WANT. JUST BECAUSE I HAVE A KEY TO MY FRONT DOOR DOES NOT GIVE ME MORE RIGHTS OR MAKE ME ANY MORE WORTHY OF BEING ABLE TO GO OUT IN MY CAR WHENEVER I WANT TO. DENYING MOBILITY TO THIS GROUP OF PEOPLE IS PUTTING THE RIGHTS OF THE DISABLED BACK 30 YEARS. . *</p> <p>3. EQUIPMENT AND PERSONAL ASSISTANTS ARE PROBABLY THE BIGGEST EXTRA COSTS. ALL SPECIAL EQUIPMENT IS EXTREMELY EXPENSIVE. IT'S VERY MUCH A CAPTIVE AUDIANCE, WITH VERY LITTLE OPPORTUNITY TO SHOP AROUND. LIGHT WEIGHT WHEELCHAIRS CAN COST ANYTHING FROM £2000 UPWARDS. CAR ADAPTATIONS ARE VERY COSTLY BUT VITAL TO AID INDEPENDANCE. ELECTRIC WHEELCHAIRS ETC. ADAPTATIONS TO HOUSES ALL COMES AT A COST. THE COST OF A PA IS DEAR JUST FOR THE HELP WITH THE BASICS OF HAVING THE CHOICE OF WHEN TO GET UP AND GO TO BED, LET ALONE IF YOU WANT TO HAVE THE OPPORTUNITY TO SOCIALISE. *</p> <p>4. THE MOBILITY RATE CURRENTLY HAS TWO RATES LOW AND HIGH, LOW BEING FOR INDIVIDUALS REQUIRING GUIDANCE AND SUPERVISION THE HIGH RATE BEING FOR INDIVIDUALS WHO ARE UNABLE TO WALK OR VIRTUALLY UNABLE TO WALK. I SEE NOTHING WRONG WITH THESE TWO RATES, THOUGH THE CRITERIA CAN BE VERY SUBJECTIVE.*</p> <p>THE CARE COMPONENT GOING DOWN TO TWO RATES SEEMS TO BE EFFECTIVELY TAKING OUT THE LOW RATE FOR COOKING A MAIN MEAL OR NEEDING UPTO AN HOURS CARE A DAY* FROM THE CONSULTATION PAPER IT DOES NOT SEEM TO COVER NIGHT NEEDS OF A DISABLED PERSON, I WOULD NOT BE HAPPY IF THESE ARE OVER LOOKED OR NOT GIVEN THE SAME STATUS AS DAY TIME NEEDS.*</p> <p>AIDS AND ADAPTIONS CAN MAKE LIFE A LITTLE EASIER BUT OFTEN ARE NOT THE ANSWER TO ALL PROBLEMS*</p> <p>5. I THINK IT IS REASONABLE THAT EVERYONE MAY HAVE TO BE</p>

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		<p>ASSESSED ON THEIR NEEDS BUT I AM SURE THAT THERE WILL BE CERTAIN CONDITIONS THAT MAY AFFECT A PERSON IN THE SAME WAY. IT SHOULD ALSO BE NOTED THAT SOME PEOPLE CAN COPE WITH THEIR DISABILITY BETTER THAN OTHERS AND MAY HAVE ALSO COME TO TERMS WITH THEIR DISABILITY. THIS SHOULD BE TAKEN INTO CONSIDERATION.*</p> <p>6. ALL BASIC NEEDS NEED TO BE TAKEN INTO ACCOUNT E.G. BEING ABLE TO ACCESS BATHING EVERYDAY, GETTING UP AND GOING TO BED WHEN THEY WANT TO, ACCESS TO A MAIN MEAL EVERYDAY ASSISTANCE WITH COMMUNICATION, SOCIALISATION BASIC CLEANING TO ENSURE GOOD HYGIENE. TO PROVIDE SUPPORT TO ENSURE SAFETY, RESPECT AND DIGNITY. :*</p> <p>7. PROPER KNOWLEDGE OF CONDITIONS THAT DO FLUCTUATE AND GOOD COMMUNICATION WITH INDIVIDUALS GP. BETTER TRAINING FOR HEALTH CARE PROFESSIONALS WHO MAY UNDERTAKE ASSESSMENTS.*</p> <p>8. AIDS AND ADAPTIONS DO NOT ALWAYS CREATE INDEPENDANCE FOR A DISABLED PERSON. IT MAY HELP THE CARER AND THE DISABLED PERSON TO COMPLETE TASKS A LITTLE EASIER. NOT ALL AIDS WORK FOR EVERY DISABLED PERSON. NOT ALL ADAPTIONS WILL FIT IN PEOPLES HOUSES. COST MAY COME INTO IT AS SOME DISABLED PEOPLE WOULD NOT QUALIFY FOR A DISABLED LIVING GRANT BUT FINANCES WOULD PROHIBIT THEM PAYING FOR THE ADAPTIONS. *</p> <p>9. QUESTIONS SHOULD NOT BE COUCHED AS THOUGH THE SAME QUESTION IS BEING ASKED TWICE. IT IS ALSO VERY DIFFICULT FOR PEOPLE TO ESTIMATE HOW OFTEN CERTAIN CARE ACTIONS ARE CARRIED OUT, E.G. HOW OFTEN NEEDING HELP TO GET OUT OF A CHAIR, GO UPSTAIRS ETC. OR HOW MANY TIMES THEY HAVE FALLEN IN A YEAR. UNLESS A DIARY HAS BEEN KEPT I DO NOT THINK ANYBODY CAN GIVE AN ACCURATE ANSWER UNLESS IT IS 0. IT WOULD BE FAR BETTER TO ASK DIRECT QUESTIONS LIKE, WHAT INJURIES HAVE YOU HAD WHEN YOU HAVE FALLEN, ANY HOSPITAL/GP TREATMENT NEEDED? *</p> <p>10. G.P, SPECIALIST NURSE, CONSULTANT, PHYSIO, SOCIAL WORKER. *</p> <p>11. SOME OF THE CURRENT HEALTH CARE PROFESSIONALS ARE NOT TRAINED SUFFICIENTLY AND TEND TO MAKE ASSUMPTIONS RATHER THAN DO APPROPRIATE EXAMINATION. *</p> <p>12. IF THERE IS A CONDITION THAT IS KNOWN TO ONLY DETERIORATE THEN EITHER AN INDEFINATE AWARD OR A SHORT REVIEW IF THE PERSON IS NOT ON HIGHEST RATES. REVIEWS CAN BE VERY STRESSFUL WHICH CAN MAKE THE CONDITION WORSE.*</p> <p>13. PERHAPS AN A4 SHEET OF PAPER WHICH HAS TO BE RETURNED, SIGNED TO SAY THAT EITHER EVERYTHING IS EITHER THE SAME WORSE OR BETTER. IF THEY SAY THERE HAS BEEN A CHANGE THEN A REVIEW FORM CAN BE SENT OUT. THE FORM COULD BE SENT OUT IN APRIL WHEN INFORMATION IS SENT OUT ABOUT ANY INCREASE IN BENEFIT FOR THAT YEAR. *</p> <p>14. TO SEEK HELP COMPLETING FORMS FROM THE VARIOUS CHARITIES THAT OFFER HELP. *</p> <p>15. ADVISE THEM TO SEEK ADVICE FROM APPROPRIATE AGENCY*</p> <p>16. YES. ALOT OF EXPENSIVE AIDS AND ADAPTIONS ARE FUNDED FROM INTEREST FREE LOANS FROM MOBILITY SHOPS, BANK LOANS, CREDIT CARDS WHICH IN A ROUNDABOUT WAY IS BEING FUNDED BY DLA.*</p> <p>17. THE SUPPORT THAT THEY NEED OVER AND ABOVE OF A CHILD OF SIMALAR AGE. HEALTH AND MEDICAL TREATMENT NEEDS*</p> <p>18. SENDING INFORMATION OUT WITH THE LETTER OF</p>

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		<p>ENTITLEMENT OF WHAT OTHER BENEFITS THEY MAY BE ENTITLED TO, E.G. CARERS ALLOWANCE, WARM FRONT, DISABLED PREMIUM. CAR TAX EXEMPTION.*</p> <p>19. Your response:*</p> <p>20. THERE IS ALREADY A CROSS OVER OF INFORMATION WITH ESA AND DLA MEDICAL REPORTS HOWEVER THEY ARE NOT ALWAYS HELPFUL AS ESA IS VERY MUCH ABOUT THE ABILITY TO DO A JOB OF WORK AND DOES NOT COVER INFORMATION ABOUT THE HELP REQUIRED TO AID PERSONAL CARE IE BATHING DRESSING ETC.*</p> <p>21. AS THIS BENEFIT IS DIRECTLY ASSOCIATED TO THE NEEDS OF AN INDIVIDUAL IT SHOULD NOT HAVE AN ADVERSE EFFECT WITH ANY PARTICULAR EQUALITY GROUP. *</p> <p>22. PEOPLE WHO LIVE IN RESIDENTIAL HOMES SHOULD NOT BE DENIED THE RIGHT TO REICEVE THE MOBILITY COMPONENT IF THEIR CARE NEEDS ARE BEING MET BY THE LOCAL AUTHORITY. DENING THEM THE RIGHT OF KEEPING THEIR INDEPENDANCE ON WHEN THEY WANT TO VISIT FRIENDS AND FAMILY, TO SOCIALISE ETC. LOSING THE MOBILITY ALLOWANCE WILL EFFECTIVELY MAKE THEM A PRISONER IN THE INSTITUTION. THIS IS GOING AGAINST THE INITIAL STATEMENT THAT YOU MAKE AT THE BEGINING OF THE CONSULTATION THAT THE AIM OF THE BENEFIT IS TO PROMOTE INDEPENDANCE AND SOCIAL INCLUSION.</p>
EM483	11-Feb-11	<p>1. Your response: lack of mobility; physical and sensory limitations; raised costs of almost everything eg taxis; social isolation; for the blind and partially sighted missing non verbal communication, as this is taken by many sighted people as "stand offishness" or even "snubbing"; vulnerability in seeing potential hazards in everyday situations; inability to see detail *</p> <p>precludes attendance at evening classes etc; cost of buying magnification and speech software for the computer; disability provision in public places is largely addressing wheelchair use and not sight issues;*</p> <p>2. Your response: There needs to still be 3 levels of payment.*</p> <p>3. Your response: Transport, or rather the lack of it, in a rural setting - taxis, getting to public transport, getting help, everything takes longer to achieve, lack of employment but cannot prove discrimination, buying goods as cannot shop around for good deals, cost of social isolation.*</p> <p>4. Your response: 2 rates may well end up meaning that many people do not qualify. Disability cannot be categorised so simply and it is likely that only the very severely disabled will qualify.*</p> <p>5. Your response: I consider that people reg blind and partially sighted should automatically * qualify. As should many other chronic, permanent conditions.*</p> <p>6. Your response: For physical health - Eating , drinking, getting and preparing food, washing, dressing For mental health - having social contact and support, getting out and about and having respite for a break for carers and a supportive environment for the disabled.*</p> <p>7. Your response: To keep reassessing and using private companies will mean that the cost will * escalate and there will be even less money to be used for essential disabled peoples' support.*</p> <p>Occupational therapists are the experts in this area and they should be consulted and used in any assessments. Variable and fluctuating conditions should be assessed once and then every * five years.*</p> <p>8. Your response: Aids and adaptations should not be taken into account as they are only * available at one place. Outside of this environment the disabled person will still suffer enormous barriers. Also aids and adaptations that might be of assistance do not result in the person being completely independent in</p>

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		<p>the way that an able bodied person is.*</p> <p>9. Your response: Claim on line with fewer questions. Have simple brochures stating the areas covered and who will qualify. Distribute through the Post Office so every household gets one.*</p> <p>10. Your response: An Occupational Therapist assessment, which is very holistic and lateral in *</p> <p>its concept, should cover all aspects. Using consultants in hospitals is not a good idea as they are very medical model focused and do not understand the broad area of problems experienced by disable people in their lives.*</p> <p>11. Your response: If the professional is an occupational therapist I think this would work. If *</p> <p>it is a social worker, nurse or physiotherapist, these do not have a broad enough understanding. In the own home would be minimal disturbance for the disabled person. The OT could see how the individual lives and the client will be more relaxed to talk. Many blind and partially sighted people feel very intimidated in strange surroundings.*</p> <p>12. Your response: If they have permanent damage then there should not be reviews unless *</p> <p>medical advances change the condition. A review for the above conditions could be a form sent out to them to complete or emailed to inform of any changes to their condition.*</p> <p>13. Your response: By email or letter as people forget whilst struggling to survive with often *</p> <p>very stressful lives.*</p> <p>14. Your response: Yes having other benefits explained and tax issues re disability, blue *</p> <p>badge, motability and appropriate charitable support. Having a simple leaflet that had a spider diagram with the PIP benefit in the centre and the other benefits they may be eligible for around the circle.*</p> <p>15. Your response: Many older people are too proud to claim and resent even the mildest *</p> <p>coercion. If it could be linked to the state pension which they accept, this might help. Simplicity and clarity of forms in large 16 pt Arial bold will help.*</p> <p>16. Your response: No, unless there is a larger payment that can be sourced as the PIP will be *</p> <p>needed just to get by. Many adaptations have Council support and charity funding.*</p> <p>17. Your response: Their physical, mental and social development,; parental support and *</p> <p>parental capabilities / shortcomings; social and school support.*</p> <p>18. Your response: It is still difficult to find out what is available. Hopefully a new website *</p> <p>for the DLA could enable people to see what is available. Plus a leaflet as previously mentioned for those without a computer.*</p> <p>19. Your response: This would result in a further diminishing of social equality.*</p> <p>20. Your response: All benefits could be streamlined and brought under one assessment *</p> <p>umbrella – having a “social passport” with a photo and unique number to include - Date of birth, name address, NI and National health numbers, tax reference, disability coding for the condition , list of professionals involved with contact details , GP, Dentist details, Next of kin contact details.*</p> <p>21. Your response: I am concerned that partially sighted and blind people will lose benefit which is essential at present to assist in their leading as full a life as possible.*</p> <p>22. Your response: With a possible reduction in eligibility for partially sighted and blind people under the PIP, I wish to make the following point - People in wheelchairs can have independence through the Motability</p>

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		scheme and can go where and when they choose . Whereas a blind or partially sighted person being unable to drive, is always dependent on others, therefore having no spontaneous independence. Personally this is one of the biggest barriers to social inclusion and fulfilment. Public transport (where and when it is available) is not the answer . It does not go from A to B, way finding is very stressful, ending up on wrong buses and trains. As is getting information from staff at stations rail and bus and assistance is often lacking.
EM484	11-Feb-11	<p>2. Everything it's not perfect but it does a good job, if you must keep one thing please keep the name.*</p> <p>3. It's impossible to give a full list but even things you*</p> <p>*</p> <p>Having your hair cut on a low income could mean using the small cheaper hairdressers around the corner from you home, but it's not accessible so you need taxi to a bigger more expensive chain in town. *</p> <p>*</p> <p>simply things like sponge on a stick, normal sponge 99p mine £15 And No mine doesn't last 15 times longer. *</p> <p>Other ongoing cost often gets over looked in keeping your home in a descent condition. *</p> <p>*</p> <p>the way I have to lean on kitchen cupboards so I can reach from my wheelchair to get things so these need replacing quite often (new brackets, doors)*</p> <p>*</p> <p>the cost of replacing dropped kitchen plates, glassware etc.*</p> <p>*</p> <p>how many times a week do you drop your dinner/food all over the floor and have to start again?*</p> <p>*</p> <p>the cost of paying for new kitchen flooring when you were too weak to hold onto that hot pan and melt the floor.*</p> <p>*</p> <p>the cost of cleaning or recovering the sofa is you have been unlucky enough to have an accident. *</p> <p>*</p> <p>the cost of new bedroom flooring when you knock over the commode bucket *</p> <p>*</p> <p>the cost of replacing doors/doorframes because you are forever taking big chunks out of them with your footrests.*</p> <p>*</p> <p>the cost of new laptop that you need because you can't sit up to use a PC the added pressure it puts if this gets dropped knocked. This is essential for paying bills shopping, communication with the outside world.*</p> <p>*</p> <p>helps with having to have a BT phone line for my text phone that I don't use much. I need a BT line for this. I would be able to manage with an internet dongle connection but this is extra expenses I need to pay. *</p> <p>*</p> <p>Cost of "ready food" ,things cost more if you can only lift a pint bottle at a time. *</p> <p>*</p> <p>Online delivery cost, heating bills, laundry bills, keeping other gadgets in working order*</p> <p>All of these things can need paying for without warning and cannot be easily calculated into £x a month. The safety net of DLA means I can with carefully saving ensure when things needed can be replaced.*</p> <p>4. Will having two support? Currently you have low or middle care and low , middle or higher care these are simply and easier for everyone</p>

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		<p>to understand. Don't see how going from 5 options to 4 makes it less complicated. What, if any, disadvantages ...cause? Having less rates will mean those at the very bottom will fall out of the syemem making way for the middle rate now to be the lower. Thus insuring only the very illest is on the higher rate.*</p> <p>If anything we need more groups not less. I have middle care needs I don't have "enough" care needs at night for long enough to qualify. This doesn't mean I have no care needs at night or don't need care frequently in the day. Under the new system its not very likely my care will be rounded up to higher, so I would be worse off by £29.85 a week. This means I will not be able to do what I am doing at the moment and will have a huge impact on my quality of life. *</p> <p>5. Some very sever conditions from birth should be done by applying when chid qualifies. There are too many variables in most condition and the vast majority are things people get or from accidents so need to apply anyway.*</p> <p>6. Most essential would be getting up dressed, being washed, fed however these in themselves do not come in to the full and active life category.*</p> <p>Everyone has different idea about what is most essential and what parts of their life they want to be active in, someone might count going to church evyday as essential part of their life. Or getting and about to shops met up with friends. If practise only the least able it ignore the more able who may have still have costs they can't keep without DLA.*</p> <p>7. This is always going to be difficult, if someone needs an electric wheelchair once a week they still have the same running costs as a full time user. SO assuming their mobility needs will cost 1/7th is misleading.* Where someone has months at a time without needed the care/mobility payments perhaps this could be reduced. But not many conditions are so good or bad in such a clear cut way.*</p> <p>I don't know how presently it is caulcated by if you have mobility needs say 3 day a week I doubt this is considered in your favour i.e. 3 is more likely to be counted as 0. Making it clear that conditions that vary can still be paid though again at a different rate (you seem keen on only having 2 fixed rates) would encourage people to give a clearly picture of a condition. Because they could get help on certain days they need it rather than nothing at all. *</p> <p>8. There are serious issues in assuming aids and adaptations help, part of being disabled is that all parts of your life cost more, or doing them in a different way cost more. For example you may only consider my washing aids to be essential but something to help me with a hobby not to be seen as essential part of my life. *</p> <p>I don't think you can say because I presently own a power chair I don't need mobility dla for example. Items break down without any notice, equipment needs servicing, insuring, new Tyres, batteries as needed. *</p> <p>When my chair blew up a few months ago I was able to get taxi home, hire a new chair for the 3 weeks, get someone out asap to take it away and examine it. In the end I did have to buy a new chair. But without my DLA savings I had put aside I would have been in hardship just paying for taxi and it getting looked at never mind the cost of replacing it. *</p> <p>Its hard to explain how it feels but my power chair enable me to leave my home, an able bodied person can't really understand the total and utter reliance you are upon technology and yes we do feel the need to save and have the comfort of knowing if needed we have the money to replace expensive items not wait for months or years before we can move again. *</p> <p>DLA currently enables me to save a little and have this kind of insurance that most people take for granted. If a new assessment assumes my power chair counts and I have no more mobility needs they are very very wrong. *</p> <p>9. It's never going to be a positive experience because you have to</p>

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		<p>asses and think about what you can no longer do. The only easier way would to allow doctors to automatically click and let you get this is you asked them and if you fulfilled a clear set criteria. *</p> <p>10. You should be able to ask hospital doctor or gp if they are willing to back your claim for dla. You should be able to print out a requirement for each rate/compound and they should be able to sign it , email a response to say you qualify. This would only work for things like mobility as none really discuss getting out of the bath or how they manage to prepare a meal, having questions such as would this condition cause problems in doing x y z would mean they did waste time *</p> <p>11. If I am only going to have to repeat the exact same answers as on the form then there is no point at all. I have no speech so I have to type out everything I need to say anyway and going out of the house is difficult and tiring. *</p> <p>While some people may find it easier to do this than a form its higher distressing form to fill in and takes many people weeks to do so a one off meeting is not going to allow you to get the same information across. Doing this instead of the form would take much longer time and resources.*</p> <p>If it's only to 'check' the answer I put on the form its going to feel like I'm being examined for telling lies. If I have a doctors and hospital letter saying I can't do X explaining again why I can't do X is not really helping anyone. *</p> <p>I can't really see what benefit this would be unless it is to replace the need for evidence from doctors or the need to fill in the form.*</p> <p>Especially for those with mental health issues this would be another hurdle to get over. And can only lead to them being d*</p> <p>12. The current system works well for those with serious conditions get indefinite awards (that is until a new government decided to change it all again) At present those with illness that may change already have to renew every 1-3y so that is a good time scale.*</p> <p>13. You need more rates for things, if for example I am able to cope with cooking a meal i.e. lift a pan to the stove, but still can't get dressed/washed alone its likely to mean my care is dropped. If there were more individual awards for each difficulty that were calculated it would mean small adjustments could be made. At present it's likely all care would be scrapped altogether no wonder people are terrified and try to keep on to care if have care needs. *</p> <p>If I do have major setback and need more help this would take months and months to sort out. If my condition improved say over 3months I would be happy to have money reduced as long as getting this back if I was worse was just as easy, sadly I know going down is almost instant going up takes months and months*</p> <p>14. It would be helpful to know what you are looking for. And what you are considering as essential. My idea of what's important to allow me to lead an active role in society may well be different from yours. *</p> <p>On one hand we are told the payments are purely to cover extra cost in mobility and care needs yet on the other hand we are told it's to help us play an active and full part in society. DLA is also used by many people to pay for things they could do before they were ill and working. Call it a pocket money allowance if you wish, should I no long have any money to spend on myself because I can no long fund this myself?*</p> <p>Is it fine to fund for us to get up dressed, fed and out of the house but then we cannot afford to do anything as part of the society in which we live? Disabled people live on a low income, imagine having to spend the rest of your life living on low income, on JSA you may get a new job on Income support as a single parent they grow up but being poor can be for life. DLA gives you the flexibility to mange and juggle income and spend a little on the things that make life worth living. *</p> <p>15. I don't know what you mean, if by access advice and support you mean forcing people to take up Therapy to overcome say mental health</p>

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		<p>issues that's not going to help. The majority of people do all they can do survive and feel well I don't really think people are not using services or support in order to claim disability benefits. Anyone using medical services has enough people pointing /telling them what they should be doing having the benefits agency as a non medical professional doing in the same can only cause a negative effect and may be the wrong sort of advice. *</p> <p>16. It could help if this was instead of a loan for building work or the cost of buying an adapted vehicle. IF you have enough money to fund everyday expenses then having this option of giving up future payments may work for some people.*</p> <p>17. I would think children need more money not less as they outgrow things more quickly and as they need to do things as part of a family everything cost more.*</p> <p>18. No it work well, showing a letter about DLA saves time and resources in applying from scratch for other things. *</p> <p>It also helps in that you don't have to give very personal information about yourself and condition especially if it's not that obvious. Though people still want to know the in and outs of everything you can at least wave this at them.*</p> <p>19. If we could not do this, it would mean applying again using different set of letters/doctors notes. It would still work just mean you can't tick a box. Would mean more effort , more time more money spent repeating what you did on the DLA forms. *</p> <p>20. There are only two disability benefits ESA and DLA, as you can claim DLA and still be able to manage a job it means that its not very helpful to combine the two. For example if I am able to working full time I will not be claiming ESA so would someone think i didn't need my DLA?*</p> <p>The only helpful thing could be to allow access to the same doctor notes so one claim could support the other. But as most ESA medicals ignore any other information and find 94% of people fit for work its can only mean more problems for claiming DLA. Since they don't seem to take into account people own medical notes and letters.*</p> <p>Ive heard of many cases when the new ESA is denied and straight away DLA is also cut, it seems enough information is already "shared". Meaning someone faces a double appeal and double whack to their income. *</p> <p>22. Please please please don't mess up the DLA, it's a life line for many people and the stress and anxiety we all feel already since you have already decided 20% of funding will be cut. *</p> <p>More importantly don't cut the mobility payments to those in reseridential homes, I have been ill enough to consider going into such care and the idea that I could no longer pay for my power chair, taxi etc would mean as a 30y old my life would be over. *</p> <p>Far from being not fit for purpose it's the benefit that gets the most praise and support from disabled people and their families changing to less rates, changing so that fewer people qualify, changing the amount available ONLY have a negative effect. It's not perfect but it does work!!!* A grateful DLA claimant.</p>
EM485	11-Feb-11	<p>I have a son who has LD, Autism, Cerebal Palsy, Uncontrolled Epilipsy. He need to have someone supporting him 24 hours a day. An exsample of this is on the 30th January 2011. At 2.00am he took a fit, having been given 20ml of Epistatus which did not stop the fit. I phoned for an ambulance and they gave him 12.5ml of Diazapam. On arrival at the hospital they gave him 3ml of Larazapam. This did not stop the fit and he needed a Phyatoin infussion. My son still did not stop so they gave more Larazapam. He had to be put onto a life support machine in ITU. On the 3rd of February he was allowed home as we agreed with the doctors that he was better off at home because he was getting very distressed. My son came home unable to walk requiring 3 people to carer for him. We are having to manhandle him from A - B with very minor help from aids.*</p>

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		On the 5th February he was sent back to hospital A & E to get checked for a DVT. This was confirmed on the 5th February 2011. He is now requiring injections of Heperin for the next 6 weeks. If you go ahead with the PIP and require to have a medical test, my son cannot speak or communicate. How do you think that you can get the full picture of what he needs.
EM486	11-Feb-11	<p>Dear Sir / Madam, Please accept this email as my response as an individual to the proposed changes to the Disability Living Allowance as detailed in the "Public consultation Disability Living Allowance reform" from the department for work and pensions.*</p> <p>I have no direct interest in the DLA, but I do have an adult sister with Down's Syndrome who relies on the current DLA to cover the extra costs she faces due to her disability.*</p> <p>Chapter 1 s 17 refers to the fact that DLA is too complex and misunderstood, with many believing it to be an out-of-work benefit. Problems with the perception of DLA need to be addressed, but not to the detriment of disabled people who rely on the support currently provided by DLA. Severely disabled people do not have any option to compensate for their lack of function in a modern market economy and therefore rely on the state to allow them to be a part of the wider society in which they live.*</p> <p>Q1: Barriers preventing disabled people from participating in society include the dependence on others to provide transport time and expert help to plan and transport them to activities. People with learning difficulties are unable to express themselves or articulate their needs fully. They will rely on others for their whole lives to interpret their needs and make sure these are being met. In our current set up of society, this responsibility fall upon the state. Any diminution of the DLA will disenfranchise disabled people.*</p> <p>*</p> <p>Q3: The main extra costs are transport, particularly for those unable to use public transport and the assistance of carers to accompany them.*</p> <p>Q4: Splitting the components introduces problems, particularly in the case where someone currently receives DLA while living in a care home. By removing one element for those in a care home, disabled people will be prevented from continuing activities essential to their well-being, which are currently supported by DLA.*</p> <p>Q5 Q9 & Q11: Permanent, unambiguous and untreatable disabilities such as Down's Syndrome should have an automatic exemption from all but the most general of eligibility criteria. It is a waste of resource to force carers and civil servants to devise methods of assessing someone who is unable to process the questions asked of them or the consequence of their answers.*</p> <p>Q17: This should apply not only to children but to those who are not capable of understanding their situation. Disabled adults should not be treated as children, but can often be much worse off with no-one to act as their advocate. Special attention should be extended to people with learning difficulties who are not in a position to express through the medium of questionnaires and interviews with officials. Yours faithfully,</p>
EM487	12-Feb-11	<ol style="list-style-type: none"> 1. Your response: Disability is not always an illness, it can be a genetic condition, inherited and yet public perception says "unclean", when it is not a life choice.* 2. Your response: I think that DLA for the disabled family person is very often incorporated into family income as a whole and to remove it would cause unnecessary hardship and poverty. Not only for the disabled person but their families.* 3. Your response: Aids that are unavailable via NHS or grant and also specialised dietary needs and care.* 4. Your response: Reassessment could mean that some unjustly end up 'stuck' on a lower rate indefinitely.*

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		<p>5. Your response: Illnesses or disabilities that are deteriorating, where there is not any cure and the condition gets worse.*</p> <p>6. Your response: Scalable according to the severity of the illness and probable outcome i.e. is the condition incurable and likely to get worse.*</p> <p>7. Your response:*</p> <p>8. Your response: Yes the possibility of aids that are necessary and access to them is increased by financial independence and though the person may not have aids does not mean they wouldn't get them if they could. *</p> <p>9. Your response: The process of applying for benefits should be assessment by the disabled persons primary health carer i.e. gp or hospital consultant. The filling in of application forms is a process which is already adequately provided for now.*</p> <p>10. Your response: A primary assessment by the disabled persons own G.P. or outpatient doctor at hospital, etc.,*</p> <p>11. Your response: I personally think a primary assessment by the person attendant physician would give a secondary assessment by another health care individual, whether at home or another location, an added surety of outcome.*</p> <p>12. Your response: I think that the reviews should be as they are now but with the added primary assessment by the persons own healthcare provider.*</p> <p>13. Your response: A regular assessment, whether at home or another location, by the person own primary healthcare provider.*</p> <p>14. Your response: The same type of information as is now needed.*</p> <p>15. Your response:*</p> <p>16. Your response: Funding for health aids at the moment is provided by various means and any change to the various sources at the moment would cause unnecessary confusion, especially to those with mental health problems.*</p> <p>17. Your response:*</p> <p>18. Your response: I think that the basic way of doing things is sound at the moment. *</p> <p>19. Your response: Unnecessary personal expense leading to hardship and poverty if various other needs were to met by the person concerned.*</p> <p>20. Your response: Possibly the integration of various benefits into one, as unnecessary duplication can be expensive to the state, confusing to the people concerned. *</p> <p>21. Your response: Cannot judge with accuracy.*</p> <p>22. Your response: I personally think most things would be better off as they are now but with an added new assessment.</p>
EM488	12-Feb-11	<p>Dear Madam, Please find attached a PDF document which I send in reply to the recently published DLA Reform Consultation document. I have completed this document from my own viewpoint as a carer to my disabled wife. We are both under 50 years old and I have been caring for her full-time for at least the last 9 years. By full-time I mean 24 hours a day. I also helped with the care of my mother until her death and have previously served as a Class 1 Combat Medical Technician in the army. Should you require any further information please do not hesitate to contact me. Yours faithfully,*</p> <p>*</p> <p>Question 1: There are numerous barriers but here are just a few. Buses, trams and trains do not have enough spaces on them for wheelchairs as in most cases there is normally only 1 or 2 spaces. This is also complicated by the fact that the DDA is not enforced by the drivers or conductors of these vehicles, most of them do not even know what the law requires them to do or maybe they just ignore it. It is also complicated by parents with pushchairs who think that the wheelchair space is for them and solely them (they do not believe that they are required to fold down their pushchairs if a wheelchair wants to get on). With trains if you go to the station to book a ticket and assistance, you can book the ticket</p>

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		<p>that you want, let's say on the 8am to Nottingham, only to get a phone call from the assistance unit to say there are no spaces on the train and can you go on the next available train which is 10:45am. There is no communication within the rail industry to tell them whether there is a space available and they also forget to tell you if a station is accessible. You then either have to spend time trying to get out some how or get them to get you somewhere suitable but they do not tell you that they should get you from the new station to your original destination. With regards to buses not all stops have raised kerbs or buses on the route with kneelers which make it impossible to get on, also some drivers are very reluctant or will not get the ramp out saying they will be in trouble with the bosses if the bus is late. Drop kerbs are not always dropped kerbs; they are lowered kerbs that still have a "drop" at the end. These cause the wheelchair user a lot of pain dependent on the height of the kerb. I have also come across kerbs that are too steep (users have fallen out) and when you question the council about them most say that "they conform to Government regulations" the only thing is in some cases they have forgotten that the gradient of the hill that it is on and that it is therefore actually a lot steeper.*</p> <p>Assistance dogs also have a problem as a lot of people from cafe owners to bus drivers to restaurant workers do not realise that the DDA also covers all assistance dogs not just guide dogs. You say that you want people to work but answer this question (as this is also a barrier to full life for a lot of disabled people). "If you were an employer would you employ somebody who could not say if they could get into work that day or that week? They may be able to get in on time but have to leave early due to their condition and may not be back for a day or two? If they did "push" themselves to get in, it could, and probably would, make their condition worse and end up with them needing more care a lot sooner than would previously have been needed and therefore the costs would be a lot higher a lot sooner. This item I feel is fundamental to freedom and is a large barrier. The local polling station is not disabled friendly but someone has come along who is not disabled or does not seem to have much experience and said it is. I have reported the fact that it is unsuitable for the last 4 years but nothing ever changes. The problem that I also see here is that it is the local school and firstly will they never have a disabled child going there and secondly why stop the children's education when there is a suitable building further in the village.*</p> <p>Question 2: The only thing that I think should stay the same is the 3 levels of care component depending on how the new form is going to be. I say this because where will you move the levels? Will medium go to high or low or will you move low to medium? I make this point as someone whose wife gets medium rate care. I have been told by many a professional that because I am up most nights (on 24 hour call!) even if only once and for 1 hour (some nights I only get 1 hour of sleep) but because I do not have to be up all night my wife does not qualify for high rate care.*</p> <p>Question 3: Transport: If you are a wheelchair user that has to use a taxi due to the location you are going to has no accessible public transport then you get charged extra just for being in a wheelchair. It would be the same car going to the same place that would take an able bodied person on exactly the same journey. The reason they give is they have to do a special course on loading and carrying wheelchairs which they would have had to have done anyway to get their carriage licence.*</p> <p>Insurance: Wheelchairs (more so powered wheelchairs and motability scooters) now have to be insured for public liability. As they are quite often the only source of independence for the person using them they are also usually insured against fire, theft and accidental damage. This can amount to a lot of money and there are not many insurance companies around who deal with this form of insurance*</p> <p>Service & Maintenance Costs: For those with any form of wheelchair or</p>

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		<p>mobility scooter these have to be serviced once a year and quite often require replacement parts (tyres etc.).*</p> <p>Petrol/Diesel: Also, this may sound wrong but as stated before, public transport is not fit for purpose for many people including ourselves (we have the most fuel economical car for our needs) and have to use a car for some or all of their transport needs this includes hospital and doctors appointments. You say you are looking at a trial of reduced fuel for rural users well I'm sorry to say but disabled people have the same problems - in the fact that they have to use their cars and have no say in this matter.*</p> <p>Vehicles: Another thing that can cost more is cars in general as I do not feel that "motability" gets the best deal possible. If you go into most car dealers and you tell them you want a car with an adaptation you only get it at list price less the VAT unlike if you just walked in to buy a car they would offer you discount after discount, and I say this from personal experience. It also save some people who use Motability is if they were only allowed to "buy" cars that were correct for their needs and the most efficient but still having a range to choose from.*</p> <p>Continence Pads: This can be another large cost for some disabled people. The NHS only allows 4 pads per person per day irrespective of size or use. This is not always enough and can cause lots of problems and distress. All people are different even if they have the same condition (in name) and may use all 4 in a day and 1 or 2 more but they may use even more if they fall ill with something else. This could be rectified if, when the assessment for pads by NHS staff is done, it is done on a personal level not blanket covered to a maximum as some will need less, others more. It is a matter of dignity as it is not their choice to use these; it is down to their condition.*</p> <p>Housing: Housing is another extra cost for people like us who need a second bedroom. This is because sometimes (normally 2-3 times a week) I have to sleep in a different bed because my wife is in so much pain and cannot stand me in the same bed. Under current rules you would have me sleeping on the floor which I must say does not help people when the carer is so tired they cannot do what is needed as well as they could.*</p> <p>Energy: The cost of domestic fuel is also a high cost for some disabled people as some need to stay warm and require the heating on for longer and in times of the year when most other people have switched it off.*</p> <p>Interpreters: Paying for interpreters, BSL signers or lipspeakers take an enormous amount of money from Deaf people. Quite often the interpreters or signers charge up to £100 plus travelling expenses for a 3 hour period. This cost is often overlooked when assessing Deaf people for benefit and has to come partly from their benefit and partly from their own pockets making access extremely expensive and prevents the person from taking part in normal social activities or voluntary or paid work. Some charities are too small to be able to fund this sort of expense and most employers see it as the person's responsibility not theirs.*</p> <p>Question 4: I would refer you back to my reply to Question 2 and do not believe it will make it any easier to understand. As I understand it at the moment, you possibly use a points system where, for instance, low rate care is 1-4, middle rate care is 5-8 and high rate care is 9-10. The only thing that may make it easier is how you do the points system at the assessment level which does not include the client needing to understand it. You could possibly use a 10 question system of important and relevant questions, give them a yes or no answer or 1- 10 scale answers that gives 1 mark for each yes and score like that. Again though I would say that you may* need extra questions as some will be of no relevance to some conditions and others will.*</p> <p>Transport and holidaying has other problems in as much as if you are disabled with some types of transport and most types of holiday</p>

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		<p>accommodation the disabled person will have to pay more, say for taking a wheelchair because it takes up extra room. Why should they have to if let's say a family with 2 children can go with the children going free? They still take up the room.*</p> <p>Question 5: Some conditions should still get automatic entitlement but for example why does somebody who is severely mentally impaired get put on high rate mobility when really they should be on high rate care and the mobility component should be assessed separately. Somebody who is severely mentally impaired may not have a mobility issue; it may be that they require a carer with them when they go out. This is not a mobility issue as if they are put on high rate mobility they are automatically given a blue badge which, I am sorry to say, is abused by some people (maybe not them but people who care for them or have access to their badge). This is also true for others as you probably know.*</p> <p>Question 6: Sort out the transport issues and I would also say that you need to look at how government/councils or private business use the consultation to planning as two things are mainly wrong. Buildings and adaptations to public areas is woefully inadequate and is only an inconvenience to most people and a tick box exercise. This was shown with the Crucible theatre in Sheffield. A person in a manual wheelchair was asked to assess the area for a wheelchair space (before any frame work was in place) and it was found to be fine. However, if you went when it was finished in anything but a manual chair (and that depended on its size), you have a problem as when myself and my wife went with a friend found. The way that we were told that* she needed to go to get out in the break or in an emergency was to drive out forward and would actually have had my wife falling between 20 and 30 feet down a set of stairs. The only way to get out safely was to reverse all the way.*</p> <p>The people who design transport, buildings, footpaths and a lot more things may be very intelligent people but need to talk to people like myself as a carer or my wife as a disabled person when doing plans because they do not see how it would work in practise. You may ask why I said carers like myself; well we have a lot of experience with lots of everyday things and have probably had to adapt a lot of things for ourselves for it to work for our situation. Councils should also get a wheelchair user, a person who is deaf and a visually impaired person to go around the whole of the main areas (and more if possible) to point out the problems with dropped kerbs, crossings and the like. This would benefit all people as well, and if you ask most they* would be willing to do this. As an example, I have noticed that some crossings no longer have the bleeping sound for people to cross (told this down to noise pollution mainly at night), so what happens if you are blind? Do you take pot luck and risk crossing or stay at home and be safe?*</p> <p>What would also be good for people would be to have like "safe zone" cafe/meeting type place where all people with disabilities, pensioners and children could meet knowing that the food and drink was reasonably priced and that they would be treated with respect but this would need to be on a local level. It could be run by a small number of employed staff and volunteers in buildings that are suitable but are basically unused at that time. This would also help breakdown barriers between disabilities, pensioners, religious groups, children and other groups as all would be treated the same.*</p> <p>Question 7: You need to ask the right questions for their condition and ask for things like the "range". By "range" I mean if you ask somebody what their pain is like on a scale of 1 -10, you need to divide the question up even more by asking what is it like on a good day, what is it like on a bad day and how many good and bad days are there in an average week. By using an average of these scores you would get a better indication of the condition of that person. Another thing that is missed and</p>

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		<p>would save you a lot of time and expense is, for instance, my wife who has numerous conditions but the main ones that are used in regards to DLA are "degenerative" and will never get better. Perhaps you should look at getting their GP to confirm that it is*</p> <p>degenerative and will never get better and put them on an indefinite section with wider review dates that mainly look at how much worse their condition has become. I am not being biased here - just honest.*</p> <p>Question 8: Forgive me if this is shouting but the answer here is NONE and NEVER. The reasons for this answer is that if you have spent any time with people who have disabilities you would know that you can give the same aid to ten people with the same condition and the level of improved life will be different for everyone of them. In some cases you may say well give them this aid and all is better but this is not always the case. For example if you give people who are hard of hearing or deaf, hearing aids it will help them on some level but as it was pointed out to me, they only increase the amount of noise that the person hears and they still need a lip speaker or signer to interpret what the noise is that they are hearing. The fact that the person has a*</p> <p>hearing aid does not mean that the person is able to hear; they are still deaf. If you give ten people self-propel wheelchairs again Independence is varied; some may also need a carer to*</p> <p>push them around, they are all different. Also with wheelchairs some people may be able to use them one day but not the next due to their condition.*</p> <p>Question 9: Ask the right questions. By this I mean you need to ask disabled people what their experiences have been with their conditions and the questions that would be relevant to them. Take a section of those questions that came up the most but leaving a section at the end about other things they feel relevant. I would also say that you need to separate the reporting of conditions into different sections and not group them together, one for physical, one for mental and perhaps neurological and so on but not every little condition. When you do the assessments it has to treat the whole person not individual conditions. One main question to ask is how*</p> <p>does one condition affect another. The main reason I have said about the question is if you think of it this way; when you were at school and you learnt something, has that ever been true to real life? I can say with complete honesty that when it comes to medical conditions you can throw the book out of the window if you are looking for exact answers as it is only a book of guidance. If you put a patient in front of ten different doctors you may only get two who agree with each other.*</p> <p>I would also suggest that you treat the person as a whole not little bits. Some things can "cross over" in as much as some things like going out is difficult for some people with a mental health problem but if they also have a physical problem as well it will restrict what they can do. Some conditions can also cause another problem; dystonia for example can cause more pain for somebody who has arthritis.*</p> <p>Question 10: There are possibly only three main people you can ask. First is the person's GP and I mean the one the person sees not the one that the person may be registered with as many practises have at least 4 or 5 doctors and the only one that can give you a true and honest answer is the one the person sees the most. You know who this is because you ask who their GP is but most of the time it is referred to the doctor who the person is registered with but they may not have seen the person for years. Second would be the main carer for the person as they see them normally on a daily basis. Third would be a friend who sees them on a regular basis say once a week.*</p> <p>* </p> <p>Question 11: I would like to point out here that this is my, and solely my, opinion based on past experiences. The level of healthcare professional has to be right but I would also say the old saying "who checks the</p>

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		<p>checker"? I have seen some very poor standards of work by some of the previous DLA checkers, that if it had been a politician doing the standard of work they would be forced to resign from office and would therefore suggest that some sort of mystery shopper type system was also used. The main problem with using a face to face discussion is on three levels; people with mental health problems that are told this is when they will be there and you can not change it or we stop everything until you are assessed. Secondly is that they only see a snap shot of the person and it may be a very good day or very bad one, which is why I earlier stated that it should be the GP the person sees on a regular basis and not the listed one. Lastly, face-to-face discussions can be very difficult for the Deaf community. Quite often the first language for those who are profoundly deaf is BSL which, as a separate language, has a different* grammatical style and so the services of an interpreter would be required.*</p> <p>Question 12: Reviews, in my opinion, should still be every three years for most people with certain conditions also taking into consideration, as previously stated, people with degenerative conditions maybe every five years or when the person reports a greater decline in their condition. The review should ask one question "What has changed?" This is because most items from the first claim will not have changed and you will therefore be going over old ground. You also have to remember that some people will not see any change in themselves due to the fact that they live with the condition everyday and some may not actually see a real change for years. I understand that under the present system when you are informed about somebody going in for an operation to help their condition you automatically stop all DLA benefits. This has to change for it is wrong*</p> <p>and I would say is cruel, due to the fact that say a person goes in for a replacement hip, they do not just get out of bed and walk they have to have rehabilitation time and this can vary for case to case. You have enough medical expertise around the UK to come up with a suitable rehabilitation time frame for most conditions but again it is not an exact science! You could come up with a set time frame and then do a review not just stop everything and put more pressure on a person who should be concentrating on getting better.*</p> <p>Question 13: First of all, speaking personally, you need to stop the double standards with people in so much as if somebody puts a claim in you expect them to fill in all documents and supporting evidence within a certain time frame then you say we'll get to your claim when we can. Some people have problems in filling out these forms and need help (my wife included) but the only places you can get help are so busy you may not get to see someone for 2-3 weeks and then it can take 2-3 appointments to complete (like Derbyshire Unemployed Workers Union, Voluntary Action Sheffield or local Disability Networks). You should also use bodies like Voluntary Action Sheffield who have contact with a lot of disability groups and therefore their clients. This body would be well suited to help these groups of people because of the fact they are known to so many groups and have their trust in which sadly is something they do not have in you.*</p> <p>I would also say that I would not put a fixed boundary on them as for example somebody in Killamarsh, North East Derbyshire may go to Deaf clubs in Sheffield because it is easier. These bodies like VAS would need help with funds but would save you more in the long run. Also, as stated in the answer to the previous question, do not treat people in a "bad" way. If they report* something do not just say right that's it all money stopped until a review is done; compromise and get a review done as quickly as possible but within reason.*</p> <p>Question 14: Personally the information that would be best to give people would be to support groups relevant to their condition and to people like</p>

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		<p>Voluntary Action Sheffield as these are probably the best placed people to help as they also know what is local and can point people in the right direction.*</p> <p>Question 15: No requirement should be made of anybody as it says in the title Advise and Support. People should be given control and choice. You can give somebody advice but they do not have to take it and a lot of people may believe that you are trying to force something onto them that they do not want.*</p> <p>Question 16: Funding their aids most people, like us, use all monies coming in to fund what they can afford this includes the servicing and insurance of cars, wheelchairs powered or not. The answer here is yes if possible if you are talking about advanced funds on their future benefit. It could be used to meet one off costs. It would help for sometimes there are unexpected costs say a puncture to a tyre and therefore less money in the house but they may also require a new wheelchair as theirs is not fit for purpose any more. You may say well get a loan from the bank, well banks will not loan monies to people on certain benefits, I know as a person on carers' allowance that I can not get one even for £100. Other people rely on their local Social Services Department for aids however with the current government cost cutting in all departments there is less and less money for this and quite often people in urgent need are going without vital aids.*</p> <p>Question 17: The only thing that should if direct, that should be taken into account with children is education as for all other needs they are the most supported and provided for of all the different categories of claimants. I would say for every 1 support group/network for adults especially 24-60 there is probably 5-8 support groups/networks for children; I am including charities in this and therefore get a lot more help to start with.*</p> <p>Question 18: This is very important and very much needed and appreciated. The only way that I can see of improving this would be to give a list to claimant of all passporting benefits* and for all relevant government departments to talk to each other so that the claimant did not have to keep repeating themselves or ringing phone numbers to get a letter to say that they are on this benefit. This would also include the NHS as they only need to know if this person is on a qualifying benefit or not because if you go to the cashier's office for help with transport costs most want a letter from DWP dated within one month of claiming. This obviously means 12 of this entire list; phone calls, people to answer phone, people to check and produce letter, postage and postal delivery persons.*</p> <p>Question 19: Firstly it would probably cost you a lot more money due to the fact that most people, if not all, would be entitled to it anyway. Therefore you would end up paying for perhaps 5 or 6 people to go over old ground and if it was done correctly would show up possible fraud earlier than you do now. Secondly if it did not passport to other benefits then you have a problem in as much as two things may happen; certain people would be missed or fall through the cracks and then when found if their conditions have worsened it will again cost more. In addition, if not passported then you will have to have all clients filling out more or less the same form for 6 or 7 departments which would, in some cases, put a lot more pressure on them and could make their condition worse.*</p> <p>Question 20: You could (and I feel you should) combine the DLA and any other benefits all together as long as it was done correctly as the information gathered is always the same; it is just the criteria that is different. I also believe that you should use the assessment from social services but you need to alter that assessment in as much as; my wife can ring for an assessment and she would duly be assessed. A week later I could request a carer's assessment; this is just going over old ground as my wife would need to be assessed again so that you know what my needs are. Therefore a suggestion would be that you automatically did a full assessment (carers) that involved all parties to</p>

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		<p>start with as this would cut costs dramatically. As for sharing information; the relevant government departments should talk to each other anyway but when you talk about local councils etc. then all they need to know is if that person is on a qualifying benefit. I make this point due to the fact that your assessment of the person's needs should be binding for the council* to use at that level. If you go to different councils they have different criteria; a bit like the "postcode medical lottery" you might say. All people should be assessed in the same way no matter where they live.*</p> <p>Question 21: There really is not any separate impact on different groups as long as all claims are treated the same. You state that in the race section of the consultation document that some are less likely to get the benefit. I am sorry to say but, in my experience, you have this totally wrong. It is not the benefit that is the problem here; you will find with some cultures and religions there is a stigma in applying for things like this benefit or to the condition itself, it is a bit similar to the "I am too proud to ask for help" syndrome.*</p> <p>Question 22: Disabilities in themselves do not discriminate between people for any reason so as long as you assess all claims equally there would not be a problem. I stated earlier that I believe that it does not make it clearer for the claimant to understand if you have two components of care instead of three. I believe this, in the main, is for you and or the assessors to understand. It also worries me where you are going to move the pay rates to as for a lot of people like ourselves it is a lifeline. To give you an idea why I say this I will tell you of a problem that I have in as much as my wife is hypoglycaemic and therefore needs to eat small and regular meals. This in turn costs more and as a result, like most carers, the one cared for comes first. I tend not to eat at the same times as this is not me and I do not need it. This in turn has caused me to have a condition (so my doctor has told me) called central obesity. I am told it is because I only normally eat two meals a day and not three due to the expense. With regards to appeals I would like to say two things. Firstly whoever you employ as medical professionals for the assessment, should not be/never used for appeals. This is due to the fact that if somebody appeals a decision and goes to tribunal that person could be sitting on the panel, and if it is the medical evidence that you are questioning then it would not be independent or fair. Before you say this could not happen I know for a fact that it has happened under DLA. Secondly the appeals panel should consist of a civil servant at* the head with a person who knows the legal side and a disabled person of similar problems; by that I do not mean that you use a blind person to assess a deaf person you would use a deaf person. *</p> <p>With regards to appeals I understand that government can use as many witnesses as it wants but the claimant can only have 1 due to time. This really needs to change but I am not saying an indefinite amount of people but perhaps 3 as in the 3 main witnesses of the claimant or of equal standing. This for me is a must; you need to have all conditions reported as separate conditions but you also need to assess the person as a whole because otherwise mistakes happen. When patients are not treated as a whole in medical situations then mistakes could happen but in their case it could be fatal. You asked how we should prioritise and or focus help for people. One thing that I would not use, especially in its current form, is what is known as a "sitting service". I would not use this for two main reasons; first it is the very expensive nature of it and secondly (as the saying goes) it only does what it says on the tin in as much as all they do is sit. They will not get the person a glass of water or a sandwich or even a biscuit and if they are like my wife, after 2 hours I could come back to an ambulance at my door. When you consider that 6 years ago I was told by a social worker they charge £15.20 for one hour it is just not worth it. I wish someone would pay me £15.20 an hour for what I do. I believe that if you ask disabled people and their carers about ideas that they have you could actually solve quite a few problems. For</p>

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		<p>example, how do you design a tram to take wheelchairs and seat people and pushchairs with very little change to the main frame work? You will find that someone can give you the main idea but then you just need to add the finishing touches. With regards to disabled people working then there are some things you should remember. The main one is that most employers do not want to employ a disabled person due to the many problems that they see (which are not always there). Disabled people may be able to do some volunteering and they only get out of pocket expenses but just because they can work maybe 4 hours a week does not mean that they can get or* hold down a full/part time job. There is a lot more that could be said on this subject and others but there is not the time to go through them now. To conclude I say this - if you start to talk and listen to people some things could probably get done for the good of everyone.</p>
EM489	12-Feb-11	<p>I receive DLA at the lower rate to help with personal care. I had breast cancer at a very young age and as a consequence have lymphoedema; a long term side effect of the surgery. This means that I cannot always do things for myself that I would wish to such as, get washed, dressed, carry shopping and many other things. The DLA I receive helps me maintain some independence but buys me help when I need it.*</p> <p>*</p> <p>When I was first awarded DLA, my letter said I would receive it "for life". Is this government going to honour that promise? *</p> <p>I believe the Government should not be making cuts of £1 billion to disability benefits because of the devastating consequences it could have for disabled people like me.</p>
EM490	12-Feb-11	<ol style="list-style-type: none"> 1. Your response: A major barrier is inadequate disabled access in public places, including on public transport.* 2. Your response: It should remain non means-tested* 3. Your response: Disability equipment including mobility aids. Transport costs such as wheelchair accessible taxis Cost of fuel as poor mobility makes it difficult to keep warm. Higher insurance premiums eg surcharge on travel insurance.* 4. Your response: Having two rates per component could be easier to understand and administer, provided those currently on the highest rate do not lose out.* 5. Your response: The most serious impairments, particularly progressive neurological conditions, such as multiple sclerosis and motor neurone disease, should mean automatic entitlement to the benefit, as these conditions are incurable and are for life, they are not going to go away or improve. * 6. Your response: It is essential for people to be able to live in an environment where they are enabled to do as much for themselves as possible, and in areas of life where this is not possible, to have someone to provide appropriate care. As well as obvious things like food and drink and hygiene, it is essential for people to have opportunities to get out to meet other people in appropriate settings on a regular basis and to take part in creative activities and follow their interests as much as possible.* 7. Your response: The dwp should recognise that many conditions, such as multiple sclerosis, are variable and should assess people on the basis of what they are like on their worst days.* 8. Your response: Whatever aids and adaptations a disabled person may use, these aids are not going to take the underlying condition away. The assessment should be of the disabled person's ability UNAIDED by anything not used by the general population in everyday life, for example mobility aids like wheelchairs which are the exception rather than the rule in normal society. * 9. Your response: Information should be displayed in doctor's surgeries, hospitals, libraries, community centres etc.* 10. Your response: A clear assessment of ability is best provided by

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		<p>health professionals, such as neurologists, physiotherapists or GPs.*</p> <p>11. Your response: When a person is terminally ill it would be inappropriate to require a face-to-face meeting.*</p> <p>12. Your response: 13. Your response: *</p> <p>14. Your response: It is always helpful when the information people need is available in one place, rather than them having to exhaust themselves making enquiries from a variety of sources.*</p> <p>15. Your response:*</p> <p>16. Your response: Yes, definitely, for example to fund a stair lift or powerchair.*</p> <p>17. Your response: 18 Your response: 19. Your response: 20.Your response: 21. Your response: 22. Your response:</p>
EM491	12-Feb-11	<p>I have been disabled since birth with Cerebral Palsy. I have been entitled to the higher rate mobility component and lower rate care component of DLA for a number of years. My disability is such that it will never improve and will, indeed it has already, become worse as I get older.*</p> <p>The consultation document, as far as I can see, doesn't make it clear what will happen to those recipients, like myself, who are currently in receipt of DLA for life and will be over 64 when they have to apply for PIP. This concerns me as I will probably be over 64 when I am invited to apply and fear that I will automatically be rejected on age grounds. DLA is currently a passport to other essential benefits, ie free road fund licence.*</p> <p>I think the legislation for PIP should include a clause that for DLA recipients who a) have been awarded DLA for life and b) will be over 64 when they have to apply for PIP the age restriction and qualifying periods will not apply. As an existing claimant during the reassessment period, I think it only fair that the present award will remain in payment until the reassessment is completed.</p>
EM492	12-Feb-11	<p>As the Chair of an organisation called Inclusion Alliance in Edinburgh and the mother of a 40 year old man with profound learning difficulties and intractable epilepsy, I respond to this consultation by endorsing everything that was said in the submission sent to you from the Learning Disability Alliance, Scotland</p>
EM493	12-Feb-11	<p>1. money*</p> <p>2 all of it*</p> <p>3 lunch and stuff*</p> <p>4 its cofussesing*</p> <p>5 check with gps and social workers*</p> <p>6 make it easy to understand*</p> <p>7 check with gps and social workers*</p> <p>8 of couse*</p> <p>9 not so silly questions and less thick*</p> <p>10 cut the jargon*</p> <p>11 dont ask silly questions*</p> <p>12 just the once*</p> <p>13 ask them*</p> <p>14 is it eaie to understand*</p> <p>15 lots of stuff like stair lifts and hand rails in the barthroom*</p> <p>16 cut the jargon out*</p> <p>17 it helps to know what outhe berfits are about*</p> <p>18 just what is important*</p> <p>19 no we are all the same*</p> <p>20 just think before u do</p>
EM494	12-Feb-11	<p>We are [REDACTED] who care for my father who lives with us and receives Attendance Allowance as he suffers from Pneumoconiosis and osteoarthritis of the spine. He is [REDACTED] years of age and has worked underground as a coal miner for 48 years. He is now housebound. My husband receives a Carers allowance. I am a volunteer with Age UK and through them visit with Inspectors from the Care Quality Commission to inspect Care Homes for the elderly, dementia and disabled residents. I</p>

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		<p>understand that the Attendance allowance is not included in the current changes but the Carers Allowance may be subject to means testing. In addition as part of my volunteer work I meet many disabled volunteers, who with their carers in attendance, play important and significant roles in ensuring others have a quality of life in Care homes.*</p> <p>2. I am extremely concerned that these disabled volunteers risk losing their DLA and their Carers. How are these people to be assessed? Who will carry out the assessment? Will the assessment be carried out over a period of time to take into account bad days as well as good days? *</p> <p>3. We care for my father at home at no cost to the tax payer apart from his Attendance Allowance and my husband's Carers Allowance. We use some of the Attendance and Carer's allowance to pay for a respite carer at home when we take the odd weekend break. Taking breaks allow us to remain reasonably sane and fit to continue caring for my father. Without these allowances we simply wouldn't be able to manage *</p> <p>4. I firmly believe that the Government should not be making cuts of £1 billion to disability benefits because of the devastating consequences it could have for disabled people and their carers. *</p> <p>5. I believe that the Carers Allowance must remain outside of the Universal Credit. Carers save the UK £87 billion every year with the care they provide and it would be wrong to take away Carers Allowance from some carers by means-testing it, as this would leave some carers without any recognition of their contribution and for many elderly and disabled people it will mean the difference from living at home surrounded by family to living in a Care home and I know from experience what that means .</p>
EM495	12-Feb-11	<p>1.Your response: My response relates to my own needs and experiences as I am not in a position to speak for others. I do receive DLA. I am happy with using the social model rather than the medical model. However in my own case it is pain, weakness, general and muscle fatigue and an intolerance of cold as well as the effects of polio that prevents me from completely caring for myself and from doing the social things I would like to do. *</p> <p>2.Your response: I am a female over the age of sixty and am concerned about the uncertainty over whether my needs will still be taken into account.*</p> <p>3.Your response: Transport costs when one cannot just jump onto a bus or a train. Extra cost if someone does not have a family member to shop or to keep a house clean for them.*</p> <p>The extra cost of buying healthy food. Junk food does not help anyone's health or medical condition.*</p> <p>4.Your response: I cannot see that having two rates are that much different from having three. It will still come down to the subjective judgement of the person making the decision.*</p> <p>5.Your response: Some conditions should be automatic e.g. blindness, loss of limbs. Someone should not be penalised for coping well with such disabilities.*</p> <p>6.Your response: Accessing food and drink. This must include whether the person is able to go out and buy it. Personal care. Help with this if needed. Social interaction. The ability to plan a journey has no connection with whether one is able to make that journey or not.*</p> <p>7.Your response: These must be treated as permanent conditions as the person will have little or no control over when and where the disabling effects will occur. Use of energy one day may mean fatigue for the following days. After several days complete rest a person may appear energetic but this is only because they have had those rest days. *</p> <p>8.Your response: Yes aids and adaptations should be taken into account. Mobility aids, manual or electric wheelchairs and adaptations in the house like bathroom adaptations. Small aids can make a difference. My wrist pains stopped when I changed all my taps to lever taps.*</p> <p>I do not think any aids and adaptations are easy to obtain. It is easier if</p>

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		<p>one has some money and therefore some flexibility to buy their own, otherwise one is at the mercy of someone who may not be sympathetic to their needs.*</p> <p>9.Your response: I do not know how this can be made a positive experience. Even listing what you can do draws your own attention to your limitations. If you try to be too positive you will risk not getting or losing the DLA for which you really do qualify. *</p> <p>10.Your response: Evidence from family carers and from a medical practitioner who understands what may be a complex condition. Personally I had polio,aged five and worked as a teacher and in social work for thirty years. I have only received DLA for the last five years when I weakened so much and began to suffer from post-polio syndrome. I had a diagnosis from a neurologist. I was visited at home by the DLA doctor. I have learned to self-manage my condition. I worry that the fact that I never bother my own GP would count against me if I was reassessed.*</p> <p>Your response: yes a face to face discussion with a professional is essential but it must be someone who is medically trained and can do a medical examination or will accept evidence from the patients GP. No one else has the training or experience to make these decisions. Some conditions are too complex for a lay person to grasp and will not fit into tick boxes.*</p> <p>People with mental or emotional conditions may have difficulties with this.*</p> <p>12.Your response: There is no point in reviewing people with life long conditions such as polio. As stated above I worry that although I am getting weaker all the time I do not see my GP.*</p> <p>There is no treatment available so I do not waste his time. Reviews must depend on the individual and the cause of the disability. There are many people whose conditions cannot improve but will only worsen with the extra wear and tear on the body that disability brings.*</p> <p>It may be that those with life long conditions should be reviewed differently to those that have recently suffered some sort of disability, although I realise that I would fit into both these categories and needed no support for most of my life.*</p> <p>13.Your response: I have no experience of this but the emotional effects and the stress created by an illness or injury needs to be taken into account. People must be treated with some sympathy and understanding.*</p> <p>14.Your response: information about support groups would be helpful if the person did not already belong to one. These groups are often more informed and more helpful than the medical profession. *</p> <p>15.Your response: I do not like the idea that one should be required to see someone. Some specialists are not sympathetic or supportive. I have been sent to physiotherapists who knew nothing at all about polio and wanted to "build up" my damaged muscles. This is against the advice of all the experts on this condition. I have had a lot of help from an Alexander Technique Practitioner which was expensive and may not suit everybody. *</p> <p>16.Your response: I fund my adaptations from my DLA. This fits in with your social model. I have the freedom to choose what is right for me and avoid being told what I can and cannot have or be given something that does not really fit my needs. It also means I do not clog up hospital waiting lists but stay independent. I buy my own car. Although I qualify for zero car tax, I pay for the car tax so my husband can use the car without me in it.*</p> <p>17.Your response: As a child with polio my parents and I received no allowances so I have no experience of this.*</p> <p>18.Your response: Personally a blue badge is a must. If I were to lose my DLA the loss of the blue badge would be my biggest loss. If I cannot park close to where I need to go or do not have the extra room to get out</p>

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		<p>of the car and into my wheelchair that would seriously alter my life. I only have energy to leave the house twice a week as it is.*</p> <p>19.Your response: I only have experience of the blue badge scheme.*</p> <p>20.Your response: I don't see any problems of sharing information except those of security of personal information.*</p> <p>21.Your response: *</p> <p>22.Your response: As I have been typing this I have really seen that the social model of disability depends on the clients being encouraged to be independent which means being allowed to spend DLA in a flexible way and being trusted to understand their own conditions. If they manage well without adding to the burden of the NHS then they should be encouraged to do so and not be forced into stressful situations. It is unfortunate that the current climate sees those who claim a benefit as scroungers even if, as in my case, they have paid taxes for many years. There are many people struggling to live their lives with their disabilities and these people should not be treated as though they are dishonest.</p>
EM496	12-Feb-11	<p>without this I cannot go to the doctors and other places I can only drive 8mph scooter and reg but will not go on road can walk 5mts i pay for every thing to be done in my bungler that is the real reason we get D.L.A and why should take more money from taxpayer catch the ones that are not ment to be on it.</p>
EM497	12-Feb-11	<p>believe certain medical conditions should automatically be approved. Whither terminal illness OR incurable disabling conditions such as multiple scoliosis. A medical condition with a medical opion on disability should automatically entitle allowance</p>
EM498	12-Feb-11	<p>1.Many people need to be accompanied to participate i.e. due to physical disability, learning disability , sensory disability , mental illness. The costs related to this are significant . *</p> <p>2.The personal care assessment needs to be retained as measuring what the fall out would be if an individual did not get the appropriate level of support . Mobility component for people in residential care is crucial to the continued inclusion in the local community. *</p> <p>3.Transport is significant e.g. taxis because buses are not accessible : double fares when a supporter is required , 24 hour residential support for vulnerable people – particularly those with a learning disability or mental health issue.*</p> <p>4.It may be easier to administer – I would not know about that – how would it be easier to understand ? The current tripartite system measure levels of need/ability/disability – the problem is with how the system interprets need and applies points. Does it take into account what would happen, for instance, if there was no support available?*</p> <p>5.Some health conditions/impairments should qualify for automatic full entitlement e.g. paraplegia, severe learning disability severe mental health conditions. *</p> <p>6.If inclusion is the objective (and I believe it is) then whatever the individual needs to access the community is essential. Physical support, mobility aids, personal assistance for care and community access . *</p> <p>7.If conditions are variable then regular checks with appropriate health professionals would provide the solution – more frequent applications for benefit ? If those with life-long impairments/needs automatically qualify for benefit then the time currently consumed in their assessments would be released to deal with those with fluctuating conditions.*</p> <p>8.Surely what should be measured is how the individual varies from the 'able-bodied 'norm' ? *</p> <p>9.I don't see how the process can be made into a positive one – if an individual (or carer) has to record all that makes life a difficult and excluding experience it is bound to be depressing ! What would help would be the assurance that the intention of the assessment is to improve the quality of life by ensuring that financial anxiety is a thing of the past. *</p>

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		<p>10. Medical reports, social reports, employers/carers/family reports will provide the necessary evidence*</p> <p>11. Face to face can be good – but it would need to be carefully done for some people e.g. with autism, learning disability mental illness. Supporters would be crucial. It is important to remember that most people try to take a positive/optimistic view of their own life and consequently an unfamiliar might not be in a position to accurately assess the level of need. *</p> <p>12. The criteria should be determined by the nature of the condition i.e. those with lifelong impairments which will deteriorate, or remain at same level of high level of support should not need frequent reviews. * Those with fluctuating needs would need reviews set at a time which the professional involved deems appropriate e.g. medical or care provider.*</p> <p>13. I am not convinced that it will be easier for everyone to understand – people with a learning disability for example could struggle without a good support service – which they would have to pay for but may not be able to afford it if their benefit level is not high enough to meet personal care/ social / and personal assistant needs. *</p> <p>14. It would be necessary to offer advice and information via a third party – but in the case of an individual with a learning disability this would need to be someone who spends enough time with the claimant to develop a relationship of trust --- this would be expensive if there is not an easily identifiable support worker in place already. *</p> <p>15. It might – but it might actually put some people off if it was seen to be a mandatory gateway i.e. implying false claimant*</p> <p>16. Some people buy their own (or receive charitable support) because it takes too long to get them any other way --- or the aids offered are not adequate e.g. heavy wheelchair rather than light weight, not motorised and therefore dependent on a strong pusher. *</p> <p>17. A small child requires the presence and attention of an adult at all times – some require significantly more due to specific impairment. For the latter group there are additional childcare costs – most registered childminders and nurseries are reluctant to take them and this has a serious impact on the parents to access employment.*</p> <p>18. DLA has proved to be an important vehicle for people with disabilities – the lower level of mobility allowance however is not adequate for those who are able to walk but cannot be safe out of doors due to special and road safety awareness, emotional vulnerability, inability to communicate etc *</p> <p>19. I cannot believe you are asking this question! We would be back to exclusion and not simply second class citizenship – more like third class .*</p> <p>20. Health and social care needs*</p> <p>21. *</p> <p>22. The concerns people have are that this is an exercise in cutting costs rather than improving lives and appropriate independence and choice. People with disabilities are made to feel as though they are potential 'cheats' rather than individuals entitled to support in a society which is still difficult to access without adequate financial resources and physical support.</p>
EM499	12-Feb-11	<p>Q1. Primarily those arising on a medical model. Regardless of the social environment, if you need a wheelchair you need a wheelchair - modern legal frameworks and societal attitudes do nothing about picking up your crutches and walking. Yes, more workplaces have ramps and lifts now - you still need the bloody thing to get up them.*</p> <p>For myself, I can say the greatest barrier is the failure of the NHS to provide desired treatment, leaving me stuck trying to do all I can to recover on my own, with limited and very slow progress. You need to get service provision right as the first step towards reducing the DLA caseload: it is not the benefit that is broken.*</p> <p>Otherwise, my biggest barrier is that I can't cope with the world and hate</p>

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		<p>myself fundamentally. DLA currently enables me to partially overcome this barrier so I can ensure greater self-care, reduce self-harming and self-neglect, and safe-guard myself from unnecessary exposure to trigger situations. It gives me the support when I need it to present a better face to the outside world and build confidence, and allows me flexibility and choice to work on my own programme in a realistic timescale towards building capability and eventually full independence. If PIP doesn't do the same I'm screwed - I can't see me ever getting out of this hole.*</p> <p>A complication faced by those with mental health problems is the fear that many of the things support allows us to do will then be taken to 'prove' we don't need the support. On the surface, I've been told, I don't "look like a mental health case". Well, that's because I have superb help, which is helping me get better. How does the examiner then assess me? What if he goes on surface appearances and decides I no longer need the help, and after struggling for a few days/weeks/months I collapse again? *</p> <p>I don't think people outside the mental health experience understand the fear the spectre of relapse provokes. I don't want to ever go back there - I am frightened of my illness. I don't know if anyone with physical disabilities can be frightened of their disabilities on the same scale. Given this engulfing fear, it is no wonder some people are scared of risking expanding their horizons - someone might decide you're fine, whip away your support and down you go back down the hole.*</p> <p>Q2. Most of it - certainly all you have listed.*</p> <p>2:12-15 are apologies for the change of benefit and are deeply unconvincing; in fact complete tosh in several places. *</p> <p>2:12 I don't find DLA's criteria unclear at all. And of course they are subjective. People don't fit into boxes, so it can't be objective.*</p> <p>2:13 I don't see that PIP is going to anything substantively different from using the current proxies, is it?*</p> <p>2:14 The current definition of mobility may well concentrate on ability to walk - I think that is how most people would first define it, now as in the 90s. There is also currently scope for 'ability to get around more generally' to be taken into account - or I wouldn't have got my award - which you appear to be trying to deny to the current system. This is factually incorrect and misleading.*</p> <p>2:15 Does not DLA do this already? Isn't that what the rates are about? You are claiming PIP is better because it will do something DLA already does!*</p> <p>Q3. aids & adaptations and their upkeep; care; public or other particular transport needs; everyday self-care; company and social contact.*</p> <p>For myself, DLA allows me to buy foods I am actually okay to put in my mouth without spitting, vomiting or losing control and going on a week-long binge; toiletries that help me not take sandpaper to my skin or try cutting bits off or out; enough phone credit that when I panic and need immediate support I can ring for help; a home environment, for the first time in my life, that doesn't make want to crawl under the sink & die; transport for when I need to get somewhere and can't face it alone, so would otherwise avoid going. I'm prepared to bet that these are not the kinds of things that readily occur to those designing the benefit, but DLA has been absolutely central in getting back on my feet and at least semi-functioning.*</p> <p>I think the mental health benefits of DLA receipt are often overlooked now, and I can't see that any proper consideration has been given to them in designing PIP.*</p> <p>Q4. a. No it won't make it easier to understand - in fact it baffles me to reduce the rates. I can't see how it improves personal tailoring of the benefit - I can just see it being easier to administrate. And are you just doing away with the bottom tier or care, so those entitled under current criteria to that tier only will now get nothing? How you rejig the tiers is not clear. I've not actually met anyone who finds it hard to understand,</p>

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		<p>George Osbourne excepted. It's obviously beyond him.*</p> <p>Q4. b. A great reduction in flexibility. Two people with widely varying needs would be more, not less, likely to end up on the same amount.*</p> <p>Q5. Apart from terminal cases, it seems fair that all other cases are viewed individually. However, the known severity of a health condition should be taken into some account when determining award and rate. For example, at the point an advanced cystic fibrosis case is denied any award, alarms should start ringing without waiting for the individual to appeal. Also you need to be careful not to start considering individuals 'within' their condition - "he's in very good shape for an MS, so lower rate - she's got the worst arthritis I've ever seen, so higher rate". I think this is a risk when experts in their field are solely depended upon to judge, who may see dozens of people with the particular disability a day, and use actually less 'normal' criteria than a more ignorant person. *</p> <p>However - what do you mean by "circumstances"? Would that mean that someone unable to find enough rent to leave home in London would get a lower rate than someone with exactly the same medical level of disability who is on Housing Benefit but on their own in Newcastle? What about the elderly widow who owns her own home in Kent - should she get less or more than the mum-of-two with a mortgage but now no job in Devon? If you bring "circumstances" into it you are really going down a dangerous path, and possibly an expensive illegal one.*</p> <p>Q6. Cut caseload not costs. Accept the cost will keep going up until the NHS sorts itself out and actually helps this who can get better, not maintain them at a stable but low level of sub-existence. Sorry - but if we decide we want to be civilised and care for the ill, we have to pay for it. I hope one day to be better and a tax-payer, the higher rate the better - and if my taxes are not going to people who need it I will not be happy. The best way to reduce costs is to reduce the number of ill people; unless we decide we don't want to be civilised, and screw 'em.*</p> <p>I would have thought creating more rates, not fewer, would allow greater breadth to the award. Those who currently might not need all the lowest rate could go lower, those who might not need all the middle rate ditto, those who need a bit more than the middle rate could go a bit higher, etc. Stretch it. *</p> <p>Essential activities start physically with eating, drinking, dressing, washing, exercising; but continue in the mind. Talking, reading, watching TV, internet access, music, playing games, having a pet, offering friends tea when they come round, choosing meals & shopping, choosing clothes, creating your own environment, access to your family - all these are inside the home. Outside you have friends, family, changes in environment, participation in local activities and governance, voting, access to countryside, access to a range of shops, exercise. I think wherever at all possible people should be able to tick all the first set (physical) and several from each of the next two sets (at home, out & about). I think it is vital anyone who can possibly, possibly get out of the home, even briefly or rarely, should have the opportunity made a right. I don't think anyone should be unwillingly limited to the first, or the first and second set. The range is important. Maybe people could tick which activities are most important to them, several from each set, and concentrate on how the benefit would help them achieve those?*</p> <p>Q7. Trying to get a timescale within which the fluctuations occur: for example, do psychotic episodes come in spates, once every few months, about twice a year but always in the winter? How many days in a week are you unable to climb the stairs? You certainly need to make sure you do not assess the person on their 'good' days. I thought the current form - which is certainly long but not really as confusing as you attempt to make out - asks about this? Well, take your cue from there. *</p> <p>But then how to adapt the benefit to that? It'd be easier with more rates. Someone with distinct episodes could be on a 'sleeper rate' with an option for immediate raise of rate triggered by authenticated notice when</p>

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		<p>an episode occurred. But that would be extra admin, and your proposed rates are far too inflexible. It would be easier to assess the condition's effects over a given time period - a year seems reasonable - and allow / rely on the recipient to save during the good times in preparation for the bad, which gives people far more independence, control and choice.*</p> <p>Q8. a. No of course it bloody shouldn't. The logic that having an aid or adaptation means you don't need it is self-evidently flawed. *</p> <p>b. none. What the hell are you thinking of? You should be assessed in your birthday suit, as it were.*</p> <p>c. oh really - if someone 'already has' a prosthetic limb, or a wheelchair, they'll never ever need a new one, will they? And what's this 'easily obtain'? Wheelchairs grow on trees, do they? Even if someone only needs a stick, that still limits their activities in ways which may require further expenditure - for example, they may not be able to use it safely on bus steps and need to take taxis - and they still need to buy new ones! If you're not wanting to assess people on a health-condition basis, why on earth would you assess them on an equipment basis?*</p> <p>Simply saying you're 'considering' that people use their DLA towards aids & adaptations is not good enough. You need to drop this threat. My friend is panicking because she depends on her wheelchair (NOT NHS provided or serviced i.e. a long way from free) to get about outside, and on her car to get to work. If the wheelchair & car are 'taken into account' and she loses DLA, she won't be able to afford them and won't be able to get to work and her quality of life will plummet.*</p> <p>Q9. a. I don't think applying for benefit is ever going to be a 'positive experience' - that's a daft thing to say.*</p> <p>b. It is a while since I filed in a form and don't feel able to comment. I remember it being depressing to have to recall things I'd rather forget & face up to my illness (refer back to comments on mental illness & fear, above). But I remember a reassuring tone.*</p> <p>c. You could tell the bloody chancellor about the old one for a start! He appears to believe DLA is an out of work benefit - in the Budget he talked about 'getting people off DLA & into work'. If the people at the top don't know, and can get away with making basic factual errors like that without being pulled up, it's obvious the media don't know either, or don't care. Wider dissemination at general population level would make life considerably easier for disabled people facing ignorance and confusion, and possibly being misinformed and put off applying when they need it, or encouraged to apply when they don't. Informing health professionals would be a good start too - I was lucky and my CPN knew about it, others' didn't so they went without. This would be better directed publicity and information than any number of racks of leaflets wilting in a corner in the GP's.*</p> <p>Q10. The people who work with and are trusted by the applicant will ahem the best quality information - far better than the independent assessor can hope to gain in an hour or so's meeting, especially with complex and mental health conditions and variable and fluctuating conditions. The weighting given to their evidence should reflect this - that should help keep appeals, which must be costly, to a minimum. When people can see their trusted professional has been involved from the start they are more likely to trust the outcome is valid. *</p> <p>It is utterly vital the decision makers are not a target driven firm, especially one from, say, France. There must not be a pay-by-rejection scheme.*</p> <p>Telephone discussions (mentioned in 2:33) seem something to keep to an absolute minimum, only when physical barriers are so insurmountable there is no other option. A lot of people are uncomfortable speaking on the phone, especially people with mental health problems or language difficulties.*</p> <p>Frankly, your GP will know sod all. It's a waste of time & paper at the moment to ask for information from GPs.*</p>

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		<p>Of course the assumption is there <u>is</u> a health care professional involved. Increasingly as people are sent home to rot for life on medication there is no relevant professional, which is scandalous for the NHS, and problematic for benefits.*</p> <p>Q11. Face-to-face is nerve-wracking to terrifying, but better than phone. Home visits sound good but would presumably be more costly to administer, and there's the issue of lone-working to consider. Time off work could be a problem for some people and out-of-work hours appointments would be needed. A choice of appointments or the option to phone and book would be better than the current terse summons & threats over non-attendance. *</p> <p>How about a dedicated advocate attached to a test centre to better enable frightened applicants get their words across? It should reduce non-attendance, confusion, wrong decisions and appeals.*</p> <p>Q12. a. as close to new assessments as possible, just with a 'no change' box instead of having to rewrite everything every time. Copies of your original / previous application sent out with the review form would be useful. A face-to-face and supporting evidence from your key health care worker should back this up.*</p> <p>b. whether or not someone's condition is going to get better is a good start. My friend with arthritis is never going to miraculously get better - her changes are going to get worse. *</p> <p>A medical model is again more helpful than a social one here - society is not going to change far enough fast enough to make any difference to any individual, even if any changes could actually make a difference to what someone needs to function.*</p> <p>c. Probably. Some lifelong conditions may only need an occasional statement that the award is still valid, and a full review would be a waste of time & money. Some conditions might need an update & statement; and some might be feasibly cured in a year or two, and need regular reviews. For example, severe autism is not going to improve, though how an individual copes with the benefit's help may do; a personality disorder is unlikely to be cured but may become better controlled with drugs or therapy so the individual functions more independently; depression can go (I hope).*</p> <p>Q13. You could not jump up and down on them sending threatening letters and stopping their payment with no warning until the letter arrives two weeks later and they've spent all their phone credit trying to get through to find out what happened when all they were trying to do was notify you of a formality to keep your records up to date. That would help. I hate having to update DWP on even the smallest things as they cock it up every time. It is seriously off-putting.*</p> <p>Better - or in fact any - advice & signposting on how to manage a new budget when the award changes would be reassuring. A phased-out change instead of a sudden cut-off would help people adjust - it's the fear of suddenly finding yourself entirely without something that was integral to how you managed that scares people from risking contacting DWP about changes. That and the cock-ups.*</p> <p>Q14. Signposting is okay, though with localism that's going to be a nightmare to administer, you'll need different letters for each commissioning area. You would hope that the avenues of care and treatment in the healthcare system would already have been made clear, but maybe that's not as safe an assumption as it might be. Advice can often be patronising - if anyone suggests I eat turkey sandwiches I may have to hunt them down and force feed them.*</p> <p>Q15. No, no, and no. And again no. If PIP is tied to sending people along to approved service providers like Working Links you will have a disaster on your hands. We go to Working Links, then to the Job Centre, then to DWP, then to the NHS, then to the Job Centre, then to Working Links, then back home to rot on meds . . . the Danse Macabre. It actively makes people iller, spending their time shuffling like the condemned from</p>

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		<p>pillar to post.*</p> <p>If you need financial support you need it - morally that need cannot be judged dependent on someone's turning up at approved outlets; this is like the Victorian ladies who wouldn't feed the starving unless they prayed first. Financially, the Danse is wasteful, as square pegs are repeatedly shoved into round holes to no purpose other than going through the actions of being seen to be doing, and as each hole decides the peg doesn't fill it spits it out towards another hole, for the process to be repeated. I'm sure none of the agencies involved particularly want a stream of PIPs turning up on their doorsteps; they are not geared up to disabled people at all. You could improve the NHS service, and stop cutting community and charity budgets, instead.*</p> <p>Q16. What is this 'one-off cost'? Cars are not a one-off cost - what about petrol, service, MOTs, tyres, insurance, etc etc. Wheelchairs need servicing and replacing; even walking sticks get worn. *</p> <p>Q17. I don't know enough to comment on this.*</p> <p>Q18. Useful, and it serves as my only written proof I'm willing to show at cinemas, coaches, etc, when I need a carer's support to travel or get out. I do not access most of the mentioned schemes so I cannot fully comment on this. It certainly cuts duplication in the system, though.*</p> <p>Q19. If the disability premiums of means-tested benefits are axed when someone is on PIP, so it is a choice between PIP & the premiums, there should be bloody revolution. That would be making a mockery of both benefits - a means-tested benefit premium is based on impacts on earning ability, DLA/PIP is not, so why confuse the two systems? The confusion mentioned in 3:5 appears to be the Government's. Is this the key clause in this consultation - that it will be an either / or? If so you are not giving it due prominence and that is underhand.*</p> <p>Q20. I have not undergone multiple assessments as I do not access different funding streams, so I cannot comment on this.*</p> <p>Q21. The hidden agendas appear to threaten the poorest in society unduly. For those in well-paid work your agenda to cut the caseload may not unduly affect them; for those unable to work, or simply unfortunately jobless, its loss may be devastating. *</p> <p>You say repeatedly that DLA is a barrier to working. You are wrong - it is entirely the opposite. For me, it is the one source of income I know would stay stable when I eventually make it into work, when everything else financial will go into terrifying chaos at exactly the same moment my life is terrifyingly new. Now it looks like that stable element risks being undermined, and that is a BIG disincentive. DLA was going to be my hands-up, my stepping stone, the bit I could depend on whatever happened in that period of change. DLA has been integral to me building my life into something liveable. If it goes because I appear too normal with its help and an incentivised company assesses me superficially, or because it is an either / or to the Universal Credit, or because you want to make disability realities fit the figures, not the figures fit the realities, I can only see myself falling back down again when I try to take off. It is a disincentive - I will still try, though others might not, but it's the NHS and DWP who will have to pick up the pieces when I crash. That is not cost effective, not right, and not fair.*</p> <p>Q22. I am completely unclear, from reading your consultation document carefully twice, exactly what will be different about PIP. I can see the re-introduction of a ludicrous entitlement criterion - having had to be entitled in fact for 6 months before you are entitled in name (2:18) - and restructuring to a less flexible 4 tiers in total. Otherwise all I can see are empty words about being more enabling, dynamic, active, etc. How exactly? In what way? You don't say. Anytime you do recognise a grey area (aids & adaptations, 2:37) all you do is say you'll think about it later. *</p> <p>This woolliness leads me to deduce you are creating a 'new' benefit to fudge the fact you are just cutting off support to many who currently</p>

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		depend on it. It's easier to get away with shifting goalposts when you're shifting the pitch at the same time.
EM500	12-Feb-11	<p>1. Mobility difficulties – unable to use public transport, difficulties walking. Difficulties understanding what help is available to them. Lack of opportunities to integrate with people who are not disabled on an everyday basis, particularly if the disabled person has mental difficulties. Limited options in terms of day care centres.*</p> <p>2. It should not become a means tested benefit. If an applicant has a disability e.g. paralysis that is clearly permanent then they should not have to go through regular reassessments.*</p> <p>3. Paying for Carers – both at home and day care. Transport. Heating.*</p> <p>4. Two rates per component should be easy to understand. The difficulty comes when the definitions are too rigid, and applicants don't know how to show the level of care that they require. There are applicants who severely disabled, requiring significant care, but who lose out because they don't know how to "negotiate the system".*</p> <p>5. Extreme conditions should mean automatic entitlement.*</p> <p>Some conditions should be tested initially and then should be a permanent entitlement for the individual thereafter.*</p> <p>Other conditions should be tested on a regular basis (but not too frequently).*</p> <p>6. Personal care – meals, showers/bathing, heating*</p> <p>1. Socialising – it is essential for disabled people to have to opportunity to get out of the house at least a couple of times a week and integrate with others to be able to make friends. Loneliness is a very real issue facing many disabled people.*</p> <p>7. Base rate with clearly laid criteria for additional benefits that are available. It is important for the applicant to know what the minimum they will receive every month is. The rate should not change in a way that the minimum amount is uncertain.*</p> <p>8. The only aids that should be taken into account are aids that the applicant already has. Consider aids only to the extent that the aid puts the applicant on par with someone who has no disability. E.g. a hearing aid which when worn means that the applicant is not disadvantaged against a person with no hearing difficulties*</p> <p>9. Streamline the evidence process wherever possible. E.g. if the claimant might have an automatic entitlement they should not have to fill in endless forms, but should be able to sign one page and have a doctors certificate showing that there is a permanent disability. The overall categories for qualification should be clear, and there should be accessible detail underlying the categories. Link the categories to the type of evidence that is necessary to show that the applicant qualifies. Paralysis might mean the applicant qualifies, but in practice for example the applicant will need to show that they are either wheelchair bound or cannot walk more than x feet in under 5 mins – this makes it clear what the applicant will need to show in order to qualify.*</p> <p>10. An OT or the GP, as long as the qualifying criteria is clear. Perhaps standardised forms/ template letters can be provided to GPs so all the GP will need to assess is whether the applicant falls into the relevant bucket/ fits the relevant criteria.*</p> <p>11. It will be beneficial only if the healthcare professional is trained to extract the applicant's actual needs. Often applicants don't really know what they need to say or what difficulties they should be highlighting. If the applicant is unable to explain their circumstances then it should be possible for a relative/ friend to attend the meeting to help the applicant to explain.*</p> <p>12. Reviews should be as infrequent as possible (maximum of once every 3 years). They cause significant burden on individuals who are already facing many difficulties in their lives. They also introduce a level of uncertainty, whereby the applicant worries that the benefit will be taken</p>

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		<p>away from them. Some conditions should be subject to reviews, and some permanent conditions should not have to face reviews.*</p> <p>13. *</p> <p>14. Qualifying categories, types of evidence required for the benefit* It would be helpful to also provide information on other ways the applicant can lead a healthier/ fuller life e.g. day care centres in the area*</p> <p>15. Access to regular support. Helping them to understand how the changes may affect their lives, particularly what other support is available to them. Putting everything in simple terms directly linking each point to the actions that the person will need to take.*</p> <p>16. Usually through grants, or through the DLA. One-off costs should be met through a separate benefit or through add-ons to the Personal Independence Payment ("PIP"), but the PIP should not be used directly for one-off costs as this will cloud the picture.*</p> <p>17. *</p> <p>18. It has been essential. It helps with mobility – through blue badges and the motability scheme.* In addition, the care component can be used to help put aside some income to pay for carers.*</p> <p>19. The applicant would be unable to actually realise the benefits and see the change in their lives. Provision of cash in the form of a benefit is not sufficient as some disabled people will not understand how to use this to actually change their lives. Schemes like motability, and subsidised carers through local authorities are invaluable.*</p> <p>20. Home care through local authorities is tested extensively, and applicants have to go through onerous reviews, if this process can be combined with the testing of disability benefits it would be helpful.</p>
EM501	12-Feb-11	<p>Hi, My name is [REDACTED], together with my wife, [REDACTED], we look after our [REDACTED] year old son [REDACTED].*</p> <p>I am aged [REDACTED] and my wife is [REDACTED]. We have looked after [REDACTED] for all of his life and intend to do so for as long as he needs us to.*</p> <p>Unfortunately [REDACTED] was born with multiple physical defects although A1 mentally. When [REDACTED] was [REDACTED] months old, due to a medical procedure going wrong, he suffered brain damage thus destroying his greatest asset. [REDACTED] has a heart condition, four defects, limiting his exercise tolerance and a bowel condition requiring a colostomy. As a consequence of the brain damage [REDACTED] also suffers from Epilepsy and that is just a few of his problems.*</p> <p>We are most concerned about the Governments plans to replace DLA with PIP, and to re-assess people like our son. Because of the care our son gets he presents very well indeed, and on first impressions you would see very little wrong. We wish this were the case naturally!*</p> <p>There are a great many severely disabled people, and their carers, gravely concerned about the governments intentions, to re-assess disabled people with the intention solely to save money is a very worrying development. People like ourselves save the country around £87bn a year in health care costs. Trying to save £1bn is commendable but may end up costing much more if people like us have our support withdrawn. Nobody chooses to be disabled! Yes we all know there are some shirkers who invent or exaggerate illness/disability but these are an unavoidable minority who can't always be unmasked. *</p> <p>If Carers Allowance is incorporated in Universal Credit, carers struggling to cope with a very reduced income will be in very dire straits. Regards,</p>
EM502	12-Feb-11	<p>We are the parents of a 47 year man with Downs syndrome who lives in a residential care home and are responding as parents who closely monitor the welfare of our son and have regular contact with him.*</p> <p>1. Our son is <u>severely mentally impaired</u>. This means he can only participate in society if he is well managed by care staff and part of that careful management is escorting my son to his daily activities such as</p>

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		<p>Riding for the Disabled by means of the in-house transport at the residential care home where he lives. *</p> <p>It should not surprise anyone if some care staff were deterred by the considerable difficulties in managing potentially difficult residents on public transport and, therefore, limited the opportunities of the severely mentally impaired to access amenities and facilities that do, in fact, bring some semblance of normality to their lives.*</p> <p>3. The company which runs my son's residential care home require him to pay £92 every 4 weeks towards the costs of providing transport and petrol. He pays this from his DLA mobility component.*</p> <p>4. It is quite conceivable that having two rates per component may lead to some people not being assigned to the appropriate rate.*</p> <p>5. A difficult one to answer but on balance some health conditions or impairments e.g. being severely mentally impaired should automatically be the main criterion.*</p> <p>6. All disabled people should receive support according to their health conditions and impairments. My son benefits enormously by being enabled to access a variety of physical pursuits which include Riding for the Disabled, a gym, a dance class, trampolining etc. <u>This regime is essential to his well-being</u> because if left to become bored in the house where he lives there are often serious repercussions in terms of aggressive behaviours and self harm.*</p> <p>7. Assessments should involve persons who have a professional understanding and involvement with the disabilities they are assessing. Where parents or siblings are still actively involved in monitoring the welfare of their sons, daughters, brothers and sisters, they should always be consulted. They are frequently the one constant factor throughout the lifetime of the disabled person and their input should always be invited. *</p> <p>9. Access to telephone advice in respect of form filling is important. It could be helpful to circulate information on the new benefit to some people on a trial basis with an invitation to flag up questions or statements that are unclear or ambiguous.*</p> <p>10. Psychiatrist's diagnosis and assessments from the psychological service. There are many parents who still have very regular contact with their sons / daughters even when they live in residential care homes. The manager of my son's present care home has consulted us very closely indeed in the composition of his various support plans. The family is obviously well placed to provide continuity of information and frequently, as in our case, maintains detailed records relating to medical and behavioural history. *</p> <p>11. It should be understood that in many cases, as with our son, the verbal abilities of the disabled person may be extremely limited and a meaningful discussion will only be possible, therefore, with those who know the disabled person best. It should also be noted that in some cases it will be very unsettling for the disabled person to be discussed in his/her presence. In many cases we would expect that reasonably intelligent and articulate parents who maintain regular contact with their son/daughter should be consulted as the first point of contact in any face to face meeting with healthcare professionals. In this instance, parents should be asked if they would like that meeting to be conducted in the family home. We would, of course, also expect that the manager of the residential care home was consulted. *</p> <p>12. It could be argued that the less serious or disabling the conditions of the applicant for benefit, the more frequent the reviews. Seriously disabling conditions where there are no expectations of significant improvement should be reviewed less often.*</p> <p>18. The mobility component of the DLA has been of vital importance to our son in so far as he has been able to access a wide range of activities in the community. This daily regime has been identified by the Behavioural Support Service as fundamental to his emotional and mental</p>

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		<p>well-being. They provide an outlet for his considerable energy. The activities give him the means to achieve success and feel good about himself. His needs are complex as he has a low IQ but relatively high physical ability combined with an emotional and sometimes volatile personality. *</p> <p>19. When confined in the pressure cooker atmosphere of a residential care home for any extended period of time with other residents who also have challenging behaviours, our son can become worryingly physically and verbally aggressive towards others as well as likely to self-harm. This is at the heart of the matter when we argue that our son and others with a similar profile in residential care homes depend on the support until now provided by the mobility component of the DLA.</p>
EM503	12-Feb-11	<p>My names [REDACTED], at [REDACTED] I had swelling of the brain and a year later I was told I had Multiple sclerosis. By word of mouth at hospital visits my family looked into how I could get help.*</p> <p>I will agree the whole process of filling out the endless forms was brain numbing but luckily I was able to ask my family for help because I couldn't have done it myself. I was lucky enough to be entitled to receive DLA and mobility allowance. *</p> <p>My hospital is over 150 mile trip each time I have an appointment. My car is my independence and my only option when I need to see my doctors and MS nurses. My DLA helps me pay towards a cleaner to come in every fortnight. Without it I wouldn't be able to afford that help. Other help I need I pay for myself. *</p> <p>I have only recently received ESA and severe disability premium as my MS got bad enough that I had to stop working. *</p> <p>My MS had beat me. These two benefits help with my outgoings but DO NOT cover them. Anyone who thinks that they are stopping people from getting back to work are very deluded and should try to live off them themselves. Don't get me wrong I am VERY grateful for all the help I receive but that is insulting. I am trying to get back into work part time but I'm finding it very difficult. I've never been out of work before.*</p> <p>MS doesn't go away, ever! Learning to cope with it is a huge thing. Trying to keep a little bit of Independence and dignity is a massive fight every day. With greatest respect</p>
EM504	12-Feb-11	<p>1. : Many people simply don't understand disability; it doesn't mean we can't do something but that we may need adaptations/help to assist us. Mobility is a considerable barrier for me, even getting out of the house let alone travelling anywhere and many buildings still don't have sufficient accessibility. *</p> <p>2. : Totally Blind people should keep the higher rate of Mobility which comes in to force in April and which has long been required.*</p> <p>3. : Adaptive technology/equipment, Building adaptations, Carer, Mobility, Travel, Food labelling for the Blind.*</p> <p>4. : Yes it is likely to be easier to understand however I would like to see what the differences are in qualifying criteria for each and the financial implications.*</p> <p>5. : Yes some conditions or impairments should mean an automatic entitlement, where the condition/impairment is profound and will not improve such as a totally blind person. Only those where there will be an improvement in the condition/impairment over time should it be necessary to be regularly assessed in order to claim the benefit.*</p> <p>6. Your response: Make the benefit automatic for those with profound conditions/impairments that will not improve therefore decreasing the administrative and cost overhead.*</p> <p>In terms of the activities that are most essential for everyday life this is clearly everything a fully able bodied person does!*</p> <p>7. Your response: I am unable to respond to this question as my condition has been the same since birth.*</p> <p>8. Your response: Yes however as from experience not all adaptations</p>

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		<p>can be used by all people even with the same condition and most adaptations are very expensive and have to be funded by the individual.*</p> <p>9. : The DLA form does indeed focus on the negative not on what we can do which is very demoralising even degrading at times, for example how many minutes do you need help going to the toilet? It should use tick boxes, for example someone either needs help going to the toilet or they don't! It will make the form quicker to use, it could be computerised and is a lot more objective.*</p> <p>10. : This will surely depend on the condition, in my case for total blindness I feel that my Carer and my Rehabilitation Worker from the KAB know me best and what I can and cannot do.*</p> <p>11. : One difficulty I can envisage is that the healthcare professional will need to know the person's individual condition and have knowledge of what affect this can have on the person's abilities. Another difficulty will be that a face to face discussion will not always visually show what difficulties the person is having especially if the discussion does not take place in the home.*</p> <p>12. : A review should take place if a claimant feels their condition has got worse, for people whose condition will not change it should not be necessary to contact the individual but merely to seek confirmation from their Doctor.*</p> <p>13. : Make this possible on-line, perhaps use email to keep people informed of any changes and remind them to contact you should their condition or circumstances change.*</p> <p>14. : I personally would like to know more about who can help me be independent, what adaptations are available, whether there are any support groups and where to get necessary funding. I think it would be very good to have this provided as part of the claim process.*</p> <p>15. : Help Line staffed by existing claimants who therefore have personal experience.*</p> <p>16. : Currently we have to save until we have enough money, being able to use the new system to meet a one off cost is not really any different unless it is the ability to apply for an additional one off cost.*</p> <p>17. Your response: *</p> <p>18. : The DLA has enabled my Mother to claim the Carer's allowance but I am not sure of what other services or entitlements there may be. If the new system is to be an improvement then it needs a clearer pathway to the various services and entitlements.*</p> <p>19. : We would drown under the extra paperwork! I would hope that there would be more automatic passports to services and entitlements and when we do need to claim that the PIP will in effect have supplied at least 90% of the information needed.*</p> <p>20. Your response: As above.*</p> <p>21. Your response: It doesn't appear it will have any.*</p> <p>22. Your response:</p>
EM505	12-Feb-11	<p>Dear Sir, My son [REDACTED] is autistic (on the severe end of the autistic spectrum), has severe learning disabilities and suffers occasional epileptic seizures. I am very concerned about the possibility that [REDACTED] may have a reduction in benefits. As [REDACTED] does not have an obvious physical disability, someone looking at him might not realise how dependant he is on the help he receives and how vulnerable he is. At the age of 22, he is unable to travel independently (he has no sense of danger), has no speech and a limited understanding of social situations and what people are saying, although he is physically healthy apart from occasional seizures.*</p> <p>If I lost my carer's allowance it would mean one more thing to worry about on top of everything else. At least at the moment carers receive something for the work they do, but less than £60 per week for more hours than a full-time job is not exactly a massive 'wage'. My husband, who works full-time as an administrator for a company, helps me in the evenings and weekends (for no additional money) and as he has been a</p>

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		<p>tax-payer for 36 years since leaving school in 1975 feels that he has paid enough into the system to justify a basic payment for me being a carer and our son receiving benefits. We are not 'sponging off the state'. We did not choose the situation we are in.*</p> <p>The Government should not be making cuts of £1 billion to disability benefits as this would have devastating consequences for disabled people like my son and carers like myself. We are already under immense pressure and like many carers my health suffers as a consequence. This could be the final straw. I leave it to others to consider the implications of this.*</p> <p>If anything, it should be considered whether carers should be brought into line in terms of the minimum wage, which would mean a significant increase in the carer's allowance, maybe to around £150 - £200 per week. I'm sure the Coalition Government would say the country could not afford this. At the very least they should protect the status quo and accept the fact that carers have budgeted based on their current income and it is unthinkable that the Government are considering scrapping the allowance. It has been calculated that we save the country £87 Billion every year - imagine what would happen if carers could not carry out the care they do and the local authorities had to step in. For example, the typical cost of 40 hours per week care with a typical care agency would be around £550 per week. *</p> <p>Most of us love our children and when they reach 18 years of age do not abandon them, particularly if they cannot fend for themselves. My son is 22. I cannot and will not abandon him, no matter how difficult it becomes. Please think carefully before you act. Regards</p>
EM506	12-Feb-11	<p>I have been an advice worker for 34 years and, I know how much difference DLA makes to disabled peoples lives, and to the lives of their carers. The whole idea behind DLA was to help people to remain in the community and to maintain a level of independence. It goes some way to recognising the extra cost of living with disability. I am horrified at the proposals to remove this benefit and replace it with something which provides less help since the overall aim is to cut 20% off the budget. At a time when consumer prices are rising rapidly and other benefits and services for people with disabilities are being cut back, I believe reducing help through DLA will be seriously damaging to the health and well being of people with disabilities and their carers. Quite apart from the humanitarian cost, I believe it will cost the government more in the long run, in terms of additional demand on the health and social care services. In my experience, it is not unusual to get requests for advice from health professionals on behalf of patients who have had to be hospitalised following a crisis brought on by their benefits being stopped. *</p> <p>I am particularly concerned about the knock on effects of losing DLA, in terms of other benefits: disability premiums, non dependant deductions from Housing and Council Tax Benefit etc. For instance a person receiving the low rate care component of DLA will have a disability premium in any means tested benefit and will have no reduction in their Housing or Council Tax Benefit for a non dependant adult living with them. The loss of the low rate care component through introducing more stringent criteria, would have a domino effect on their income. The level of non dependant deductions are being increased significantly which will make the impact of this knock on effect particularly harsh. *</p> <p>I believe that to make cuts to DLA by replacing it with another benefit with more stringent criteria, will cause serious damage to the quality of life of people with disabilities and push some into a downward spiral of despair. To proceed with this proposal at a time when many thousands of people with disabilities are going find their sickness benefits removed (due to the ESA transfer with more stringent criteria and due to time limiting contribution based ESA to 12 months) would be a grave mistake.</p>

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EM507	12-Feb-11	<p>1. Your response:fear of the"ss"reproach . fear of the forms. fear of the tribunals(very military).obviously their medical condition.stupid question.*</p> <p>2. Your response:stupid question.*</p> <p>3. Your response:surviving with costs relating to travell, special diets ,transport,parking, carers, medication,extra medical therapy not nhs based*</p> <p>4. Your response:as it is then. useless b*</p> <p>*</p> <p>*</p> <p>*</p> <p>5. Your response:both. an individual's needs are measurable .fear is your agenda. this makes people put a brave face on as they are so scared *</p> <p>6. Your response:a stupid question designed to remove the lesser tear. to shave off or move the goal posts is a regular activity of a fascist system. it is not care based, it is affordability based.this will encourage , from you, constant shaving.untilt nothing remains.good for you , bad for us*</p> <p>7. Your response:talk to their gp*</p> <p>8. Your response:another stupid question aimed at getting the result you want. an aid is there to help the quality of life. not neutralise the relevant condition.people are allready prisoners of there condition. this would stop the use of an aid as the loss of benefit would be catastrophic*</p> <p>9. Your response:don't send it to the patient.send it to the gp or social worker.use people who are helpfull and sympathetic to the service user.*</p> <p>10. Your response:gp records*</p> <p>11. Your response:the power associated with the interrogation by a stranger from the "ss" secret medical police is inhuman. it makes me physicaly and mentally ill , just thinking about what is going to happen *</p> <p>12. • Your response:another stupid question aimed at getting the response you want. ask the service users doctor or gp. leave them alone as the pressure is not healthy*</p> <p>13. Your response:by threat of death. extrication from society. is it any wonder people don't inform you as the result is increased mental suffering. you lot are very scary.i live in fear of the descisions you make. we are all stuck i broken bodies. we have no options.that makes you all bullies*</p> <p>14. Your response:how to access volutary euthanasia.*</p> <p>15. Your response:stop employing people who are only interested in the departments interests.stop managers analysing statistics.remove the pressure of loss of benefit entitlement from any consultation . stop being partisan and judgemental*</p> <p>16. Your response:as the goal posts are constantly moving, i pay for all my aids. i can only see you removing grants not improving them*</p> <p>17. Your response:the ability for the carers ,mainly parents , to be able to not lose their humanity ,something you are all very good at removing*</p> <p>18. Your response:stop being b*</p> <p>*</p> <p>*</p> <p>*</p> <p>*</p> <p>. your remit is to save money at all costs.*</p> <p>19. Your response:a stupid question aimed at getting the answer you want. the pip is a joke . the system is becoming a maze. another new system to learn. it has allready been mentioned in the lords that it is above degree level understanding as to how to fill in the form, which is only there to catch us out.the implications are a higher suicide rate*</p> <p>20. Your response:any good gp will have all the necessary information.you want to reform the nhs to give gp's power.except in this because you know you will get the answers you don't want*</p>

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		<p>21. Your response:the aim seems to be to divide the country into haves and have not's. the equality question is a "double talk " statement meant to confuse.your interests are not our wellbeing.they are your pocket,your mates and how to get a corporate job after "civil service". now there's a contradiction in terms*</p> <p>22. Your response:you are trying to intimidate us to not claim.you are trying to infringe our human rights. this is a political action to appease your corporate sponsors.namely the city and the private medical system.i wonder how much money will go to the cronies who are responsible for this. you are all corrupt</p>
EM508	12-Feb-11	<p>Dear Maria, I am a member of your constituency in Basingstoke and we have corresponded before. *</p> <p>I was shocked to hear about the new PIP via a friend of mine who has disabilities, I have three illnesses which contribute to the fact that I am disabled. I receive a motability vehicle, without which I would no longer be able to live an independent life. I work for the Local Authority, and hope to continue doing so despite the fact that I am disabled. I could not tell you today how I will fill tomorrow. I am in pain every moment of every day but adapt my management of this appropriately. I use the aid of a walking stick, although I am still in great pain, without it I am unable to walk. Every so often I use a wheelchair. I probably use this less than I should, but I really do not like using it as it takes some of my independence away. If I go out for the day, I need to use my wheelchair.*</p> <p>Every day I take my children to a friend's so they can go to school, I then go to work, when I finish work I collect my children from school, and then I can finally go home. I am not one of those people who use their disability as an excuse not to do anything. I am stubborn and wish to carry on with things for as long as I can.*</p> <p>I really do not understand why you are targeting people with disabilities and taking away benefits, the use of motability cars, bus passes and tokens. If I didn't have the car, I would not be able to get to work. If I don't work, I would not be able to afford to pay my mortgage. Why are the bankers still getting such huge bonuses? These are the sorts of people that need to be tackled. How could we bail out Ireland, if we are in such dire straits that you have to forgo these benefits that disabled people really need. Why is it the rich remain rich but the rest of us have to suffer. Are we not good enough to care about? Maybe if we were born into richer families we would get everything we need. Why is it that high income families still have the same rate of child benefits as those of a lower class family.*</p> <p>Why is it that the government can afford to give to third world countries yet ignore the poverty that is in our own country? Why is it that you make all these promises but cannot realise these? Charity starts at home does it not?*</p> <p>I would really love you to spend the day in a disabled persons body, then maybe you may realise that what you are intended to do is wrong.*</p> <p>I agree that there are those people who are receiving benefits when they shouldn't. I had a friend once who stated they wish they could bust up their knees so she could get a motability car. I have also been told how lucky I am that I received a car. Yes, I am very fortunate that at present I do get a car, but I would give anything to not be in pain every day, anything for being able to get down to my children's level and talk to them, anything to be able to go for long walks and bike rides, anything for not having to upset my children because there are days where I am so frustrated and upset with the body I am in that I begin to cry, anything to be able to get in and out of the bath without having to get help, or that fact that I have to use the shower instead because it is too difficult to get in the bath, anything for people not to give you disapproving looks when you park in a disabled bay (with a blue badge) and for people to see how young I am and for them to think there is nothing wrong with me because I should be more able given my age. I would love to be able to have a</p>

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		<p>cuddle without having to grit my teeth because I don't want me children to see that they are hurting me, anything to not have to ask my husband to help me off the toilet when I can barely even wipe myself. I could go on and on and on.*</p> <p>I beg of you to reconsider these new plans and look at how to stop people receiving benefits they don't deserve. Look at all the people that live in our country that need your help, not for you to look at who you can take away help from. This country is turning into an awful place. Please don't let what happened in Egypt happen to this country. Be a hero and help those that need it.</p>
EM509	12-Feb-11	<p>This response is from an individual presently in receipt of DLA, with indefinite entitlement.*</p> <p>Preamble - Disabled people face many extra costs if they are to access the same life opportunities as nondisabled people. Some of those costs are evident, such as paying for taxis where public transport is not accessible. Those are the easier ones to identify. But then there are the less evident costs: paying a little bit more for preprepared food because you don't have the strength or the energy to chop up a swede or cut up chicken; having to buy a new pair of shoes very frequently when they wear out because you don't walk with an even gait. It is the unspecific funding for such costs - obvious or subtle - that DLA provides and that makes it possible for many disabled people to continue without significant support or intervention, or to receive fewer hours of support than they might otherwise need. This is the very essence of independence, choice and control. There may be many ways in which DLA needs to be reviewed or modified; after all, the barriers that disabled people face that DLA helps them to tackle have changed over the years since it was introduced. Some have been removed, but in some cases new barriers have been erected by a society which doesn't take account of the needs of disabled people, such as access to the internet. It is entirely legitimate, in my view, to look at DLA and work out whether it's currently fulfilling its purpose - even whether it is the best use of society's resources in the current climate - but it's crucial to retain that support for people for whom, without DLA, the barriers in everyday life would become unsurmountable so that they lose their capacity to participate as active citizens.*</p> <p>Question 1 It is impossible to list the barriers that prevent disabled people participating in society. Those barriers vary from person to person, place to place, support mechanism to support mechanism, creating so many permutations and combinations that they cannot sensibly be enumerated. In particular, it is not possible to correlate the barriers that people face with the condition that they have. I shared the same medical condition with my sister, but our access needs were very different and the ways in which we chose to tackle the barriers that we faced were also very different. DLA played an important part in enabling us to choose our own approach to overcoming them. An important foundation for any review of DLA has to be research into the ways in which disabled people use DLA, listening to what they have to say with openness and respect. In my own case, I use DLA to pay more for prepared food, clothes that fit, more expensive transport, subsistence for my personal assistants, more expensive holidays, the holiday costs of my personal assistant, additional heating, additional water, additional electricity (for various pieces of independent living equipment) and almost certainly other things that I might not realise until I no longer have that money to use. It is hard to recognise what one spends money on that might be different from a non-disabled person unless one has someone living alongside to compare with.*</p> <p>Question 2 I believe that the upper age limit for DLA should NOT remain the same. It seems to me entirely arbitrary that just because one is an older person one cannot access money that creates choice and control when one becomes disabled.*</p> <p>Question 3 Again, identifying the extra costs is difficult precisely because</p>

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		<p>they vary so dramatically from person to person. My extra costs, or at least some of them, have been identified in answer to question one.*</p> <p>Question 4 Whether having two rates will be better or not depends on whether people can access the right level of support. If people are forced onto the lower level of support because they don't quite meet the conditions for the higher level, it will not be an improvement.*</p> <p>Question 5 As DLA is intended to meet extra cost, and extra cost depends on a whole range of factors (see above), it is unlikely to be appropriate for claims to be based on a health condition or impairment.*</p> <p>Question 6 Which activities are most essential for everyday life depends on what kind of society we want to live in. If we just, for want of a different frame of reference, take Maslow's hierarchy of needs, then are we prepared that some members of society should achieve only the most basic level: should be fed and watered and kept alive but no more? Or do we prefer that people become active citizens, and the option of self-actualisation is open to them? My preference, naturally as a disabled person, is for the latter. I would no longer wish to live in a society where disabled people are treated like cattle or worse. But the very nature of this question, if we don't consider the underlying value system we are working within, may lead us down the latter path and I find that terrifying.*</p> <p>Question 7 Where a person has a variable or fluctuating condition, the nature of the barriers that they face will vary. It seems most appropriate, following a social model approach, that the level of DLA that they receive should reflect the barriers that they face. The only way to achieve this, it would seem, would be to trust people in their own assessment of the extent of barriers and relative amount of time that they experience those barriers. To try to make an 'objective' assessment would be extraordinarily administratively expensive.*</p> <p>Question 8 Aids and adaptations can assist in overcoming barriers. However, acquiring such aids and adaptations is itself an extra cost. It is appropriate to take into account those that are paid for by the state to avoid 'double counting', but those are increasingly few and far between and any such consideration has to be realistic. Even social care professionals assume that we can access support that is impossible, and that, for some obscure reason, it turns out we are not entitled to. For instance, I use ceiling hoists. I cannot obtain these from the state but have to buy them myself and maintain them myself. Without them, I would need significantly more social care support: two personal assistants for all tasks and more hours of personal assistance than I currently have throughout the day. This is an important use of DLA; alternatives are that the state needs to pay more to support disabled people or disabled people are driven into debt and consequential poverty. Again, we have to consider what kind of society we wish to live in.*</p> <p>Question 9 One of the most positive ways in which the experience of applying could be improved is to remove people's fear that they won't get the support they need. This requires a much greater level of clarity as to what the benefit is for (not the specific items it is intended to cover at the nature of the problem it is intended to solve) and assurance that people's own assessment of their ability and the barriers that they face will not be ignored or denied. Case studies are often very helpful to show people what is meant by barriers and extra costs, as many disabled people may not think about their lives in this way, having been led by the health professions in particular to believe that they cannot do things because they have a health condition or impairment. A straightforward explanation of the social model (without using the 'model' terminology) will thus be critical.*</p> <p>Question 10 Disabled people themselves are best placed to provide the evidence that is needed to demonstrate eligibility. A caveat to this is that the information and the form need to enable people to understand the nature of barriers and extra costs (see above) in order that they can determine for themselves what evidence is appropriate.*</p>

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		<p>Question 11 Healthcare professionals rarely understand the barriers that disabled people face. Healthcare professionals understand conditions but, as mentioned above, barriers and conditions rarely correlate. However, should the government insist on this requirement, then Occupational Therapists would be the best professionals for the job, because they generally have a better understanding of the way in which disabled people address physical barriers. This still does not address the non-physical barriers that disabled people encounter such as communication and stress. Furthermore, healthcare professionals are human beings and are subject to the same misconceptions and are prone to the same tendency to stereotype as the rest of us. Meeting disabled people in their homes can lead to them making judgements about people's ability to 'cope' or even ability to pay that may be wholly inappropriate. An alternative location, assuming the disabled person can travel, might be more conducive to an objective assessment.*</p> <p>Question 12 The frequency of reviews may be more dependent upon the level of impairment or condition. Where someone has a permanent condition that is not amenable to medical intervention, it would be appropriate to have a review less frequently. Reviews might still be appropriate at longer intervals (such as 10 years), however, because the nature of the barriers that the person faces are likely to change over time. Where someone has a condition that is expected to become more severe, unless they are already on the highest level of the benefit it would be appropriate to review more often so that they can receive more support should they need it.*</p> <p>Question 13 Clarity about what changes should be reported would help. Often, changes are incremental and slow, and reviews should help to identify such changes. It's not always possible for disabled people themselves easily to recognise when their circumstances have changed, whether that's because of a change in their health condition or because of a change in the barriers that they face. And it may not be possible for them to report a change if, for example, they go into hospital because they are seriously ill. Had I not known about the 'rules' of DLA, my sister would have continued receiving it during her hospital stay after the specified period as she was not in a state to stop it herself. This would have had serious repercussions when she had to pay it back.*</p> <p>Question 15 It doesn't seem appropriate to oblige people to access advice and support. Not everyone finds 'advice' or 'support' particularly useful and it can be time- and energy-consuming and add to the barriers that people face. Offering it is one thing, and extremely useful, but obliging people to take it is unhelpful verging on tyrannical.*</p> <p>Question 16 The mobility component of DLA is already used to meet one-off costs such as scooters. Enabling people to avoid interest payments by taking payments ahead of time in a consolidated lump (which I assume is what this means) would be preferable for some people who don't like debt. As mentioned above, DLA is already important for me to pay for aids and adaptations. It isn't as straightforward as my using the specific DLA payments to pay for things, it's more about having the financial flexibility to use different bits of money to pay for those things others don't have to and still be able to put food on the table.*</p> <p>Question 18 and 19 There are certain additional entitlements that I am able to access because I am in receipt of DLA. These include the Blue Badge and the Disabled Person's Railcard. It is certainly useful for me to be able to do this, but it is more likely to be the organisation providing the entitlement that benefits most because there is significantly less administrative input from their end, and they may at least feel less exposed to fraud as someone else has 'checked' the applicant. The knock-on effect of this might be that other organisations are less inclined to give disabled people preferential rates or terms.*</p> <p>Question 20 In principle, there could be one assessment for all benefit. Certainly, during research undertaken for Muscle Power! in 2000</p>

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		(Maynard Campbell and Maynard Lupton Bureaucratic Barriers), respondents were favourable towards the idea of a single assessment - a 'passport' to all benefits and entitlements. However, were this to happen, it would need to be very carefully thought through and based clearly on a social model approach, identifying all the categories of barrier that an individual disabled person might encounter in all aspects of their life. Achieving this would take a significant amount of political will and possibly further research into the nature of barriers.
EM510	12-Feb-11	<p>1. A lot of disabled people do not join in with other people because the help and support that they need, they simply do not have. There are people who do not have the necessary aids and equipment or facilities in an environment and carers who can help and support them with their physical needs, communication and emotionally when anxiety is a part of their disability and the help people need to insure they are safe. (e.g) learning difficulties. A lot of places do not have wheelchair access and a lot of people who are unable to travel in the usual way e.g walking, public transport, either find it impossible or find it a great strain and find it hard to cope, they're too exhausted or in pain maybe both, that whatever they were planning to participate in, they just aren't able. As well as having to deal with their disabilities there is a lot of prejudice out there creating a lot of distress for a lot of people with disabilities.*</p> <p>2. It is vitally important that care needs not only include physical needs but mental and emotional needs too.*</p> <p>3. The extra costs disabled people need to spend money on Aids/Equipment/Adaptions; Home Help - Personal Hygiene* Dressing; Cooking; Cleaning; Shopping; Laundry and fuel bills, help from someone to sort bills ect.*</p> <p>People will need help, extra costs for Care and support for - Mobility. Communication. Going out shopping or other places they go and need care and support with. Emotional Support. Day Centres where a person can go and socialize and be involved in an activity of their choice.*</p> <p>4. 1. I'm not sure what to make of the two payment plan.* 2. I'm sceptical that a lot of people will not get the necessary payments that will help enable them to fund the things they need.* 5. There are people who need 24hr care support and I think they ought to get the benefit automatically.* 6. It's vital that people with disabilities have their needs recognised, mental, emotional and physical to enable them to have the help they need to help themselves or help from someone else to help them for all aspects of living, whether it be at home, work, a place of learning, medical centres, places of leisure etc.* A person who has disability has the right to be in an environment where discrimination is not tolerated and have the necessary care and support and facilities where their needs can be met. Governments and professionals and persons of influence have a duty/responsibility to put this into practice and set a good example to the public and let it be known discrimination will and shall not be tolerated.* 7. To have a section on the form so the person can inform you of changes which can occur.* 8. When a person makes a claim all aids and adaptations should be taken in to consideration, what aids work for one may not work for another and they should have the right to choose and have the necessary funds to help get the ones suitable for them as not all aids are provided by local councils.* 9. There needs to be less questions and also less questions that contradict each other. It needs to focus on the needs of the person applying. Mobility should focus on the help they need not how many yards or metres they can walk. People should not have to struggle with pain unnecessary, they should have the ways and means to get about so they can get involved in activities, work if they are able to, for a lot of disabled people that choice is taken away. Care and support should also</p>

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		<p>focus on the needs of the person, physical mental and emotional. People are not machines it takes whatever time is necessary to care and people should not be pressurised in a certain time as people will not get the proper help and support they need. I'd like it to be recognised that anyone who has a disability and is in need of help and support that this benefit will help them. Information at public places - civic centres, medical centres, libraries, job centres and internet. *</p> <p>10. The best people to tell you about the needs of the person applying for benefit are the persons themselves who have the disability their carers, social workers, G.Ps/nurses, therapists, specialists.*</p> <p>11. An independent person could be useful if their own objective is to recognise the needs of the individual however if an opinion is based on what he/she sees on that day then the needs of that person will properly not be seen for what they really are. It is vital the individual be listened to or whoever is speaking for them and base their opinions on the individual's needs not the money that can be saved.*</p> <p>People who are severely disabled or terminally ill need not be seen by an independent person.*</p> <p>12. I don't think it's necessary to have the claims applied for in such short periods as done at the present moment. As it is made clear in DLA forms, people are informed to let you know of any changes. If and when it is time for a person to make a new claim they shouldn't need to apply for it in the same way. They could inform you of any changes, if there aren't any, continue the payments if their needs change in anyway, decrease or increase payments.*</p> <p>13. You make it clear as in DLA forms that people should inform you of any changes when they occur.*</p> <p>14. There are people who will need help to fill in forms for them. People should be made aware of who and where to go for that help. Anyone who has a difficulty for whatever reason filling in these new forms should have that help.*</p> <p>15. A lot of people have to pay for aids and or adaptations themselves.*</p> <p>As I understand NHS pays for certain aids and equipment. Local councils pay for certain aids and adaptations and provides grants to those who are eligible to receive them to help pay for Aids/Adaptations.*</p> <p>I think people should be given the opportunity to use the new benefit to pay for a one off cost if they choose.*</p> <p>16. It is vital that a child's needs need to be recognised, have the necessary help and support to develop into young healthy confident adults who feel in control and can live an independent life.*</p> <p>17. It is vital that people on low income or benefit continue to receive other benefits and services automatically to help them cope with the extra costs to enable them to live an independent life.*</p> <p>18. The information what can be shared with other services is the help and support that is needed as well as the help they are receiving.*</p> <p>19. Needn't be an issue for different equality groups. Each and everyone is human and has the right to have their needs recognised and get the help and support they need.*</p> <p>20. People with disabilities ought to be confident that they will have their needs recognised and to be taken seriously and get the benefit due to them and not be in fear of losing their benefit as stress can make any condition worse defeating the whole reason why they're receiving the benefit in the first place. A lot of people receiving DLA are struggling to cope to meet extra costs that comes with their disabilities, lower payments would certainly create more strain.*</p> <p>Even though there are new medicines, there are people who do not have the pain relief they need, a lot of people are suffering and have done so for a long time and the distress it causes can be intolerable to bear, their health deteriorates and needs increase, it should not be made light of when decisions are made concerning their benefit. It's disgusting that a person who is suffering is expected to go to a tribunal to prove what was</p>

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		originally written down in their application. People have the right to take their needs seriously and their needs recognised, without further misery and distress. Thank you*
EM511	12-Feb-11	<p>I am Registered Blind and all my responses reflect my experience of moving from Partially Sighted Registration to my current position.*</p> <ol style="list-style-type: none"> 1. The huge costs of accessible technology and aids and services which are not supplied free to blind people. Lack of affordable skilled training to enable use of technology etc. Difficulties in using public transport and in some places the lack of these services. Taxis prove to be very expensive.* 2. The 3 levels of the Care Component are necessary as they reflect the changing needs of people with progressive disabilities.* 3. None of the following are available from Health or Social Services. My extra costs include paying for RNIB Talking Book Library (the only extensive digital audio book library in the UK). Cost of membership (£80 pa) even though I pay my Council Tax which includes only a very limited local audio books service* <p>Purchase of PC adaptive technology (Jaws screen reading software costs £800 initially with frequent costly upgrades) A Closed Circuit TV magnifier which costs over £1000 and probably has to be * replaced every 7 years. Regular purchase of Long Canes and replacement roller tips (£26; £5). Purchase and eventual replacement of Ultrasonic Mobility Aid to assist safe mobility (£300). Accessible mobile phone with speech availability - current cost £130 when a sighted person can get one for £15. Regular taxi fares. Replacement of clothes damaged by accidents arising from sight loss. Purchase of kitchen aids like talking scales, talking timer, talking thermometer. Payment for home cleaning to ensure that my home is kept clean.*</p> <ol style="list-style-type: none"> 4. The current DLA regulations are very confusing eg. I am over 65 and am not eligible for the Higher Rate of Mobility even though I receive the lower rate and more taxi costs accrue as I get older.* <p>If there are only two levels Of the Care Component some may lose out early on in their sight loss if the lowest level disappears. This may be the time when they urgently need the support as they struggle to maintain independence.*</p> <ol style="list-style-type: none"> 5. Those Registered Blind should automatically receive the middle rate of Care and the Higher Rate of Mobility.* 6. Being able to go out alone and learn to cook and care for themselves and to own and use technology to assist independence.* 7. Regular Medical and Specialist Social Care assessment required.* 8. Aids and adaptations need to be discussed with specialist Care Workers and funding for training to ensure aids are used, must be provided.* 9. This is too complex a question for an ordinary person to answer . But the tedious and copious amount of information required and the high level of decisions reversed at Appeal are costly to applicant and the Benefits system.* 10. Social Care/Rehabilitation staff and medical personnel as well as the applicant.* 11. Face to face interviews for speech impaired and learning disabled people are of limited value unless an advocate is present who knows the applicant's needs well.* 12. Frequency of reviews must relate to the impairment and the stage it has reached. There is no purpose in reviewing someone who is blind and already assessed as eligible for the Benefit.* 13. Send forms to be completed and counter signed by a Health Professional in order for the the PIP payments to continue. This should not be necessarily when the impairment is not reversible. This review should be required every ?2/3 years. It is essential to ensure that such forms are supplied in alternative format for print impaired people. (This applies at every stage of the process)*

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		<p>14. Yes. The information needs to be made available in hospital Eye depts where people are Registered .*</p> <p>15. See 14. above*</p> <p>16. Funding is usually from personal savings and other family members, supported by DLA. Those without savings go without the technology which they cannot afford and which would support their independence. One off payments for technology which would include training to use the aid, would be a good idea.*</p> <p>17. Education professionals need to play a central part alongside carers.*</p> <p>18. I am only aware of being passported to receive my Blue Badge. Otherwise I am not aware of getting passported by DLA but am sure we need to maximize the potential of this device to save staff time and applicant's energy in the future. Also to enable people to get their entitlements. Disabled people and their relatives can get "Benefits application fatigue".*</p> <p>19. See 18.*</p> <p>20 I have not been eligible for any other Benefits so cannot comment.*</p> <p>21. Heightened attention needs to be given to enabling people with first languages other than English to be fully informed and involved. I expect that there is lower take up in this group and this may be exacerbated by major changes to the Benefits System.</p>
EM512	12-Feb-11	<p>1. Your response: Limited ability to move without support or assistance, whether in or out of their living area, coupled with a lack of ability to pay for assistance.*</p> <p>2. Your response: people who are known to have suffered from these problems for an extended period and who are currently dependent on DLA should not face the delays in receiving assessment and the delays that can then occur in receiving the allowances*</p> <p>3. Your response: assistance in achieving even the more limited mobility that follows from their disability*</p> <p>4. Your response: The issue is not about administering the benefit, rather the problems that can be expected to arise from the need to assess which rate, if any, will apply*</p> <p>5. Your response: If an individual has a clear and 'self-evident' need, which the relevant GP can readily 'endorse' this should mean entitlement, and will of course provide the justification of the need and circumstances.*</p> <p>6. Your response: Movement and the ability to access the services available to the general public can be considered essential *</p> <p>7. Your response: In situations where the condition is clearly not capable of improvement, e.g. age constraints, loss of limbs, permanent blindness or deteriorating eye-sight, which is recognised as on-going, it is difficult to accept that the cost of assessment is justified. *</p> <p>8. Your response: Any or all existing or potential aids should be taken into account, provided any not already in use by the applicant, which can be expected to be beneficial, will be provided within a specific and limited short period, together with any necessary training in their use*</p> <p>9. Your response: Claim forms need to be readily understood and available with provision for a 'carer' / helper to participate in their completion. Likewise, the information needs to be clearly presented and available on a wide range of 'locations' *</p> <p>10. Your response: the views of any qualified health /social services / legally trained individual should be taken into account, together with the views of trained carers who have been involved with the applicant for a reasonable period (perhaps for a given number of hours, days etc as appropriate*</p> <p>11. Your response: Applicants often lack the self esteem to share with 'strangers' the extent of their problems, especially where these are not obvious to the person conducting the interview. This is certainly the case where the meeting is to be held away from the individual's home / place of residence and involve significant travel; likewise where the meeting is</p>

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		<p>not carried out in the applicant's first language, by a person fluent in that language. *</p> <p>12. Your response: The assessor should be free to judge the frequency required. There should be categories of the types of condition which are considered to merit each type of review and the applicant should be able to expect to have the type of review most suited to his/her condition *</p> <p>13. Your response: by requiring anyone involved in supporting the application to submit a report on the condition at possibly 6 monthly basis *</p> <p>14. Your response: A clear indication of the terms/conditions that will be applied by 'assessors, and this should certainly be available when submitting an application*</p> <p>15. Your response: It would probably help provided the advice and support was readily available without having to travel to obtain access and again should make clear the terms/conditions on which the assessment will be made.*</p> <p>16. Your response: mostly by drawing on their own funds even if these are from other benefits they may receive or from their pension whether age related or not. There should certainly be an option to use PIP's to meet a one-off cost.*</p> <p>17. Your response: The position of the parents, especially where only one is involved – for whatever reason. The frequent inability of children to fully understand the meaning and /or the implications of the questions asked and the significance of the answers.*</p> <p>18. Your response: An increased readiness to accept that most individuals are honest and in no way seeking to obtain unjustified benefits*</p> <p>19. Your response: an increased liability that in many cases the individuals would become increasingly destitute and/or reliant on other public funds whether these are provided through the NHS, Social Services or some other source.*</p> <p>20. Your response: there is no apparent justification for insisting on separate assessments where the information about applicants knowledge of the applicant of course. is not shared – with the *</p> <p>21. Your response: I am not in a position to offer an opinion*</p> <p>22. Your response: No</p>
EM513	12-Feb-11	<p>Approach about DLA reform, from individuals. Case study: [REDACTED] suffers from progressive Multiple Sclerosis.*</p> <p>* </p> <p>1. We attach a letter submitted to the Prime Minister in 2010, David Cameron MP. He replied saying that genuinely disabled people have nothing to fear from the proposed changes. However we are not confident this is so.*</p> <p>* </p> <p>2. Further points to the letter. *</p> <p>* </p> <p>A) WORK SELF-FUNDS DLA - We say that DLA enables many people such as [REDACTED] to remain in their jobs on a reduced, part-time basis despite a worsening of the condition. In [REDACTED] case having to reduce full time working hours significantly then work from home for much of the time. *</p> <p>We say that despite the physical struggle, her reduced work earns the Inland Revenue both Income Tax and NI, as well as making a contribution to society. We say emphatically that such non means-tested DLA payments in this instance can be considered self-funding and effective by enabling work, meeting the government's aims of inclusion and a lowering of dependency on overall benefits. Isn't this a good, clear example of what the government is trying to achieve?*</p> <p>B) EXAMINATIONS - We say that if disabled people with progressive long-term disabilities such as MS etc are to be examined, that such examinations should not be made by a 'health professional' un-versed in</p>

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		<p>the particular medical condition. We say such examination would be grossly inappropriate.*</p> <p>C) CONFUSED/VULNERABLE - We say that examinations/assessments must be handled with great care as, whilst disabled people are protected by disability laws in their own right, they remain confused and vulnerable at all times. In the case of damage caused by myelin loss, for example as in MS, the brain is damaged. Recognition of vulnerability is important. *</p> <p>D) RATES - We say that rates of DLA are already ungenerous and feel this proposed change in approach should not be used as a pretext to lower overall rates paid. Instead the change should seek to increase rates in recognition of chronic illness and disability. *</p> <p>E) PROGRESSIVE/FLUCTUATING - We say that examinations, assessments and the approach to those should take into account the progressive nature of certain medical conditions equally as to the persistently-fluctuating nature of certain conditions.*</p> <p>F) MEANS TESTING - We say that it is self-evident that DLA or its successor should remain non means-tested.*</p> <p>G) INDEFINITELY - We say that where an award base has already been confirmed 'indefinitely' that this decision was made properly and should not be reversed in these changes as that would go against natural justice and be retrospective. Thank you in advance for considering these points seriously and respectfully.</p>
EM514	12-Feb-11	<p>1. The purpose of this exercise must be to assess 'need' thereby enabling disabled individuals to live life synonymous with their able-bodied counterparts. The needs of disabled people must not be underestimated, yet the starting point should be a medical review of those who are currently claiming DLA benefit 'illegally' – this has a significant unwarranted cost. Establishing this level of fraud should be a precursor to reviewing all DLA recipients. This approach would see a more immediate return to Government revenues. Given the nature of DLA and its intended purpose why are drug-users and alcoholics automatically eligible for this payment? – has Government completely lost sight of their original intention in awarding DLA? Government must not attempt to deprive the 'real' disabled further. To do so would represent an infringement of human rights and should be considered carefully.*</p> <p>In terms of problems/barriers preventing disabled people participate in society, one must look at 'access issues' to goods, services and facilities where the Disability Discrimination Act must be written into Statute and policed as law, with repercussions attached for non-adherence. Currently, although this piece of legislation exists, the use of the term 'reasonable adjustments' provides an exit which ensures that disabled individuals – who often are not in the work-place – remain unable to access support mechanisms to progress cases through the court system, in order to bring about much needed positive change. Reasonable adjustment allows retailers and such-like find a means of either limiting or not carrying out essential changes. Public perception and that of the retail/business community indicates that in the absence of clear ramifications from non-application of DDA 'guidelines' - hence the legislation is without recourse and less than worthy of thorough application/consideration. The resultant impact is that the lives of disabled people are in the main confined to a lower level of acknowledgement and resultant existence than that of the able-bodied population who do not face such restrictions/barriers in terms of living on a day to day basis. Even in this 21st Century a stark lack of disabled access exists among the providers of goods/services and facilities. This needs to be examined in legal terms.*</p> <p>2. The principle of supporting people living with a disability to enable them to undertake reasonable activities in line with able-bodied individuals must be upheld.*</p> <p>I believe that long-term permanent conditions must not be subjected to</p>

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		<p>the threat of removal of the award e.g., those diagnosed with illnesses such as Multiple Sclerosis, Motor Neurone disease where no cure currently exists. To do so would introduce unnecessary costs to administer - significant savings could accrue via the provision of an up-front 'long-term degenerative disability-specific condition flag' - the removal of the award of DLA would not then need to be reconsidered unless a cure has been established. To review individuals with such stress-related illnesses simply increases stress thus making the condition worse and hence increase costs longer term. Such long-term, degenerative conditions should sit at the core of where DLA is essential and should be exempted from the review entirely. Often many people have to give up careers where DLA becomes increasingly essential to support living costs in the absence of other benefits.*</p> <p>3. Payment of increased heating bills to cover 24-hour periods due to decreased mobility*</p> <p>Purchase of mobility aids – unavailable via NHS*</p> <p>Purchase of specific health foods etc e.g., staple condition-specific dietary supplements*</p> <p>Costs of seeing experts (often outside the basics provided via NHS) i.e., to have condition-specific vitamins/minerals prescribed.*</p> <p>Purchase of personal care – e.g., overnight care – prior to its being provided by Social Care*</p> <p>Purchase of essential services needed in addition to that provided by NHS e.g., regular mobility-enhancement/flexibility support as NHS provides 6 one-hour sessions only to have client put on review to be seen at an undesignated point in the future; also purchase of essential proven health-benefiting remedial massage treatment*</p> <p>Purchase of items not available via healthcare – repair of mobility aids*</p> <p>Additional and enhanced costs of securing suitable transport *</p> <p>Long term benefits versus short term costs? Some conditions such as Celiac are NHS supported in terms of specific food-provision yet other long term conditions which warrant specialised foods are not NHS funded although research outlines the long-term benefits. Non-provision results in short-term savings yet medium to long-term additional costs. The cost-benefit analysis must be conducted up front.*</p> <p>4. This really needs to be tested and assessed prior to posing this proposition but MUST work for all disabled conditions. *</p> <p>Having two rates could present a straightforward approach but application/administration must be kept similarly straightforward. I do not think that having two rates will make DLA any easier to understand as the current specification is reasonably clear. It is the length of the current application form which is the principle cause of stress. To address this would be a huge step forward. 'Ensuring appropriate levels of support' is open to debate and potential cost. Is there any clear benefit in taking this approach? – if it is merely a 'change' for 'change' sake, this is without merit. The difference between both rates is going to need to be specific and clear definition must be built in but this could still result in a black/white approach which cannot hope to meet all potential scenarios. The degree of difficulty must be assessed e.g., how many steps can a disabled individual take and how can this be factually rated within two scenarios? Ease of understanding is paramount yet reference to administration should not become a factor at this stage. It suggests that administration could be the key and this must not be the case.*</p> <p>• What, if any, disadvantages ... cause?*</p> <p>It is likely that two rates may present difficulty as 'grey' areas always exist. To have two rates suggests a black or white approach. This in itself could present core problems and in a vain attempt to ease admin costs, the application of a non-standard approach may see costs escalate.*</p> <p>5. The condition must be the primary driver but as outlined above, long-term progressive and degenerative conditions should automatically</p>

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		<p>provide for allocation of the award. Costs could be hugely minimised by taking this approach. If the condition is currently without cure with a further deterioration prognosis, any re-assessment is merely a cost and not worthy of consideration if the overall aim is cost reduction.*</p> <p>6. Begin with conditions to which there is currently no cure and ask the individual to specify their core needs. Social workers and such like provide for limited objectivity as many disabled-individuals put on a brave face. The disabled individual knows best where (a) getting out of the home into fresh air on a daily basis will be above vital as a starting point and (b) Interaction with people is of similar importance. Furthermore, (c) having suitable levels of home support is essential and must meet the specific needs of the individual. One size does not certainly fit all.*</p> <p>7. It is absolutely essential that ongoing assessment is carried out by knowledgeable & understanding assessors – ideally some of whom must be disabled and therein understanding more acutely the precise circumstances the applicants are facing. No matter how well trained, or well intentioned, able-bodied individuals are, they cannot hope to understand nor represent the needs of the disabled community. * Time should be spent on review, perhaps annually, in terms of fluctuating conditions. This may well only call for a GP report.*</p> <p>8. Not enough information on this topic is provided to provide a full answer. *</p> <p>What aids included? *</p> <p>Anything the disabled person currently sees as essential and uses on a day-to-day basis within the home, and those used less often outside the home but which are essential to mobility - these are the items the individual finds essential to allow them live in relative normality. Yet it will be difficult to ensure that information is provided and the interpretation of any answer is likely to be less than objective.*</p> <p>• Should the assessmentobtain? *</p> <p>If the assessment is likely to be repeated, then only current positioning should be presented in this initial staging. Future needs can be met via future assessment. None, if any condition can provide for a specific/accurate 'crystal-ball' projection due to the sphere of differences likely to be experienced by any one individual. *</p> <p>9 • How could we make the claim form easier to fill in? *</p> <p>Long term conditions should not warrant completion of a form. Is a form essential if the person has to undergo a range of medical reviews - you are in danger of increasing administration and cost base yet again? Any form must be kept short, precise and detail-specific which can be assessed speedily and accurately - allocated directly into either of the two brackets you suggest will become applicable.*</p> <p>• How can we improve ... to qualify? Ensure that those conducting the assessment understand what it means to be disabled and the impact of such level(s) of disability on everyday living. *</p> <p>Keep the assessment form clear and concise. *</p> <p>Limit to number of pages - the current form appears to ask for the same information in several ways and wastes time for both administrators and the disabled applicant. *</p> <p>10 What supporting ... provide this? A consultant/specialist report to provide the factual medical evidence on serious long-term medical conditions in order to reduce on unnecessary time delays and costs – supported by a GP report as necessary*</p> <p>For other conditions - a GP report to present evidence of general medical detail outside the specific domain of the expert consultant can be made use of A one-off MRI scan for all those presenting with back problems – essential – and can discount all those where evidence is not present. This had been proven worthwhile.*</p> <p>11 • What benefits or difficulties might this bring? The value of such face to face discussion is highly dubious in terms of value-added. How does this improve upon the judgement of the Consultant/Specialist and/or GP?</p>

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		<p>Whilst the person under review may on occasion need to be spoken with – to have a 'healthcare professional' conduct interviews is only seen to present delays, open the door for objections and appeals and increase costs in the short term. Certainly, such interviews are not necessary where a long-term degenerative condition is diagnosed. The person conducting the review must be totally objective and work on facts only – not opinion. Hence this particular element is a cost which should only be enacted where the condition warrants. Be very careful of the one cap fits all strategy. It certainly does not where DLA and disability is concerned.* If a face-to-face interview is needed, then the person conducting the interview must have a thorough knowledge and understand of the condition and not simply be an administrative-type pen pusher! This is vital to the output.*</p> <p>• Are there any location? See above.*</p> <p>12• Should there be differentcondition? Yes, see below.*</p> <p>Severe level disability should speak for itself and warrant only a Consultant and/or GP update report where in long-term prognosis cases, these should be 8-10 yearly as a shorter timescale is seen as a waste in administration and elevated costs.*</p> <p>Where, however, the disability is of a more reduced level or difficult to determine in the absence of an MRI, reviews should be conducted annually. An MRI should – as a one-off exercise - be used to eradicate all dubious back/knee/leg claimants. *</p> <p>13The system for in circumstances?*</p> <p>The above reports should provide for appropriate update where you can easily assess those conditions which warrant annual or 8-10 year reviews. You already illustrate a semi-complete listing of those who receive DLA automatically. Complete this listing to include all long-term degenerative conditions etc and an easy assessment of review is clear to determine. Regular reviews for borderline cases are warranted. As long term cases will only need 8-10 year reviews this should bring about a positive balance and reduce costs in administering the PIP system.*</p> <p>14 What types of advice and information process? 1. Detailed information of the 'proposal' to each applicable applicant without causing reason for heightened concern 2. Telephone advice line 3. Advisor 4. Job Centre/CAB or details of organisations with social responsibility with whom the applicant should/could liaise.*</p> <p>YES, to provide such detail up-front would be invaluable.*</p> <p>15 Yes, if approached sensitively, this could support many. Yet to make it essential might be too heavy-handed. Getting information out into the Community via Doctors Surgeries/Leisure Centres/Occupational Therapists/Social workers could be invaluable. Many disabled individuals are left to fend for themselves where they are predominantly house-bound and sadly remain in the dark as to what is available where not one specific service provides a full overview.*</p> <p>16 Disabled people, without doubt, are generally not working where DLA on many occasions support day-to-day living. For many it supports their ability to pay for:*</p> <p>(i) Food; (ii) Additional Heating for elongated period due to immobility; (iii) Household maintenance*</p> <p>In addition, many disabled people need use their DLA to buy-in extra help in the form of (i) Supported physical exercise to maintain bones and mobility – unavailable via the NHS due to lack of resource where individuals are put on general review after 6 weeks and left to wilt for much too long. Short term benefit: long term cost to NHS as a result of 6 wk support!!*</p> <p>(ii) Supported mental wellbeing in the form of essential massage to ensure bowel and bladder operation – something which ultimately saves the NHS significant monies and where insufficient resource exists in the first place*</p> <p>Short term benefit: long term cost to NHS as a result of minimal NHS</p>

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		<p>support!! But as DLA pays for it, it gets supported by the individual.*</p> <p>(iii) Petrol for their Motability vehicles (something which should not under any circumstances be removed as this would cut-off a vital lifeline. Arguably the most important life-line).*</p> <p>(iv) Purchase of many adaptations not available free of charge for Motability vehicles*</p> <p>(v) Purchase of off or on-road scooters which are not funded if you have a Motability scooter. Therefore months of saving for a scooter comes directly from DLA monies*</p> <p>(vi) It should not be forgotten that Disabled individuals often pay friends for running errands they are incapable of running themselves. The associated costs can be significant on a monthly basis where a little bunch of flowers or a box of chocolates eats £10 - £15.*</p> <p>(vii) There are many more one-off costs which are applicable to the individual and would need to be assessed on a one-to-one*</p> <p>17 No knowledge*</p> <p>18 No knowledge*</p> <p>Are there things we can do to improve these passporting arrangements?*</p> <p>To improve these passporting arrangement we believe such options should be clearly laid out and presented to the individual – not the social worker or other professional – directly to the claimant is the only way to ensure they are in hand of the comprehensive knowledge as to what is available.*</p> <p>19 By your providing the information - yet under no circumstances imposing your beliefs - would ensure that the individual is in hand of all necessary information. The remainder is up to the individual. DLA is not a great amount once all of the above considerations are sufficiently understood by those conducting the assessment. By giving choice to the individual, you are concluding your responsibility.*</p> <p>20 Jobseekers/Housing Benefits and other major benefits under the Government system could be reviewed as a whole. Sharing information on any one individual which is open to data protection issues is fraught with difficulty and open to challenge. *</p> <p>21 Human Rights considerations must be viewed. Existing legislation which acknowledges the difficult circumstances under which the disabled live must never be 'watered down' simply to effect cost savings – the disabled are not at liberty to increase profitability in prosperous times and should not be negatively impacted by virtue of a cost-cutting exercise.*</p> <p>22 I fear that the proposals may have been written with a cost saving motivation. I accept that fraud prevention and detection is essential and should be focused on as a priority. *</p> <p>Extreme care must be exercised in conducting the assessments as it is vital that only those who are either fully au-fait with disability i.e., living with a disability or hold an absolute knowledge of the physical limitations such group experience on a day-to day basis should conduct the assessments. *</p> <p>Respect for the genuine claimant among the disabled is most important; this is why it is and should remain a scheme that should be independent of other benefits and their rules etc.</p>
EM515	12-Feb-11	<p>DLA is not a benefit with a history of abuse. The official DWP fraud rate for the benefit being only 0.5%.*</p> <p>The Minister acknowledges that Disability Living Allowance (DLA) helps it deliver on its commitment to help disabled people exercise choice and control over their lives - yet it proposes to replace DLA with PIP's which will require expensive rebranding. *</p> <p>The few criticisms that there are of DLA can be easily remedied with the cost associated with the introduction of a new benefit, particularly at a time of fiscal austerity.*</p> <p>The proposed new benefit, Personal Independence Payments (PIP's) looks remarkably DLA so why effect the change?*</p> <p>The significant difference is that the proposals seek to re-define what we,</p>

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		<p>as a society, mean by mobility. The current measure of mobility is the ability to walk unaided, which, to most people, is the most logical and fair benchmark of mobility. This is the element that may seriously disadvantage wheelchair users and requires a much broader debate than the narrow medium of the proposals. *</p> <p>As it stands, the proposed DLA reform simply looks like an opportunity to ensure that even fewer people are eligible whilst giving an opportunity for private healthcare to profit at the taxpayers' expense *</p> <p>This isn't what I voted for.</p>
EM516	12-Feb-11	<p>To the Consultation: As a mother of a young lady with PMLD aged [REDACTED], I have a special plea that you do not inadvertently cause people with profound and complex learning disabilities to be a casualty of DLA reform. Vulnerable people seem to be being hit from all sides by this coalition government and this is exactly what they said they wouldn't do.*</p> <p>A second plea is to have a look at The Campaign for a Fair Society and you will see what I mean. The points are well made and just. I would be very happy to give more substance to my views if asked but in the meantime thank you from those who have not the understanding to thank you themselves.</p>
EM517	12-Feb-11	<p>I would like to comment on the proposed changes to the DLA I am the main carer for my wife. She is registered blind as well as having other disabilities. It seems that the on face value that a simplified form/assessment may be welcome. The forms are very difficult to understand and seem to repeat the same questions. One of the anomalies at the moment with DLA is that my wife does not qualify for the higher rate of mobility allowance despite her disability of blindness. Why is this so?*</p> <p>I would ask, however, a number of other questions for your consideration. With permanent disabilities (My wife is blind) how would you assess this on an ongoing basis, as it cannot be treated or cured? You mention in your consultation paper, that this may mean that she may see a approved healthcare professional. Would that be a fully qualified doctor / specialist etc? Could this be interlinked with Social workers and help that disabled people receives from local social services? She has a personal care plan and a personal assistant, would this be effected by the changes? Would this new assessment be a scoring system? If so, how would we know if her needs were correctly assessed? Is this again subjective to interpretation/judgement of an individual or a total points scoring system? My wife has struggled for many years with her disabilities and has part-time work. She is on min wage. She has found getting employment very difficult due to her disabilities but wants to work. Could, what you proposed to do, inadvertently effect her independence by penalising her desire to work? i.e. she works and therefore as a result, does not need her benefit! What measurements will be put in place to monitor this proposed change to DLA and how often would this be reviewed? Who would you involve during its design and implementation stage to ensure consistency and fairness? The big question is how would we know that the new changes and assessments are fair to people with disabilities both physical and otherwise. Yours faithfully</p>
EM518	13-Feb-11	<p>1. Your response: I would suggest the biggest difficulty comes down to people's attitudes. By people I mean absolutely anyone that a disabled person might meet in the course of a day, ie from MPs to the milkman. If you have a visible disability, for example you use a wheelchair, when you enter a room there will be people who look at you in a 'wondering' way. Another example might be that you want to go for a coffee. Firstly access might now be improved due to the DDA so that will be fine. Getting through the heavy door won't be possible unless someone holds it for you or if it is a big chain of coffee shops and they have electronic doors. Once through the door you will find all the tables have chairs around them so there is nowhere to park your chair near the table unless you can</p>

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		<p>get someone to move a chair for you – of course most of these coffee shops are packed to the gills so that they can have a maximum number of people in them so there isn't anywhere to put the spare chair. The DDA improved things BUT there is still a long way to go and until everyone accepts disabled people have as much right to live a 'normal' life as everyone else then problems and barriers will always exist.*</p> <p>2. Your response: The Mobility side of things. Motability is a fantastic organisation and enables so many people, who would otherwise be mobility restricted to get out and about and with as little stress as possible. Personally I can't see the problem with the three Care criteria levels. They are simple to understand. The decision makers definitely could use some lessons in how to work with disabled people but on a personal note I find the criteria for the different levels perfectly understandable and do not understand why they should be said to be 'subjective'. Decision makers that I have spoken to seem to work from some sort of 'book' which tells them what to expect from say a stroke patient. Patients suffering strokes are never the same as the next one. For example despite my having a number of conditions for which I received dla when I did my renewal after adding a stroke to my list of diagnoses I was told that with rehabilitation I might improve. Since the stroke simply made the other conditions worse I thought I'd check what rehab I could be having with my gp. He apologised but said I'd had all the rehab that might have helped and there was nothing on offer. I was left questioning whether the decision makers knew of a rehab that neither he nor I knew about. I would definitely like to see the forms changed as they are degrading, bureaucratic and far too exhausting.*</p> <p>3. Your response: These costs will depend on the individual. For me one of my main extra costs is heating. I get very cold very quickly due to my lack of mobility. Other extra costs include clothes – I need clothes that are easy to launder, (so laundry is an extra cost too), easy to get into, wheelchair friendly, etc etc. I also use my Care money to pay people to do some jobs for me or to take me out or perhaps if they won't accept payment I will pay their expenses, ie buy them a ticket for a show if they are happy to drive me, unload/load my chair, help me with the loo if I need it, etc etc. Being disabled is expensive. By using my mobility allowance for a car I then have none left for a chair. Due to my variable condition I need a couple of rigs for different occasions and they have to be paid for from my dla. The sorts of chairs offered under the nhs scheme are old fashioned, clunky and not fit for purpose.*</p> <p>4. Your response: I haven't see what the two rates are so this is difficult to comment on but it strikes me that this is simply making matters more complicated and will involve greater levels of bureaucracy. I suppose it could be argued that it will make it more possible to find a 'perfect fit', but I suspect it is simply going to complicate matters more than it need be. *</p> <p>5. Your response: I would suggest that once someone with a condition that is deteriorating as life goes on it is ridiculous to continually spend money checking and rechecking their entitlements as obviously they are not getting better and therefore, will not be claiming for less benefit. If a disability is not one where improvement is possible why spend money putting people through more assessments and costing the public purse more? It doesn't make sense. It would only be possible for a properly experienced diagnostician to decide whether or not improvement would be likely – certainly not a decision for someone trained to work in an office. *</p> <p>6. Your response: I believe DLA already targets those in most need. For example low care offers support for those with minor needs, middle care for those with care needs during the day and high care for those needing care around the clock. *</p> <p>With regard to the second question I would suggest looking at Human Rights legislation as a starting point in discovering what activities are essential for everyday life. *</p>

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		<p>7. Your response: Look at medical science to see which conditions are fluctuating ones. I appreciate that you are trying to get away from medical models but medicine can tell us which conditions are likely to be fluctuating and it would be ridiculous to discount this evidence. If someone has a variable or fluctuating condition then surely it needs working out whether they have the condition more often than they do not.*</p> <p>8. Your response: I believe this is very fragile ground. For example if I am well enough to use an electric chair all is well provided my environment is amenable to the chair. Meet gravel or if it should rain then the chair is not usable. There will always be shops, etc that are not accessible due to their listed status and what happens when the chair has a puncture or needs a repair? Simply having a chair does not mean you are as mobile as someone able to walk on their own two legs. Another example might be the tool I use to open ring pull tins. Someone who is able will simply open the tin in seconds. I have to find my little tool, use it, hope the tin isn't one of those that is particularly stiff, get the tin open, etc. All this takes time. I will have used the aid to open the tin but quite apart from the time element I will also have used valuable energy resources. The aid can only go so far in levelling the playing field.*</p> <p>Aids are expensive – the minute a company develops an aid somehow the price seems to go up. Chairs for example can be state of the art and are far more likely to help level the playing field but will be far outside the reach of the average disabled person. Even if the assessment only takes into account aids people already have what happens when they break, need repair or replacement? I suspect there would never be enough money to ensure disabled people had the best aids available in this day and age. Another example is that I have a powerchair – bought second hand and I'm still paying for it monthly. When it breaks down how long would it take my PIP to come up with the money to replace it? What happens in the meantime? I am only eligible for a manual wheelchair from the nhs but having had a stroke I don't have enough upper body strength – especially in my left side – to manoeuvre it. If I had to use this chair I would have to have someone with me to move me all the time.*</p> <p>9. Your response: I would suggest that ensuring claim forms are appropriate to the conditions people have. For example at present I have to complete the same form as my husband. I have many physical ailments and he has Aspergers. Our needs are vastly different as is the support we each require. Quite how you do this I do not know but I am only too aware how complicated it is trying to fill in a form for such varied needs.*</p> <p>With regard to improving information about the new benefit surely you need to start by sending out information to everyone you already know about, ie dla recipients. Simple, easy to read leaflets in all the necessary formats need to be available from doctors surgeries – doctors could/should be involved in ensuring they are able to hand appropriate leaflets to their patients as and when necessary since they are the ones who will know what their patients needs are.*</p> <p>10. Your response: The individual, their carears, everyone involved in their care including their gp's, practice nurses, etc. Ask for all appointment letters, reports, etc which a person might have available and which might help build a picture of someone's difficulties. I would also suggest an occupational therapist – (very underused people in my view), should visit someone at home. There are many small clues as to a person's abilities in their home environment. For example someone who claims to use a wheelchair in the house will not have furniture crowding every room. They will need room to manoeuvre. Someone who suffers fatigue, or difficulty moving will have all their 'needs' clustered on a top by the side of their chair. They won't want to be moving around all over the house all the time. If they claim to have problems with stairs – do they</p>

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		<p>have two banisters or if they're lucky a stair lift? A home visit could also be used as an opportunity for an OT to look at whether there is something that might help make an individuals life better. I suspect there is a danger that all this could involve the need to invest in aids, adaptatations, equipment, which otherwise might not have been identified as a need and therefore, end up costing the government more money in the long run. *</p> <p>11. Your response: See above. Seeing someone in their home environment and spending time with them going through such things as making a cup of tea is likely to be very revealing if the assessor is properly trained and observant. I believe home assessments would be preferable in most situations. Seeing someone in an office is likely to simply give completely the wrong information.*</p> <p>12. Your response: Evidence needs to be based on medical information about a person's health, disability and/or needs. If someone has a condition which will only deteriorate over the years then it doesn't make sense to be spending money on undertaking reviews on a frequent basis. Presumably people will be told how to apply for increased levels of PIP as deterioration occurs. Decisions about different types of review need to be made by proper diagnosticians. It would be completely inappropriate for a Psychologist to make decisions about someone with a Rheumatological condition. *</p> <p>13. Your response: The person who will know if someone's condition has improved will be the gp. If someone is no longer asking for repeat prescriptions, or no longer asks/needs referrals to specialists the gp will know about their improvement. Some onus must lie on the gp to inform the department of improvements in peoples health needs. Some people are unscrupulous and losing their 'income' is likely to cause them great difficulties and therefore, act as a disincentive to telling you about their improvements. In this situation the onus needs to be removed from them. I believe though that despite what the media would have us believe there are fewer people having miraculous improvements than the general public might believe.*</p> <p>14. Your response: Information should be freely available from places where people who have become disabled might encounter them. Such information needs to be in whatever format might be helpful. People such as doctors, hospital staff, social workers, etc should all be encouraged to offer such information freely and widely. *</p> <p>15. Your response: There should never be coercion in any form. Making sure that information about the benefit should be made freely available especially for minority claimants who might otherwise not claim. Some people will never claim and it is their right that they should not be made to do so.*</p> <p>16. Your response: At present I have to fund my electric chair and a more comfortable lightweight manual chair from my dla. I have also bought an electric bed and chair from it. If I could have claimed for their one off cost it would have been very helpful but I suspect the government could not afford to buy such equipment for everyone who might benefit from it. I have also had some limited help from a charity to help me buy an electric chair. I would much prefer to have been able to claim from a benefit for something.*</p> <p>17. Your response: That they are children!!! Their needs may be different but they are no less expensive to meet. My son has Aspergers and we have all manner of expenses to meet. Forms should be applicable to the sort of disability the child has – the form I have had to complete covers such things as his toileting needs - this is more applicable to a child with a physical disability.*</p> <p>18. Your response: I have no personal experience of any problems in this area. Perhaps one of those if it aint' broke don't fix it situations.*</p> <p>19. Your response: It would add to the minefield of bureaucracy already faced by vulnerable people.*</p>

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		<p>20. Your response: Simply link IS, IB, ESA, Tax Credits, HB and CT etc all together so that people don't have to be filling in forms with all the same information all the time. It might even cut down on some of the fraud or the errors made administratively.*</p> <p>21. Your response: Listen to disabled people, individually and in groups. Listen to all the different equality groups who might have some input and most of all act on what has been said.*</p> <p>22. Your response: I noticed that under point 19 people claiming higher rate dla were less likely to be seeking work or be employed. Surely this is obvious as you are talking about people who need care around the clock. This means that they are likely to be sleep deprived due to their need for regular disturbances for care in the night and hardly able to carry out any tasks/employment. *</p> <p>I speak from experience. I rarely sleep more than 1 and a half to 2 hours at a time and am exhausted constantly. I am lucky in that my husband is willing to help me out of bed for the loo or to arrange my pillows after turning me over. The bottom line is that I'm permanently exhausted, mentally and physically, so it should be obvious that having the cognitive ability to work, let alone the physical ability, would be impossible. People who work need to rest well in order to prepare for the next day and anyone receiving care during the night is not going to be able to do this.</p>
EM519	13-Feb-11	<p>Question 1 Misunderstanding of 'invisible' illnesses ie: Fibromyalgia. Lack of mobility, poor access to shops, transport, leisure facilities, social isolation, having to depend on other people, loss of independence, lack of carers, low incomes, lack of finance, depression, cognitive difficulties, unable to leave the house without making arrangements for wheelchair, parking etc. Constant pain, nausea, dizziness, muscle weakness, poor cognitive skills, memory loss, visual disturbances and constant lack of sleep makes very difficult to leave a safe environment ie: home. *</p> <p>Question 2 Being disabled leaves the sufferer feeling very vulnerable and not 'in control' therefore being in charge of your finances enables you to gain financial independence, and DLA should not be taxed or mean tested. It should be a personal choice of the recipient on how the money should be spent. The low, medium, and high components in mobility and care should stay the same or should be increased in line with inflation. DLA should be paid monthly.*</p> <p>The choice to use complementary and alternative treatments and medicines must remain. I am unable to tolerate many drugs and have no choice but to use different types of treatments and medicines. Being able to ring the DLA to advise them of any new circumstances for example, new health conditions that have been highlighted that require increased care and support. Also to ring DLA with any reductions in symptoms.*</p> <p>Question 3 Heating costs, disability aids (ie: kitchen appliances and tools to make food preparation easier.)*</p> <p>Special diets and nutritional needs; Alternate and Complementary therapies to relieve pain and suffering; *</p> <p>Holidays – extra costs for disabled needs; Prescription costs; Transport ; Vitamins and minerals and other NHS and non NHS medications; Cleaners, gardeners; Specialist furniture (adjustable beds, reclining settees etc.); *</p> <p>Adaptations to home; Paying someone to do general maintenance in the home ie: changing light bulbs, moving furniture, general DIY jobs, cleaning windows, housework, put rubbish/recycling out, gardening, washing car, lifting heavy items. *</p> <p>Question 4 • Will having two ratessupport? Applying for, and maintaining receipt of DLA needs to be kept as simple as possible. It is not possible to fit every body into two rates because disability is so diverse. Also disabilities can be degenerative and get worse, so being able to request a higher rate when your circumstances worsen is important. *</p> <p>• What, if any, ... cause? No two disabled people are the same, and there</p>

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		<p>are many and varying disabilities, having only two components cannot possibly cater for all disabled people. *</p> <p>Question 5 People suffering from terminal illness, and those suffering degenerative conditions should automatically receive the entitlement. Visually impair people should also have automatic entitlement.*</p> <p>Question 6 Disabled people should be able to be part of any community in the way able bodied people are. This isn't always possible, but receiving DLA means they at least have a small chance of achieving this. Being able to go shopping and using Shopmobility (scooters etc.) is a small but important step to some people, but it costs money. Having a car from Motability is a Godsend, I would be housebound without my car. *</p> <p>Question 7 Letters from health professionals could be provided to explain an individuals health needs. Xrays could be copied onto CD to show changes. Acupuncturists and other complementary health practitioners should be consulted to support claims, as should support groups. *</p> <p>Question 8 Absolutely not. Using aids brings about problems themselves. Using walking sticks or crutches cause blisters and sores so for them be taken into account would be wrong. It can be hard work using the aids and adaptations even though they are designed to help. *</p> <p>What aids and adaptations should be included? None • Should the assessment ...easily obtain? No *</p> <p>Question 9: • How could we make the claim form easier to fill in? The form is too long and ambiguous. Questions are repeated and not easily deciphered. There should be more help available to complete the form, as writing is quite difficult for many people. The thought of completing another DLA form fills me with dread. It was so long and difficult.*</p> <p>• How can we improve ...qualify? Have a person who is fully versed in the benefit in Citizens Advice Bureaus, GP surgeries, hospitals, etc. *</p> <p>Question 10 Doctors, consultants etc. could support a persons claim. DLA claimants should be able to provide letters of support from health professionals in the NHS. It should be remembered that most *</p> <p>DLA claimants are genuine, and it is the minority who claim fraudulently. I would have no problem be 'checked up on' however it is distressing to be felt to be a 'scrounger.' Having worked in a 'front line' job for 34 years, and being an active, independent, a useful member of the tax paying society, it makes one feel 'useless' and on the scrap heap, and to be disbelieved only compounds this. Having medical evidence should help support a claim *</p> <p>Question 11 • What benefits or difficulties might this bring? Some people have cognitive or anxiety/mental health difficulties, and facing healthcare professionals can be very intimidating, so any face to face discussions should be conducted with care and understanding, it can also be difficult to put your point across when you are in constant pain. People who cannot verbalise their conditions adequately could be discriminated against. It could prove difficult for people with mobility problems to attend interviews. • Are there any circumstances ... location? As above *</p> <p>Question 12 • What evidence ... reviews? It should depend on the disability • Should there ...condition? As above*</p> <p>Question 13 Perhaps GPs should be made aware of who of their patients are in receipt of DLA, and they can advise the department when and if their patients condition changes*</p> <p>Question 14 The name should be retained, there is no need to change the name from DLA to PIP. Agencies such as the CAB should have trained people available to assist claimants. *</p> <p>Question 15 No requirement should be made. Just make the form easier to complete and advise people to whom they can go for help to complete it. People are more than able to take responsibility for themselves but just need information.*</p> <p>Question 16 How do .. adaptations? I don't know. I certainly have to fund a lot of it myself or go without, and struggle!!*</p>

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		<p>Should there be an option ... one-off cost? Maybe, if for example, an adjustable bed needs to be purchased. *</p> <p>Question 17 *</p> <p>Question 18 It appears that if you receive the higher mobility rate, a blue badge is easier to obtain, although I think this should be automatic. A reduction in council tax could be made available to claimants. *</p> <p>Question 19 *</p> <p>Question 20 Don't know.*</p> <p>Question 21 Every body should be treated fairly*</p> <p>Question 22 Please don't tar us all with the same brush just because there are a few fraudulent claims. I am terrified to lose my DLA, as my pension just won't cover my needs. DLA is a lifeline to many people, and the quality of life of thousands of people would be suffer severely if they lost, or had their DLA cut.</p>
EM520	13-Feb-11	<p>1. Where does one start?? a. Attitudes of both the general public and of service providers in more or less every area of life which can be condescending, patronising and disabling b. Lack of money that is necessary requirement to enable full independence and active lives. It would be useful here to commission research into the link between disability and material and social poverty and the proportion of those with a disability who live on or below the 'poverty line' as opposed to those within the general population c. Lack of appropriate services and access to opportunities d. Not being able to understand, let alone implement, Michael Oliver's 'social model' of disability as opposed to the 'medical model' of disability. It is likely that many health care professionals including general trained nurses and doctors do not understand the 'social model'. Some may not even have heard of the 'social model'. Without a sound understanding of both the concepts and their application, the 'social model' cannot be implemented.*</p> <p>2. No*</p> <p>3. This cannot be answered properly outside a BPhil or MPhil thesis!! What does one include as disability? Physical? Mental/psychiatric? Learning? Each of these will present with totally different needs and, therefore, costs. To give a very brief list, this could include the costs of:*</p> <ul style="list-style-type: none"> § Mobility equipment up to and including cars* § Special dietary supplements* § Special eating/drinking equipment* § Adaptations to housing/residential property* § Specialist clothing* § Sanitary ware* § Access to social and leisure resources* <p>The above list is by no means exclusive and no attempt has been made to put an actual financial cost to these for obvious reasons.*</p> <p>4. Having two rates for each component will probably make the benefit easier to understand and administer. However, a major disadvantage of having two rather than the current three care rates is where does one place those people who are in the middle, who currently claim the middle rate care component? Will they be re-assessed as having a higher level of need or will they be re-assessed as having a lower level of need?*</p> <p>5. Despite the stated aim of moving towards a more individualised form of support, which in itself is not a bad thing, I still feel that the conditions give in 'annex 1' is appropriate as long as it is made clear that such a list applies. Again, the move to a more individualised form of support implies significant time spent by the assessing officer (be this assessing officer a nurse, a social worker, a medical doctor or whatever) with each and every person with a disability (and their family, where appropriate). This will be needed to gain an accurate assessment of the needs of the person both as an individual and within the wider context of their family. Would such an in-depth assessment be achievable given the likely vast number of possible claimants and the decreasing size of the assessor (social worker...) workforce? I am aware of the voluntary and compulsory</p>

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		<p>redundancies currently being imposed on local authorities and their social workers.*</p> <p>6. There are a number of answers here:*</p> <p>a. Carry out a full, in-depth and holistic assessment of abilities, disabilities and needs, placing this within the family context if appropriate*</p> <p>b. Points system – allocate each identified need and severity of need a certain number of points (if that makes sense!!)*</p> <p>c. The activities may well be different for each and every individual. Myself, my son and my wife (all of whom have disabilities) will interpret this question differently. One way of answering this second part of the question is to look at and adapt “Maslow’s hierarchy of needs”.*</p> <p>7. By carrying out a full, in-depth and holistic assessment of abilities, disabilities and needs, placing this within the family context if appropriate and by annually reviewing this assessment*</p> <p>8. No. I feel that it would be fairer to ‘start from scratch’. It could be argued, for example, that a Motability car is a piece of mobility equipment which needs to be financially serviced every month. If having a Motability car or scooter as mobility aids or equipment influences the outcome of the assessment then the continued use of these may be threatened. If such aids and equipment be taken into account, then only the aids and equipment that the person already has should be taken into account. *</p> <p>9. The language used in the forms should be clear, precise and unambiguous. As some peoples level of function may fluctuate from day to day or even hour to hour, dependent upon the form of disability, this should be taken into account. Peoples mental state should be given more prominence as they may not have a physical disability but may have a mental health condition such as severe depression, bipolar, ADHD or schizophrenia that may have a profound effect upon their ability to physically function within ‘normal or acceptable parameters’. The existing forms and assessments are so hung up on how many minutes a person takes to carry out or needs support to carry out physical activities such as dressing, personal hygiene and preparing and eating a meal that the quality of these activities could be lost.*</p> <p>10. Holistic supporting evidence or information from a variety of sources would be better than a single supporting letter from a single source. Appropriate people would be anyone who knows the claimant well. This may not necessarily be a care professional such as a GP, nurse or social worker but may be a personal friend or family member.*</p> <p>11. The benefits could include the level and depth of knowledge that the health care professional such as a nurse or medical doctor would be expected to hold on disabilities and the effects on individual people. The disadvantage is that nurses and doctors do not know everything there is to know about every form of disability. I know from years of person experience that many if not most nurses and GP’s for example know very little or nothing about autism spectrum conditions (ASC). If a health care professional such as a nurse or doctor is to be used to assess each and every claimant, each and every person with a disability, then that health care professional MUST have an in-depth knowledge and experience of each and every type of disability that they are likely to encounter. This is the barest minimum in order to carry out an accurate assessment of ability, disability and needs. This is not going to happen!! Thus it would be inappropriate to assess someone with an ASC by a nurse whose clinical knowledge, experience and expertise is in nephrology or oncology as they won’t have a clue!! Again, face-to-face assessments may be difficult if there is a possibility of the nurse and claimant knowing each other as this may influence the assessment or if the claimant may become aggressive or violent.*</p> <p>12. Yes, there should be different types of review depending upon the individual as a ‘one size fits all’ approach may not be appropriate for all individuals and will also run counter to the underpinning ideas and thinking behind the new benefit. The paragraph associated with this</p>

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		<p>question (paragraph 33) appears to answer this question.*</p> <p>13. One way would be to make the benefit time limited for a year but make it renewable each year. The renewal of the benefit could then be made contingent upon an annual re-assessment. It MUST be made clear and unambiguous to each claimant that they MUST attend a re-assessment or carry out an holistic self-assessment in order to continue to claim the benefit.*</p> <p>14. Clear and unambiguous guidance for what the benefit is intended and for what it is not intended. Clear guidance as to how to complete the form and assessment. Clear and appropriate signposting to other agencies and forms/sources of support. Someone independent of the process that the person can talk to would be helpful.*</p> <p>15. Yes it would. Clarity and appropriateness of signposting and information would be the key features of such a system. What would need to be avoided would be forms of signposting to services that does not exist or that has very limited value!*</p> <p>16. From a variety of funding sources. To put it more accurately, from whatever funding source and grant making bodies is prepared to assist with funding, equipment or resources such as respite care. Yes, there could be an option to use the new benefit to meet a one-off cost.*</p> <p>17. Unsure how to answer this*</p> <p>18. I would consider DKA to be very important and useful in acting as 'passports' to other benefits, help and support such as motability cares and scooters. This should remain. Providing clear information to both existing and new claimants as to the type of additional help and support that the DLA 'passports' to would be useful, although I do accept that there may be a cost implication to this.*</p> <p>19. The answer to this question requires at least an MPhil length piece of original research and not something that can be answered here! However, I believe that the quality of life for those with a disability would be adversely affected although from a service provider perspective money could be saved. An MPhil research question here becomes what is more important: quality of life or saving money; what is ethically appropriate as a trade off?*</p> <p>20. The use of assessments carried out by different agencies for different purposes may have value. However, the value of such sharing sharply decreases if the differing purposes are so differing as to make the sharing irrelevant. The purpose of JSA assessments and DLA assessments are so different as to make any sharing irrelevant.*</p> <p>21. See the first part of my answer to question 19 above! However, much of the information given on page 28 of this consultation appears to be lacking in any credible evidence. The main issue that MUST be considered in developing the policy is to provide solid evidence to support information on equality and diversity. For example, under 'race', it is stated that 'at this stage, there is no evidence to suggest that the policy would impact disproportionately...'. Where is your evidence to support this statement?*</p> <p>22. I would like to offer the following comments:*</p> <p>a. I am a carer for my wife (who has a physical disability and mental health problems) and son (who has autism). I have 'high functioning autism' and am a registered nurse (learning disabilities). *</p> <p>b. As my wife currently receives the middle rate of the DLA's care component and that I currently receive carers allowance, I am very concerned about losing carers allowance should my wife be deemed to need only the lower rate of care component if she is assessed on a 'good day' by an assessor who does not have the clinical experience in cerebral palsy and mental health.*</p> <p>c. This will have a drastic and critical effect on my family's finances. I would have to choose between caring for my wife and son or seek employment which, at the age of 51, may not be easy due to underlying 'ageism' within society. These will also a profound effect on my own</p>

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		<p>physical and mental health. I would be worried about paying my basic bills, and would not be able to afford to do anything for myself. It could also mean that caring for my wife and son may become unaffordable for me and I couldn't carry on. *</p> <p>d. I believe that the Government should not be making cuts of £1 billion to disability benefits because of the devastating consequences it could have for disabled people and carers like myself and my family.*</p> <p>e. I believe that Carer's Allowance must remain outside of the Universal Credit. Carer's save the UK £87 billion every year with the care they provide and it would be wrong to take away Carer's Allowance from some carers by means-testing it, as this would leave some carers without any financial support or recognition of their contribution.</p>
EM521	13-Feb-11	<p>1) It is difficult to concentrate one's answer only on a physical disability as I have chronic fatigue syndrome/fibromyalgia and sjorgrens syndrome which means I am often disabled and fatigued and in pain, all of which create both their own and integrated problems. I think there should be a distinction made between people who are generally well and in good health although they may have a physical disability i.e. losing legs after an accident, and people who have a chronic illness which causes them to be both unwell and to be disabled all or some of the time. Disabled people who have a physical disability but who are well are far more likely to be able to lead a full and active life, for example, the disabled people who compete in Paralympic games. *</p> <p>Chronic fatigue syndrome and fibromyalgia affect various parts of the body at different and unpredictable times and to varying degrees. Whilst one day I may be virtually unable to walk more than a few steps, my hands may be working fine but my brain may not be working correctly. On another day I may be unable to use my hands but can walk a little further. *</p> <p>I can therefore only answer these questions from my personal experience. Having very limited energy precludes me from being involved in anything that needs regular attendance as it is virtually impossible to predict when and if I will have the energy to go out. It is therefore very difficult to join any kind of group or indeed to make any kind of appointments because of the fluctuating nature of my illness.*</p> <p>Being unable to walk very far, i.e. to a bus stop, or walking around a shop, or standing and waiting for a bus, or waiting in a queue (in a shop for example) causes enormous difficulties in leading an independent life. Some days I can't even walk around my house because the pains in my legs/lack of energy make this impossible. *</p> <p>If a disabled person has fatigue/pain problems then they are not able to go out independently even with a wheelchair as they cannot move the wheelchair themselves, or have the strength to get a wheelchair in or out of a car. The same is true with a mobility scooter, as it takes quite considerable strength to dismantle it and lift it in or out of a car. *</p> <p>Having chronic fatigue has made it impossible for me to work for several years. I think there is nothing greater to someone's well being than feeling you are a useful part of society. A regular and local social meeting place for those with varying disabilities would be beneficial to everyone because most people could offer some assistance to others, even if it was just to be able to talk to someone who understands. Maybe speakers could come along to talk about various subjects to make it more interesting. Being disabled and ill is extremely lonely and I have been unable to find anything that I can go to. *</p> <p>Being unable to stand for more than a few minutes greatly reduces the ability to be part of any kind of normal social gathering because invariably people stand and chat. *</p> <p>2) I think the way it is now works well for most disabled people. The fact that the mobility and care component are both looked at individually is so important as someone may require full assistance with mobility but may be able to cope with their own care needs to varying degrees. I think that</p>

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		<p>if these components were lost it would be a massive shame.*</p> <p>3) Disability aids i.e. mobility scooter, wheelchair, stair lifts etc. Having groceries delivered. Convenience food. Hired help around the home i.e. general housework, decorating, gardening. Cabs . Heating as being still does mean you feel the cold a lot more than an active person. *</p> <p>4) I don't think this will make the benefit easier to understand. Only grading people as lower or higher will create problems. There are many people who will fall somewhere in the middle and they will lose out as I am sure they will be awarded the lower benefit.*</p> <p>5) I do think that certain conditions should automatically receive the benefits. It is difficult enough living life whilst chronically ill without having to jump through hoops to get the benefits you require. I also think that people who are well find it difficult to comprehend the additional anxiety and stress that both applying, and possibly more importantly, awaiting decisions about benefits causes. *</p> <p>6) This will be very difficult to achieve as with DLA, there are always going to be some claimants who people feel shouldn't get it, and quite possible people who should have it who are unaware of it. Maybe a good advertising promotion would be a good idea - or leaflets sent out with blue badges, incapacity benefit claims etc.*</p> <p>What ... independent life? Being part of the local community, no matter how small a role, can help. For my part my illness has totally isolated me as I am unable to belong to anything but if local groups were available that I could attend at times, even just to talk to someone to help them or to be listened to would help. Being independent just doesn't mean being able to get about, it also means being accepted and valued.*</p> <p>7) This is invariably and unfortunately, always very difficult to quantify. As I have said, my illness means that my condition changes all the time, from one hour to the next can make a huge difference to how I am and what I am able to manage. A simple medical, which may only last an hour (if that) cannot possibly show this. I think that certain illnesses, that are known to be generally more fluctuating, should be easily accepted as such, without the need for claimants to have to try and prove how it can change. *</p> <p>8) Reading between the lines it seems to me that if you did take these into account very few people would be eligible for any kind of disability benefit. Would you assume that if someone has a wheelchair they would no longer be disabled? Would anyone who can drive no longer be disabled? Where would you draw the line? In my own case, I have a mobility scooter and a wheelchair and a walking stick. I use these at different times, depending on how I am. The problem is that with my illness I am often feeling too ill to go out at all. I tend to only use them when I am having better days, but when my legs are particularly bad, or in instances when I know I may become stuck somewhere - which is very frightening - for example in the middle of a large shop when I suddenly lose my energy, which can happen within moments and without any warning. I try to walk as much as I can and we often have my wheelchair in the car as a back up in case I need it, as I can normally sit somewhere whilst my husband goes and gets it. Its so difficult to know when to use it and when not to. Losing your independence is one of the most difficult things to overcome.*</p> <p>What aids ... account? None*</p> <p>Should we only ... uses them? They should not be taken into account.*</p> <p>Or should we ... easily? They should not be taken into account.*</p> <p>9) From a personal point of view I think that forms that can be completed online would be easier. I find handwriting extremely painful and quite exhausting and it takes me forever to complete the forms, whereas I can type easier, use a spellcheck and cut and paste different answers.*</p> <p>• How could we ... benefit? I think that patient care groups would be a good place to start to offer advice to their members. Fortunately most people now have access to the internet and an easy to read and</p>

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		<p>understand information section within the government pages would be very useful. *</p> <p>10) I think that if a disabled person lives with someone else, they would be the best person to say how their illness affects them. The problem with asking GPs is that they are normally very busy and haven't the time to really sit and discuss how a patients illness affects them on a daily basis. I am sure my GP has very little understanding of what I go through and what my needs are. My problem too is that I have moved so my new GP doesn't know me very well at all and also didn't know me before I was ill, so he would find it difficult to judge the difference in my capabilities from when I was well and fully capable. *</p> <p>What information ... cannot do? Again I think that certain illnesses should be listed as there is knowledge widely available that gives information of what a person can reasonably be expected to be able to do - although this of course is different depending on the severity. I think a tick list within the application form would be the easiest for a person to complete. I know I have kept a daily diary at times to be able to show my GP what has been going on, and maybe something like that might be a good idea. At a lupus clinic I attended they gave me a form to complete which listed various symptoms and the effect they had a on daily life. I had to give everything a rating from 0 to 10, depending on severity. That would make it easier to comprehend. I thought it was a very good idea and gave the consultant and really good understanding of how I was at the time. If this was always included in the claim form it could be compared over the months or years. *</p> <p>11) If the person was truly independent, and not part of a company who are paid for results, then this might be a good idea. I think the personality of someone like this would be very important. Unfortunately many people, who have never been ill, or been involved with anyone with a chronic illness, find it very difficult to understand the difficulties that are faced every day. Due to my permanent health insurance claim, I have had meetings in the past with so called professionals who have supposedly met with me to offer advise and assistance, but who in reality have been trying to break my claim. They have shown no empathy or understanding and have left me feeling desolate and totally misunderstood. I fear that this may be the case again.*</p> <p>Is there any time ... else? I think that these meetings should definitely be in a person's own home and there should always be another representative for the claimant present as well.*</p> <p>12) Some disabilities are life long i.e. downs syndrome, so I think that it would be a waste of time and money to keep looking at these claims as a person with this would never suddenly become well again. I also think that you should look at how long someone has been ill/disabled, as that too can be a good indication of whether there is a chance of improvement. I know in my case, sadly, that the longer a person has had chronic fatigue syndrome, the less likelihood of making a recovery. Only last year I was awarded DLA on permanent basis and you have no idea the relief I felt at that decision. Sadly however, I now feel very worried again that I will have to keep going through the claims process again and again and with that all the emotional stress every time I am waiting for a decision to be made. It is hugely worrying for me, everytime that my claim comes up, as to what decision will be made and the ongoing effect it will have to my life.*</p> <p>Should the way ...disability? Definitely. Certain health conditions and disabilities, do not improve, no matter what, and in these instances I do think that it is unnecessary to look at the claims again.*</p> <p>13) A simple letter, sent, say every six months, would be sufficient, enquiring about any changes. A tick list that could be completed and returned and then kept on record, would be a good idea.*</p> <p>14) A listing of where help is available would be wonderful. Its only through trial and error that I sometimes find assistance is available, but it</p>

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		<p>is very difficult to find these things out. Anything to make life easier would be beneficial. *</p> <p>15) I paid for my own wheelchair, mobility scooter and walking stick, but I do use my DLA to have a car, which has made a MASSIVE difference to us. It means that whilst my husband is at work I can drive somewhere if I need to go out. Being ill for so long and unable to work would have meant that we couldn't have afforded two cars, and as my husband needs a car to get to work I would have been stuck at home all the time. Now though with my DLA car I can go out if I want to, even if its just for a drive to be able to get out of the house, or to be able to visit my sister.*</p> <p>Should disabled people ... one-off cost? I think that you should be able to decide yourself what you use your benefit for. Most of mine is used for my car and I have used other household money to pay for my wheelchair etc.*</p> <p>16) I am unable to answer this as I have no experience of this.*</p> <p>17) What can ... better? The blue badge scheme is brilliant but I do think that some kind of disabled 'passport' would be jolly handy. The number of times that I have had to use my blue badge in my car for parking, but then need to prove I am disabled for something else - i.e. cheaper parking or facilities - but been unable to as my badge is displayed in my car! A 'passport' like this would make travel on trains etc easier too as at the moment you have to send off for a disabled rail card and it is quite time consuming. Anything to make life easier would be great. A disabled 'passport' that was listed on a national register would be wonderful because it would save so much form filling and confusion.*</p> <p>At the moment services? For me, the blue badge scheme, has made a fantastic difference to my life. Being able to park closeby to shops, hospitals etc, has meant that on good days I can have a little independence. I think people really do not understand how fantastic this is. Before I had the blue badge I would have not been able to consider going out on my own at all because of invariably having to walk too far. I do hope that in completing this, which has been no mean feat, will make a difference to how you view this new benefit, from a claimants point of view.</p>
EM522	13-Feb-11	<p>Dear Sir/Madam, Reference the Public consultation-Disability Living Allowance reform. In particular to Chapter 2: The new benefit: our proposals (from the government). In particular Question 1 "What are the problems or barriers that prevent disabled people participating in society and leading independent, full and active lives? Since the illness and disability is not stated with its degree, this appears to be the thoughts of someone with very little knowledge of how the various types of disabilities influence peoples lives. *</p> <p>Consider the case of an elderly severely disabled person suffering from Arthritis of the spine with restricted body movements who overbalances when looking upwards while shaving. His walking ability is very limited by his painful back problem putting pressure on the nerves causing causing him to limp and occasionally stagger. He has an average standing time of about 6 minutes before being compelled to sit on a chair to recover.</p> <p>There is also an eyesight problem with the loss of vision in one eye and the other having been subject to surgery to arrest further deterioration. With the sight now having a limited field of vision, three pairs of spectacles are required for distance, reading and computer use with a working focus distance of 20 Inches 508 mm. The computer magnification is set at 175%. The sight presents a problem with dazzle and reflection in a store like Tesco. To look out across the water from the Welsh Assembly building in Cardiff Bay, the reflection from the water is blinding. To walk into a public house or restaurant from the outside light the vision is impaired due to the change in the lighting level causing him to risk walking into the tables or people until his sight slowly becomes accustomed to the surroundings. Imagine getting out of a car, being led into the Post Office by a friend to join a queue knowing that in six minutes</p>

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		<p>time a chair will be needed to sit on to recover your walking ability to get back to the car. *</p> <p>Due to the risk of overbalancing and falling and the sight problem, his GP has advised him not to go out alone. When going anywhere he uses a taxi for transport to the venue and carries a mobile phone as advised.*</p> <p>This person gets the DWP Mobility benefit and the care allowance to allow him to be taken out a couple of times a week by taxi. His friends and neighbours care for him by doing his shopping, house cleaning, washing together with preparing and cooking his meals because he can't bend down to use the oven without the risk of overbalancing and falling. His bungalow has a walk in shower with a seat and a safety rail costing £4,000. It is on the community alarm system with an emergency call out system. *</p> <p>With both DLA Mobility and Care Benefits amounting to under £100.0 per week, considering the modern day living costs with VAT and rising taxi costs. This is insufficient These benefits prevent disabled people from being deprived and confined to their homes as if within the walls of a prison cell to suffer from loneliness, boredom and depression with the health service picking up the treatment costs. What suitable housing does Cardiff City Council provide for such people?</p>
EM523	13-Feb-11	<p>I am horrified and appalled at the government's proposals to change the criteria for the disability living allowance making people with long term degenerative illnesses re-apply periodically rather than offering indefinite support. I consider this to be placing an intolerable burden on people whose lives need to be made easier, not more difficult. Yours Sincerely</p>
EM524	13-Feb-11	<p>Hi, Please find the below responses to the DLA reform questions. I thank you for the opportunity to voice myself. Regards,*</p> <p>Question 1 Many work places do not have wheel chair access. Inadequate healthcare in some cases. The right healthcare may reduce the disability allowing the person to require less support or none at all.*</p> <p>Question 2 Yes. Reviewing each case will be costly. Some health conditions should be automatically entitled to benefit to avoid this additional cost. Also, in these cases the reviewing of the benefit should be less frequent as this will avoid unnecessary costs. *</p> <p>Question 3 Mobility. A disabled person may find it difficult to use the transportation systems a non-disabled person uses. For example buses and trains. In many cases they need to rely on taxis to get around and in some cases use taxis to get their groceries delivered.*</p> <p>Question 4 Yes, I think it will be easier to understand. There is a possibility that if there is a large difference between the two rates that someone who needs a rate in the middle will either get too much or too little.*</p> <p>Question 5 Yes they should. Some health conditions do not require the assessment of the individual. Assessing these cases will waste the Assessor and Decision Maker's time.*</p> <p>Question 6 By having a list of essential activities a person should be able to do. Each activity would have a weighting as to how important it is. This weighting would be decided with disabled people and healthcare professionals.*</p> <p>Question 7 Health conditions that can fluctuate can be reviewed periodically. Other long term conditions can be reviewed less often or not at all depending on the advice of health professionals.*</p> <p>Question 8 All adaptations and should be included.*</p> <p>Question 9: Having easy access to someone who can help fill the form.*</p> <p>Question 10 A report from a healthcare professional.*</p> <p>Question 11 Have a competent person with objective information about the health condition. Allow the person who is claiming the benefit to be part of the discussion is an excellent idea. I would also recommend allowing a small panel of 1 – 3 people who care for the disabled person consisting of care workers, family and friends to be at the discussion as</p>

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		<p>well the Decision Maker.*</p> <p>Question 12 Medical evidence should be used to set the frequency of the reviews. Yes, there should be different types of review.*</p> <p>Question 13 By making it easy to get in touch with whoever can review / cancel the benefit.*</p> <p>Question 14 Who the benefit is for, the levels of benefit and help with applying for it. Yes, this should be part of the claiming process.*</p> <p>Question 15 If claimants need help and support, it should be available but not a requirement. *</p> <p>Question 16 This should be provided by the state. Either in the form of a Personal Independence Payment or some other grant.*</p> <p>Question 17 Advice and support should be targeted to their parents or guardians.*</p> <p>Question 18 The existing passport to other support should be continued.*</p> <p>Question 19 This would be a very bad idea. Access to those benefits and services would require additional applications making it more expensive and give the disabled person another hurdle to get over.*</p> <p>Question 20 I don't have the answer for this. But, I feel it warrants investigation. Possibly having a forum for consultation?*</p> <p>Question 21 I feel there will be no effects compared to the existing DLA benefit.*</p> <p>Question 22 No, thank you.</p>
EM525	13-Feb-11	<p>1. Your response: lack of mobility, not having the resources to get them out , joining in stopping themselves becoming isolated. The freedom to enjoy family, friends work , hobbies.*</p> <p>2. Your response: I think the doctors are best qualified to make the judgements re peoples health . The esa have been scandalous and caused great stress for many with conditions like MS that fluctuate. Stress in MS and other conditions causes exacerbations of their illness. These medicals have proved themselves incredibly stressful for people getting by on low incomes . The whole process is degrading for people trying to hold on to shreds of pride with debilitating illness.*</p> <p>3. Your response: Getting around, travel fares , taxi fares , always having someone with you that often necessitates that you pay for there travel, food refreshments. Special food needs , high quality food expensive healthy microwave food. Paying for services that help you sort out everyday things like computer problems , personal correspondence and other affairs. Just about everything you can think of costs a heap more. You cannot do thing the cheapest way you have to do it the way your disability allows.</p> <p>4. Your response: I have a lifetime award for higher rate mobility and middle rate care. I have found it a complicated system as it is further complications wouldn't help . I have cognition problems . *</p> <p>5. Your response: MS means you will have problems so should be automatic and those probleems certainly are not going away . So I think the lifetime award is suitable. I am sure there are other conditions that follow the same pattern. These types of conditions are very stressful and I think they should be eliminated from any stressful application process. A process that is undeniably detrimental to a persons health*</p> <p>6. Your response: As now ask doctors and health care proffessionals . They know patients .*</p> <p>7. Your response: They should be assessed as being at there worst always as things change quickly and people will be left without the provision they need . No system can keep pace with the daily changing needs of these. Placing again damaging stress on an already dangerous situation where stress will make things worse. Stress undoubtedly brings on relapses in my MS. Every relapse I have had i can trace to a stressful event. Many others I know with MS feel the same. Doctors back this up. I am always told to keep my stress levels down . The rehabilitation hospital I attend has put me on stress management courses. *</p>

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		<p>Conditions like MS should be assessed at their worst as reapplying is not practical. It will mean a life in admin chaos. *</p> <p>8. Your response: I have drop foot . I have had many adaptations over year none of them has cured it . I still fall over without help. I still find it difficult to walk with it. some aids i have not got on with and given back. But I always have difficulty with aid or not. Its incredibly hard still with aid*</p> <p>9. Your response: keep the people who have a lifetime award with what they have been promised they can expect. MS and lots of conditions arenot going to get better. reapplying wastes goverment money and causes problems inhealth for applicants make sure new applicants have assisssstance to fill form.*</p> <p>10. Your response:As now . All Drs and health care proffesssionals . Proof of appointments medication health services. people do not get involved in these regimes unless they are sick*</p> <p>11. Your response: I dont think so. I have MS and have innumerable amout of face to face discussions with people that are genuinly conserned about my condition. I would not want another psudo concerned chat re my MS. Actually I would find this , as with the esa medical rather humiliating*</p> <p>12. Your response: AS before MS and other serious conditions should not be pressured*</p> <p>13. Your response:*</p> <p>14. Your response:*</p> <p>15. Your response:*</p> <p>16. Your response: quite often through our own pocket. I have tried out FES which I found very helpful. but I did not get the funding for . My physio gave me the address of who I could buy it from directly. It cost £800. I'm still saving*</p> <p>17. Your response:*</p> <p>18. Your response: good .its known its a stringent systm, so it respected as a yardstick of disability*</p> <p>19. Your response: confusion*</p> <p>20. Your response:*</p> <p>21. Your response:*</p> <p>22. Your response: Let people with MS keep lifetime awards and give those with othcer serious conditions lifetime awards . It is an extra burded on those whos lives are already very heavy having to reapply and go through humiliating medicals.people suffering from these serious conditions have usually seen a drastic decline in their financial circumstances along with their health.the dla payments allow them that extra bit of security that helps with there expensive lifestyle.</p>
EM526	13-Feb-11	<p>1. People with disabilities face two types of barriers, the barriers imposed by their condition and, perhaps more significantly, attitudinal barriers. Many disabled people also have low incomes which means that they are limited in the amount of independence they can buy. Attitudinal barriers lead to the view that all disabled people are helpless and to a society where, despite all that is said, officials with no knowledge of disability make ill informed decisions about what is best for disabled people, often leaning to policies which suggest that one size fits all. *</p> <p>2. People with conditions which automatically qualify under the present system should retain their benefits and the existing conditions which automatically qualify should be retained.*</p> <p>3. The extra costs depend on the disability. A blind person will pay for taxis to travel safely. While decision makers who never use public transport laud its efficiency, the reality is quite the reverse. Public transport is often infrequent and accessed in ways that are not safe for a blind person. Pedestrian precincts are often the most dangerous places imaginable for people without sight because of street furniture, plants and trees, seats for the public, sudden flights of steps, crowds of people who do not look where they are going and groups of people standing in the middle of the pedestrian way - and that's without roadworks. Blind</p>

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		<p>people also need help with dealing with post, reading necessary information such as food packaging and general mobility, eg finding a toilet in a strange building. They need technology to help with everyday tasks, eg the colour of a shirt, and have the cost of providing this technology. The proposals in this consultation take away the choice of technology from the individual.*</p> <p>4. • Will having two rates ... support? It will depend entirely on how the information is prepared for those reading it. If it is the usual policy of making 'government speak' incomprehensible, then nothing will have been achieved. *</p> <p>• What, if any, disadvantages .. cause? Without knowing more about the rates and administration it is impossible to answer this question.*</p> <p>5. Existing conditions with an automatic entitlement should remain. There should also be automatic entitlement for stroke patients and people with rheumatoid or osteoarthritis. *</p> <p>6. This is a pointless question. What is essential to one person is not necessarily so to another. For example, one totally blind person may have easy access to help with reading while another may not.*</p> <p>7. Make sure that medical practitioners have a knowledge of the disabled person's condition. Under the present system, I know of blind people going to appeals tribunals where the medical representative was an orthopaedic surgeon with no knowledge of sight problems. It is also essential to take advice from the major support organisations such as the RNIB, RNID, MS Society, Arthritis Care and the Scottish Society for Mental Health.*</p> <p>8. No. Why should people be penalised for investing in their own independence? Also, some people are 'gadget' people while others are not. The danger of including aids and adaptations in the assessment is that the usual suspects of wheelchairs, ramps and toilets will be considered while items like colour detectors, labellers and audio devices will not. There is also the danger that assessors will recommend the products they supply which happens at the moment under Access to Work.*</p> <p>9. DLA is supposed to be a benefit to promote independence. The present application process is so depressing and negative that people are in danger of adding acute depression to whatever condition they have. The revised process must stress the independence that DLA allows, stop treating disabled people like parasites and encourage people to apply as valued citizens.*</p> <p>10. The evidence depends on the person. Some people have regular contact with a GP or other medical practitioners while others do not, eg there is no point in someone who is congenitally totally blind wasting an eye clinic's time. The process should give a list of the 'usual suspects' (GP, employer, course leader, carer) but should also accept evidence from a responsible third party.*</p> <p>11. It depends on the individual. There are people whose paper application should be enough. A health professional should be involved only when it is felt that it can help the applicant, not when it is felt that it will help to save money. *</p> <p>12. If a person has a congenital condition which is not going to change, there is no need for a review.*</p> <p>13. This document repeatedly states that the process for PIP will be easier to understand but does not set out in what way this easier understanding will be achieved. We need the information before we can answer the question.*</p> <p>14. People need the right information before they start to apply for the benefit. It is essential that Pip is well publicised as a positive benefit that promotes independence and enables people to reach their full potential. People need to know what it is, who can qualify, how to apply, the amount and the purpose of the benefit.*</p> <p>15. See above. Wide publicity through the media, support organisations,</p>

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		<p>the press, information centres, online. It is also important to educate DWP staff to realise that they are not giving handouts but encouraging independence.*</p> <p>16. How people fund depends on circumstances. As most major adaptations, eg bathrooms, are means tested, many people fund themselves instead of going through a mass of bureaucracy which can take years and can depend on the efficiency of social services in any given area. Whether PIP should be used for a one off cost would depend on the circumstances and could simply endear to the government by saving money while denying the person long term independence.*</p> <p>17. Every individual should be assessed on individual circumstances regardless of age. However, in assessing children, parental responsibility must be a key factor.*</p> <p>18. It depends on the service and the area. There needs to be more consistency, eg in the charge policies for blue badges.*</p> <p>19. Eligibility for benefits and services needs a benchmark and DLA has provided this evidence. As the underlying thinking behind DLA reform is the government's desire to cut spending and save money regardless of who suffers as a result, any change to eligibility would disadvantage vulnerable people.*</p> <p>20. Surely DWP should look into this question and then present findings for consultation. There is no justification for saving money at the expense of individual wellbeing and independence.*</p> <p>21. DLA is about disability and therefore the other equality groups are relevant only if they have a disability.*</p> <p>22. Firstly, these consultation questions have been badly set out to comply with the guidelines for making information accessible. The person who prepared the original document has not followed Microsoft Word styles.*</p> <p>This consultation has been put together as a means to appear to consult without giving people the information they need to consult meaningfully. It is clear that the coalition government has not thought through the questions to which people will want answers, eg passport to other benefits, PIP rates, application and assessment process. There is need for much wider discussion with the lead disability organisations prior to this consultation. 2013/2014 is getting very near the next general election and there are 10 million disabled voters in the UK!! It is worth remembering that people with disabilities are not disabled through choice and should not be penalised simply to save money.</p>
EM527	13-Feb-11	<p>Dear Sirs, I am responding to your consultation document as an individual, who has been disabled since 1967 and in receipt of the Disability Living Allowance (higher rate for mobility and middle rate for care), since its inception, on an indefinite basis; and continued in employment until my retirement.*</p> <p>* Mobility:- Transport, either by car including adaptation: accessible public transport *</p> <p>Access to buildings – work/study/shopping/leisure and social activities*</p> <p>Access to information:- Noting needs of people with visual and hearing impairments - Lack of affordable, available and appropriate assistance in the home - Availability of aids and adaptations - Inadequate provision and maintenance of systems such as “loop” in public places.*</p> <p>DLA should remain the same, not means-tested, not taxed and not restricted to a particular age group and can be awarded for an indefinite period.*</p> <p>Transport costs – maintaining and running a car including costs of adaptations of controls etc. – taxis and minicabs.*</p> <p>Care – additional care in the home both local authority and private provision; domestic help etc. Extra costs to participate in social and leisure activities, for example some theatres do not offer reduced ticket prices for disabled people and some travel companies require able-</p>

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		<p>bodied companions.*</p> <p>There is no reason to assume this. Without specifying the criteria for each of the two rates, it is not possible to list the disadvantages and problems.*</p> <p>Yes. Otherwise the timescale required to assess every individual claim is likely to tax resources beyond any manageable level.*</p> <p>No response.*</p> <p>You cannot: too many factors involved.*</p> <p>Most aids and adaptations are unlikely to alter substantially the problems and barriers listed in Q.1.*</p> <p>No response*</p> <p>So far we have no definitions of "ability".*</p> <p>The practical implications, e.g. timescale/suitably qualified personnel do not appear to have been taken into account.*</p> <p>Again, need awareness of practical constraints. No there should not be different types of review: impossible to set appropriate criteria.*</p> <p>No response*</p> <p>Yes, if you can*</p> <p>I doubt if there is an easy answer to this.*</p> <p>A wide variety of methods. An option, but <u>NOT</u> a requirement, to use PIP.*</p> <p>No response.*</p> <p>Very important but lack of clarity and understanding can limit such access.*</p> <p>It would have considerable negative implications. This "passport" should be maintained and circumstances clarified.*</p> <p>Where feasible and fair, this should be explored.*</p> <p>No response.*</p> <p>Re. Executive Summary, point 19: surprised that DLA can be viewed as a barrier to work. In my own case, DLA not only assisted with the cost of travel by car to work, but helped meet the high costs of adaptations to my car. Many disabled people would not be able to follow study courses, leading to enhanced employment opportunities, without using this for assistance to travel and obtain essential equipment. With reference Section 2 of The New Benefit: Our Proposals, what will stay the same? Points 8 and 9 - I hope there is no question that these will remain the same. Point 10 – the provision for individuals in receipt of DLA or PIP before age 65 to continue to receive this after 65 should definitely be included.*</p> <p>*</p> <p>I look forward to your response to my comments. Yours faithfully,</p>
EM528	13-Feb-11	<p>Question 1. It is first of all important to define carefully what is meant by a full, active life - for example, being able to volunteer online for an hour a week in between managing one's condition is just as valid as being able to work full time and manage one's condition.*</p> <p>The lack of a definition is a barrier in itself, leading to inappropriate 'solutions' to the 'problem'. The attitudes of people are important, especially in valuing other people's contributions to society and not forcing them to change to fit some prescribed rules. Disabled people may identify a barrier but, because of the attitudinal barriers, have problems convincing anyone that their requirements are genuine, so nothing changes.*</p> <p>Finance is important - participation in society costs money, whether it is an internet connection, transport to venues, etc, and before that, maintaining a home and food etc also requires funding.*</p> <p>Question 3. Disabled people face extra costs compared to non-disabled people in terms of managing their impairments and in facing barriers in society. *</p> <p>Personal care and treatment, obtaining suitable food and drink, getting around (both inside and outside the home), managing activities such as going to work or interacting with others, and housing, including</p>

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		<p>maintaining the home in a suitable condition (heating, lighting, equipment, location, cleaning, etc) are all areas where extra costs arise. *</p> <p>Question 4. It is irrelevant to talk about 11 combinations of rates making the benefit difficult to understand, since all that matters is that people receive a suitable level of support for each of their requirements, which means 3 and 2 rates for DLA - small numbers as they stand. *</p> <p>The main disadvantages and problems would arise from people with particular needs being unable to tick all the boxes for a particular rate, being ineligible for the relatively small amount of assistance that the benefit would provide and ultimately requiring a large amount of resources from councils and health services because their initial needs were not met and led to greater problems, such as poverty-related issues and worsening of their conditions.*</p> <p>Question 5. Where needs and circumstances are clear, such as people with cancer who need to travel to hospital on a regular basis, and those in Table 3, then automatic entitlement would make the benefit easier to understand and administer.*</p> <p>Question 6. The definition of "full and active lives" is required again here. Someone who is able to easily demonstrate they satisfy the criteria for support, whether it be Social Care, or Disability Living Allowance, etc will be better able to live a full life than someone who struggles to match their impairment and experience to the criteria, even though their needs are equally substantial in different ways and still lead to significant extra costs. Therefore the only way to ensure those people least able to live full and active lives are supported is to ensure that everyone who faces additional costs because of disability receives the support.*</p> <p>Activities essential for everyday life are eating, sleeping, toileting, shelter, security, and communication with others (Maslow) but disabled people should also be able to have access to opportunities that non-disabled people can expect to enjoy - leisure, culture, etc.*</p> <p>Question 8. To be fair and useful, it should not take aids and adaptations into account. *</p> <p>There are issues around the definition of aids that are "easily obtained" - if someone has e.g. approached wheelchair services and failed to obtain a wheelchair that increases their mobility, including it in an assessment for benefit would see them failing again and experiencing even more financial hardship because they will have to buy their own and have less money to put towards it. If you already have an aid, then you would require finance for maintenance and future replacement or upgrade. In both situations, the absence of the benefit would reduce independence.*</p> <p>Taking adaptations into account will also disadvantage disabled people further in the housing market - if one's home is adapted, and the benefit were withdrawn because of that, it would make it even more expensive to move house for purposes such as moving near family or finding/retaining a job.*</p> <p>Question 9. Since the benefit cannot respond to individual changes in disability depending on circumstances (in/out of work, bad day/good day, visiting accessible/inaccessible venues, etc) and nor should it because the administration would be hugely expensive for little advantage, asking about all the things mentioned in previous questions is not necessary - one example of specific requirements or extra costs incurred in relation to food and drink, getting around, etc should be sufficient. *</p> <p>People are unlikely to take notice of it until they need it, so promotion via GPs etc is useful so that eligible people do not lose out. However, promotion will result in increased caseload, just like it did for DLA (and increased caseload through promotion, combined with inflation, naturally increase expenditure).*</p> <p>It does not matter what people think of a benefit (mention of thinking of it as compensation was criticised, but for people disabled as a result of healthcare, they could sue the NHS for millions of pounds to ensure they are in a sound financial position to obtain support for the rest of their</p>

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		<p>lives, or be happy with what DLA provides in terms of day to day support).*</p> <p>Question 10. It should be remembered that some people have conditions that do not change and hence have no contact with consultants and only visit GPs etc for health matters unconnected with impairment or disability. Here, demand for evidence would lead to an increase in administration costs within the Health Service, etc.*</p> <p>Question 11. A healthcare professional may not understand all disabling conditions, especially in cases where the cause of impairment is not immediately obvious, and could lead to the disabled person's experience being denied. Employment and Support Allowance is already assessed by interviews with healthcare professionals unknown to applicants and the appeal success rate indicates that they are not always successful at identifying disabling conditions.*</p> <p>Question 12. Even though this benefit has nothing to do with work, there is much discussion in the consultation document of how it enables disabled people to work, and frequent reviews requiring attendance at face-to-face discussions would not help with employability.*</p> <p>Some conditions will not change. The nature of disability may have changed over the years since DLA was introduced but it just means that the barriers faced are different. Simple reviews may be useful in some cases, but it should not mean having to apply for the benefit all over again - those people who are able to e.g. volunteer for an hour a week do not want to waste their functional time on forms and assessments.*</p> <p>Question 15. It would be inappropriate for such a requirement to be part of an assessment for benefit - suitable advice and support should be determined between a person and their known healthcare professionals. Prescribing unsuitable treatment for someone, that results in them losing entitlement to benefit when they refuse, would cause more problems and solve none.*</p> <p>Question 16. Disability Living Allowance can be used for ongoing costs or infrequent but large expenditure, promoting maximum independence in managing impairment and disability.*</p> <p>Aids and adaptations are available through a variety of methods. (Separate from benefit reform) Promoting what can be obtained from social services etc, and removing postcode lotteries, would be very helpful, but choice is also important.*</p> <p>Question 21. The impact on disabled people is huge. Justifying reducing support to some groups because other groups are considered to need it more is concerning - a need is a need, and lack of support leads to greater need.*</p> <p>Gender is included in your impact assessment, but not transgender. Transgender people may experience problems in accessing healthcare etc and face additional barriers in society. The same may also be true of people in relation to sexual orientation. *</p> <p>Question 22 Disability Living Allowance is a benefit that promotes independence as it is paid to people identified as having particular needs, but can be used very flexibly both in terms of managing conditions and in addressing barriers in society, so it is still not clear why a new benefit is proposed (with all the associated costs of establishing it).*</p> <p>It is also not clear whether the proposed benefit will address factors such as those discussed in the Leonard Cheshire report Disability Poverty in the UK http://www.lcdisability.org/?lid=6386 or will in fact increase disadvantage because of restricting eligibility even further than DLA does.*</p> <p>Recent research by Warrington Borough Council in relation to Housing Benefit showed that increasing takeup by eligible people reduced expenditure in other areas. The amount paid out in benefit was more than recouped by savings in relation to health, community safety, etc. The same is potentially true for benefits in relation to disability and more research in that regard should be carried out.</p>

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EM529	13-Feb-11	<p>1. Your response: Lack of wheelchair access to places. Some people's attitude that disabled people are unable to contribute to society. Not enough care hours to allow people to live their life fully. Illness causes severe limitations on their life. Fluctuating conditions mean some people can't work proper part time, for example, as they have good days and bad days, so their lives are unpredictable.*</p> <p>2. Your response: I think the self assessment should stay the same – the person knows their condition better than any visiting doctor who sees that person for such a short time. The forms should be more simple though and shorter.*</p> <p>3. Your response: Extra heating bills, maintenance on wheelchairs/scooters, travel costs as some can't drive and need to pay for transport. Having to take a carer with you means it is double the cost to the average person, accommodation, food, travel etc. *</p> <p>4. Your response: I don't see why you shouldn't have two rates – high and low needs. I don't see this as a problem.*</p> <p>5. Your response: Some conditions are not going to change over time, so they should get an automatic entitlement. *</p> <p>6. Your response: Priority should be care needs, getting up dressed and fed, but also to counteract the isolation of people with disabilities should be a high priority – to be able to go out and participate in life, socially and in work, if they are well enough. *</p> <p>7. Your response: This is the biggest worry. A visiting doctor will not see the true story of someone's life. I feel there should still be a self assessment form, but a far less complicated one. *</p> <p>8. Your response: Aids and adaptations should be considered, but remember these break down and the person can be left very dependent again. If the person hasn't got this equipment, you can't take into consideration aids which they don't have. *</p> <p>9. Your response: The claim form should be simplified – people are often too ill to fill in the form. There should be an easy reading form too, for people with learning difficulties. If there are no changes since the last claim, we should be able to say that and not have to re fill the arduous form in.*</p> <p>10. Your response: The carers and family of the person with a disability. They see the every day life of that person.*</p> <p>11. Your response: People are often too ill and find this very stressful. People are often more likely to paint a rosier picture about their lives with someone visiting. Often they don't like to focus on what they can't do, but what they can. This can give a very distorted view of their illness.* A visiting healthcare professional has their own values and prejudices when it comes to some illnesses – they are not impartial and some may not listen to what the person is saying, but write their own interpretations of the person.* Nobody knows better than the person living the life how their life is affected by an illness. *</p> <p>12. Your response: If someone has a long term illness, than every five years maybe it should be reviewed. Maybe a letter to see if there are any changes, rather than all the form filling in and visits. Their own social worker/care manager could be involved.*</p> <p>13. Your response: People should report changes themselves. If not, maybe their GP, social worker or care manager could report changes, or even better encourage the person with the disability to report changes.*</p> <p>14. Your response: They need to know what the criteria is for applying and the different rates and levels. Keep it simple and short!*</p> <p>15. Your response: CAB could help here and maybe an independent network. When direct payments came in, they had direct payment advisors who spread the word and spoke to disabled groups and individuals. You could follow that example.*</p> <p>16. Your response: People often have to fund their own adaptations, or part fund it. It would be good if a PIP met the cost in this way.*</p>

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		<p>17. Your response: I don't see a huge difference in assessing children. Obviously having a parent present and listening to what the parents says - they know their child. *</p> <p>18. Your response: Not sure on this one – don't really understand what passporting arrangements means.*</p> <p>19. Your response: As above. *</p> <p>20. Your response: You should liaise with social work departments so not to duplicate.*</p> <p>21. Your response: Again, the prejudices of the visiting healthcare professionals. This does happen, it is a real problem! *</p> <p>22. Your response: I am all for getting people off benefits and back to work, who are fit enough to work, but targeting people with disabilities who are ill and vulnerable is going to add to their burdens. They are an easy target maybe.*</p> <p>It is vitally important to listen to the person and not for the healthcare professional to decide what the person can and can't do. There is so much instability in someone's life with an illness/disability that you mustn't add additional stress to their lives by complicated form filling and unsympathetic professionals.</p>
EM530		<p>Resident of A Sheltered Accommodation of 11-02-11*</p> <p>Conclusion*</p> <p>I welcome this opportunity for considered debate on the proposed future of the above. Albeit the failure by government to use the framework guidance i.e. 12 Weeks thus, allowing many sufficient time to give a much more profound viewpoint. Which brings me to the point of many being placed at a disadvantage level; through all this, the Government will not be able to receive many consultation conclusions/summary as the bill proceeds through both Houses?*</p> <p>The consultation document made a commitment to supporting people with disabilities and the degree of challenges they encounter, yet the very heart of this debate time is greatly reduced because of the allocation of 9 weeks allowed for a variety of diverse points of view.*</p> <p>The majority of people with disabilities are financially dependent on the state for assistance to sustain their basic social care needs/ and living costs which is directly associated with their varied impairment. I also recognise that the propose changes would not come into effect until * 2013-14*</p> <p>It is quite clear the document have outlined some very good proposals about the benefit simplification, its barriers which will allow a better understanding. This is not quite clear, and very confusing to those, who cannot understand, as to how the changes would be beneficial to those in need. *</p> <p>It is already widely documented that this Government commitment to supporting people in their quest to lead independent and active lives. Yet Disability Benefit Payments will be reduced by £9 billion pounds over the course of this Parliament.*</p> <p>Disabled people are among the most disadvantaged group presently residing in the UK and quite frankly, their experiences vary from various forms of discrimination, victimisation, ridicule, mental, physical distress, harassment, short and long term effects and not being able to participate in certain activities, and are three or four times subjected to living in poverty.*</p> <p>DVLA reform & estimated affected numbers*</p> <p>* In highlighting the DLA's reform I cannot in all honesty support the government's overall objective of a 'reduction target' of 20%. I see this as a way of reducing cost, although the Government has stated its commitment to supporting disabled people in its approach to the reform. There is no clarity in regards to the numbers of people with disabilities likely to receive or refuse a reduced rate of DLA as a result of these proposed changes.*</p> <p>Affected Numbers: It is therefore my belief the impact would be felt by at least 3 to 400 000 within the UK and approximately a further 150.000 or so carers.*</p> <p>Disabled people with greatest needs: The Author is of the view that any focus on disabled people with the greatest needs will certainly disadvantage others through the addition costs which is associated with the very nature of their varied disabilities. Quite often the people accessing the lowest rates of DLA are often unlikely to be able to access who are in the position the access support</p>

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		<p>elsewhere and cuts to these groups normally put extreme pressure on social care or NHS Budgets. In the context of council budget cuts and the NHS being under considerable pressure, people's needs could remain unmet elsewhere.*</p> <p>The DLA Mobility Component: The removal of the mobility component because of people living in residential care is unacceptable and a turning back of the time we are presently living in, this will also restrict their involvement in community activities thus denying around 90-100.000 people their basic human right i.e. their Independence. This clearly will justify the Government's non- commitment to promoting social justice for people with disabilities.*</p> <p>Increase in qualifying period: This proposal from the Government that the new benefit will only be available to people with a long-term health condition or impairment which has lasted for at least six months. This proposal is unacceptable as it would prohibit a large proportion of people access to rehabilitation support following the aftermath of severe accidents, even death, could prove very difficult to some conditions where any future care/need can be difficult to predict.*</p> <p>The assessment process Concerns: The work from the Capability Assessment identified certain conditions were disadvantaged, including those with less apparent disabilities, and those with past and fluctuating disabilities. The impact of these living conditions can be much harder on a daily basis to determine any short term assessment process.*</p> <p>The Impact on those over 65 and Children: The reform sets out in the DLA consultation document apply to working age claimants. It also states that the Government are considering whether to apply the new eligibility assessment criteria to children and adults over 65 years of age. Some clarification is needed here as to which group exactly the reform will affect.*</p> <p>The Impact on carers: The Author has some concerns of and the removal or reduction in disabled people's benefit on carers. Many families could be grossly affected as the DLA is taken away and Carer's allowance is lost or taken away as a result. Unpaid care could be drastically undermined by making caring financially unhelpful for some families.*</p> <p><u>Response to D L A Reform*</u></p> <p>The Impact on People with Disabilities*</p> <p>Reform Approach - The DLA fail to mention in its consultation document the savings which the Department of Work and pensions hopes to achieve through its reform.*</p> <p>The government predicted savings to the DLA reform by 2014-15 is estimated to be over £1 billion. The Minister for Disabled People, Maria Miller MP, has confirmed that the Government is "looking at a saving of 20% of the Disability Living Allowance in line with the Chancellor's commitment in the Emergency Budget however the document provides no details as to how this reduction is likely to be achieved, nor does it provide any details on any level of awards for the*"</p> <p>(P I P) personal Independence Payment.*</p> <p>*</p> <p>The Author whilst welcoming the fact that the consultation document recognises that "people with disabilities can and do face additional challenges to leading independent lives, and it's commitment to maintaining an extra costs, non-mean tested disability benefit to support people with disabilities. However, it also refers to supporting those people who "Encounter the greatest challenges to remaining independent and living full and active lives" Sadly focusing on people with higher disability needs, this will exclude many who will still encounter additional costs as a result of their disability or condition from playing an active part in our society. *</p> <p>If it is, the Government's intention to create a "sustainable system" this approach risks the encouragement of unmet needs to develop into crisis situations, which have higher costs to individuals, families and public resources. Therefore meeting lower level need is important in terms of preventative benefits as well as proving essential support*</p> <p>The tightening of the social care eligibility criteria means that many people with disabilities who currently claim Disability Living Allowance receive from their local social services department. Resulting in a situation where many people having to use their DLA allowance to access care and support. Some consideration must be allowed to the potential impact of a reduction in DLA on already overstressed social care budgets. *</p> <p>Those who are not deemed "disabled enough" will be unfairly treated. Thus losing both their DLA and not meeting the threshold for social care. It is misleading to suggest, as the document does that DLA is "part of a wider range of support and</p>

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		<p>services available to people with disabilities, including the form of services or direct payments from Local Authorities to meet social care needs" a large proportion of people with disabilities are not eligible for other services. For these people, DLA is their lifeline.*</p> <p>It must be understood that for many disabled people the DLA allowed them to live independently, it provides them with choices. Any restriction imposed upon them would certainly reinforce widespread negative stereotype labelling. These proposals may save the DWP budget but certainly not on the ordinary tax payer.*</p> <p>The Legislation which led to the Introduction of the DLA in 1990 explicitly focussed on people with additional costs, but lower needs who were unable to access alternative support. It was the DLA intention to benefit the many people who now fear losing access through restricted eligibility as the DLA intended.*</p> <p>The Introduction of the DLA*</p> <p>The author believes careful consideration needs to be taken of the original purpose of the DLA and a more profound understanding as to how its, supports a wide range of people with varied disabilities. It has been described as a "financial contribution towards the generality of extra cost experienced by disabled people as a direct result of their disabilities by the DLA. *</p> <p>The DLA was introduced as a policy response to the evidence that people with disabilities and their families suffered greater poverty and disadvantage than their non-disabled counterparts and preceded the opening up of the disability rights framework, including the introduction of measures to tackle discrimination against people with disabilities.*</p> <p>The description of the DLA is seen as an "extra costs" benefit; it is paid not on the basis on medical diagnosis, but to compensate people with their disabilities for the extra costs they incur by the effect their condition has on their mobility, or looking after themselves. This allows the consultation to offer or provide little detail as possible as to how the new PIP will assist in meeting the higher cost of living expenses people with disabilities may occur?*</p> <p>DLA further recognises the additional costs incurred by families with children with disabilities, and by their disabled parents (both as a consequence of the combination of both their parental responsibilities and their disability). It is therefore vital that the Government ensure that any changes to the DLA are not based on meeting arbitrary targets, but rather on better supporting people with disabilities and their families to compensate for any additional costs and barriers they may encounter which may place them into the poverty gap.*</p> <p>The Assessment*</p> <p>Focus of new assessment - The author welcome the focus of the new participation and the impact an individual's impairment on health condition has on their daily life. The author also welcomed the newly named 'daily living' component to replace the existing care component of DLA: however, the author are very concerned that the new 'daily living' component will only have two rates of payments i.e. focusing on disabled people with higher and lower level needs.*</p> <p>It is essential that any new assessment reflects the broad range of 'daily activities' that reflects an individual needs to undertake in order to fully participate in society. The Author is very concerned that the assessment be made robust enough to reflect the varied range of disabilities and conditions or whether the 'impact on everyday life' proxy (as opposed to 'care' and 'support' used in DLA) will effectively measure the multi-dimensional drivers that impact on the costs that disabled people incur. *</p> <p>It is difficult to imagine how assessment looking at everyday activities such as "planning and making a journey" and "communication with others" will take into account some of the ways in which the DLA is currently spent- an example, being to help with increased electricity bills associated with doing laundry more often or for more expensive specialist clothing.*</p> <p>The Learning Curve of the Work Capability Assessment*</p> <p>WCA Following the proposed introduction of an 'objective assessment' for PIP, there is much to be learnt from the development of its Work Capability Assessment which the recent review has concluded is "not working as expected". In particular, the review notes that some conditions are more difficult to assess than others - e.g., mental health and other fluctuating conditions.*</p> <p>The review states that some of the descriptors used in the assessment may not adequately reflect the full impact of that condition on individuals. In addition many of our organisations have expressed concerns about the limited knowledge of some of the healthcare professionals, another issue which was acknowledged in the independent review. Clearly, it will be essential that all independent health care professionals have the skills and awareness about the differential disabilities</p>

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		<p>and conditions in order to make very accurate assessments.*</p> <p>Another of the Authors concern is the time the government have chosen to re-assess all current working age DLA recipients with the possibility of including children and those over 65 at a time when of considerable squeeze on government spending. The cost of the introduction of and implementation of a new assessment is immense. Regular review of all claimants will be necessary as well as appeals under the new process which will in my view, outweigh any savings. *</p> <p>Therefore clarity is sought on the budget being provided for the exercise. The Author from experience has heard of a large proportion of high appeal cases which have been very successful. So to adopt another model of the same nature to reassess DLA claimants may further undermine the Tribunals Services ability to meet the demands and would be very costly.*</p> <p>The Author is aware that under the current DLA individuals and the DWP can initiate a review of a DLA Award - including by a DWP- appointed Medical Examiner. It would be interesting to learn why the more affordable option available within the existing system has not been fully considered , with the consultation document misleadingly stating that there is no process to check that awards remain correct '. Since 2000 a change in the ADLA legislation has made all awards subject to review after appropriate periods of time (based on the individuals' circumstances).*</p> <p>Medical or a Social Model*</p> <p>We welcome the increased focus on 'use of evidence as part of the assessment process in order to consider thoroughly the impact of an individual's disability on their day-to-day life. However, while there is commitment to the social model of disability, the Budget referred to an "objective medical assessment" for DLA. The policy co stings document for the June Budget published by the Treasury states that. "This measure will introduce an objective medical assessment and revised eligibility criteria for both new and existing working -age claims for Disability Living Allowance, to be rolled out from 2013-14. The assessment will follow a similar process to the Work Capability Assessment (WCA) used for claims to Employment and Support Allowance". *</p> <p>It has since being stated by Maria Miller MP that there is "no intention to introduce a medical assessment of individual need. However, as noted above, the involvement of a face-to face meeting with an independent healthcare professional" appears to be very similar to the WCA. Given the current problems with the assessment and surrounding processes, an increased amount of anxiety is being caused to, too many people with disabilities and has associated cost implications for Government.*</p> <p>It should also be noted here that DLA is already said to benefit which based on a social model of understanding-that is , that disability is rooted in social and environmental factors which renders a person's condition or disability' disabling'. *</p> <p>From this perspective, DLA recognises that it is these factors which drive a person's disability costs- not just their impairment or condition. It will be a challenge to establish an assessment which looks at both the functional impact of a person's disability, as well as one that takes into account the social and environmental factors impacting on an individual's day-to-day costs.*</p> <p>Taking more Aids into Account*</p> <p>The Author is very concerned with the proposal i.e. That the PIP assessment will take into account more aids and adaptations, Being that under the PI P, the individual's ability to get about in a wheelchair will be considered , rather than ignoring it as under the current DLA process. This could then affect their eligibility for PIP, yet it is based on, then incorrect assumption that using a wheelchair will mean that all barriers and additional expenses are overcome. A further example could be aids for people with sensory impairments; such as hearing aids and long causes. *</p> <p>These are just one part of successful mobility and communication for people with single and dual sensory impairments; they work in conjunction, for e.g., with any human support or transport. Taking more aids and adaptations into account must not create a perverse incentive whereby individuals do not take up aids and adaptations for fear this could jeopardise their entitlement to PIP.*</p> <p>Eligibility, automatic entitlements and reviewing awards*</p> <p>Increase to qualifying period - The consultation document also states that" to ensure that support goes to those with the greatest need,</p>
EM531	13-Feb-11	<p>We would be grateful if you would give consideration our response (attached) to your proposals to reform Disability Living Allowance. We have had a long experience of living with chronic illness and disability and</p>

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		<p>have tried to look at your proposals from two perspectives: (1) that of a young couple with a family where the breadwinner is diagnosed with a chronic and progressive illness (2) the situation of a couple later when the illness has progressed regards*</p> <p>We have read and heard reports of the coalition's proposals for DLA reform with mounting concern both for our own situation and with sympathy for others like us whose lives are overshadowed by chronic illness and increasing disability. We cannot understand how current proposals are consistent with your stated aim to maintain the vision of the previous Government's National Carers' Strategy ... that "Carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen".*</p> <p>When my husband [REDACTED] was finally diagnosed as having Multiple Sclerosis he had already been suffering from the disease for more than ten years. At this time we had five dependant children. With his spirit of independence and determination and the support of an excellent employer my husband continued to work for as long as possible, paying tax, national insurance and contributions to a pension scheme. Eventually this could no longer be sustained and it was necessary for him to cease paid employment. After a medical examination he was immediately found to be eligible for Mobility Allowance (the forerunner of DLA) and in addition received Incapacity Benefit. *</p> <p>Sadly as our children grew up and became more independent my husband's reliance on my support increased. Therefore I have only been able to work part-time whilst claiming Carers' Allowance and now that his illness is very advanced care for him full-time. It was not easy for us to bring up our family, and to ensure that they had equal opportunities with other children, but we have found a way through. It seems to us that twenty years ago we had an advantage which will <u>not</u> be given to a young couple who find themselves in the same situation in 2011 – a degree of financial security.*</p> <p>although my husband was occasionally subject to a medical examination we never felt that his entitlement to Incapacity Benefit and DLA were seriously at risk. It appears that this is no longer so. Under your proposals in the case of a couple with the "breadwinner" suffering from MS there would be a risk of losing benefits during a period of remission, a struggle to find new employment, only to suffer a relapse. This could become a vicious circle corrosive to personal relationships and family security.*</p> <p>my husband's entitlement meant that I in turn received Carer's Allowance. Carer's Allowance would not be payable if DLA were suspended imposing a second blow and a further destabilising effect to family income.*</p> <p>This loss of financial security in addition to all the other anxieties will put an additional strain on relationships resulting in breakdown and further personal and social problems costly to the welfare state.*</p> <p>Carer's Allowance has never been paid at a rate which compensates for the loss of employment opportunity which caring brings, but does at least acknowledge the contribution made by carers. The proposal to include it as a "working age benefit" under the heading of Universal Credit would be wrong in principle and destabilising in effect.*</p> <p>My husband's mobility component is used to provide a wheelchair accessible vehicle. This gives us the opportunity to get out together and very importantly for him to gain access to health care. We cannot believe that should things reach a stage when I can no longer care for him and he had to move to a residential setting we would have to relinquish this. Because [REDACTED] is a very tall man his wheelchair will not fit in a taxi and even access to an ambulance or hospital transport is difficult – the loss of</p>

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		<p>his DLA would therefore mean that he could not come home to spend time with his family, join in with their activities, gain access to routine health care or interact beyond the confines of the care setting*</p> <p>The measures you propose will impose additional problems of financial insecurity on families already struggling with the implications of chronic illness and deny those suffering the effects of advanced illness the ability to interact with the outside world. We would ask you to think again.</p>
EM532	13-Feb-11	<p>1. Your response: Attitudes, prejudice and lack of understanding. An arbitrary benefits system that leaves some in poverty and others comfortably provided for.*</p> <p>2. Your response: The self-assessment works if DWP use reports from social workers, specialists and other professionals.*</p> <p>3. Your response: Heating, transport, assistance to live a fulfilling life. Pre-prepared food, dietary needs, specialist equipment, cleaning, decorating, garden maintenance, even the smallest DIY type job has to be paid for.*</p> <p>4. Your response: *</p> <ul style="list-style-type: none"> • No* • Decision makers will err on the side of the lowest rate. Those that have low needs will be given as much as those with moderate needs. At what point does one suddenly deserve the higher rate? There needs to be more graduation, not less, in order to personalise the benefit and make it fairer.* <p>5. Your response: All claims should be based on individual needs.*</p> <p>6. Your response: Social interaction and inclusion. Whatever activity makes a person's life meaningful and satisfying.*</p> <p>7. Your response: A person should be assessed at the highest level of need. Financial support has to be stable to allow a person the time to benefit from any rehab which could improve their condition. A fluctuating condition needs to be stabilised for a year before there can be deemed enough stability to cope with less support.*</p> <p>8. Your response: All aids and adaptations should be regarded as an indication of need whether in place or not.*</p> <p>9. Your response: Remove such questions as "How many times a day do you need assistance with toilet needs". These are demeaning.*</p> <p>10. Your response: Reports by medical specialists, social workers, care managers, GPs and carers.*</p> <p>11. Your response: It is less costly to use reports from professionals already involved. Spot checks would be a good way of checking up on claimants.*</p> <p>12. Your response: *</p> <ul style="list-style-type: none"> • How permanent the illness/disability is.* • Yes* <p>13. Your response: By making payments flexible enough so people are not afraid of losing a substantial amount of their income.*</p> <p>14. Your response: no comment*</p> <p>15. Your response: no comment*</p> <p>16. Your response: *</p> <ul style="list-style-type: none"> • Smaller aids are provided by local authority. Otherwise one has to obtain a loan or save up for building works or struggle without having one's needs met.* • Possibly* <p>17. Your response: no comment*</p> <p>18. Your response: no comment*</p> <p>19. Your response: no comment*</p> <p>20. Your response: no comment*</p> <p>21. Your response: no comment*</p> <p>22. Your response: At present DLA middle rate care entitles claimants to disability premiums if they are on Income Support or Pension Credit. The difference between getting lower rate care and middle rate care is actually around £100 a week because of premiums. A huge difference</p>

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		<p>dependant on the arbitrary judgement of a Decision Maker. *</p> <p>* A points system would be fairer and would bring meaning to the word "Personal" in the new benefit title.</p>
EM533	13-Feb-11	<p>Dear Sirs / Mesdames I am personally in the happy position of not being in need of the allowance under review. However, I have friends and family who are or are about to be reliant on these forms of support. With one living octogenerian parent-in-law currently in a care home, and my wife and I having supported three other parents through terminal illnesses, I appreciate the difficulties facing those involved in accessing state aid. *</p> <p>Whatever pattern of support is offered, the process of application and the triggering of awareness of an entitlement needs to be more transparent than was the case when we were last involved with accessing care allowances. I shudder to think how citizens fare who themselves, or whose family, do not have degree level education or experience in public administration. The impression we recieved was of a system designed to save money by obfuscating application processes and delaying decision making. Some monies were only received a year after the death of the intended recipient as a result of appeals. Those currently in need are rightly suspicious of any review which starts with the avowed intention of saving 20%.*</p> <p>I am anxious,too, about entitlements deriving from medical conditions being assessed by staff without medical qualifications in "tick-box" processes. The decision making needs to be made by medical practitioners, but this does not mean funding administrative staff can be scrimped: rapidity of implementation is important.*</p> <p>Another concern is what would appear to be a suggestion that reassessment will be more frequent. Laudable though this seems at first hearing, making the experience non-threatening, non-condescending and well administratively resourced could be more costly.*</p> <p>Those about to take a "hit" in straightened times are amongst the most vulnerable in society; it is a minor though bitter irony that the public consultation period on this issue closes in the week following the announcement of pathetically reduced stringency of strictures long promised to curb the profligacy of the most powerful, in our financial sector. Yours faithfully</p>
EM534	13-Feb-11	<ol style="list-style-type: none"> 1. Mobility, fluctuating health, other's perceptions, poor employment prospects, money* 2. * 3. Keeping independent means of travel, frequent hospital visits. Prescription charges, specialised clothing/ equipment: a lower wage, * 4. People may need to move to higher rates, there is too much bureaucracy attached to re-applying* 5. Progressive conditions, eg Parkinsons, should attract automatic entitlement* 6. Personal care, feeding self, being mobile outside the home, communication skills* 7. Your response: Maybe assess person over time? Consult medical specialists, find out from an expert exactly how these fluctuations manifest* 8. Are you going to provide funds to obtain these adaptations?* Any aid to everyday normal life should be included* 9. Simplify form. Consider people who do not read easily. Only leave space for comments if it really helps clarify:* 10. GP, specialist nurse, consultant neurologist, other specialists eg physio therapists, neuropsychologists and the claimant!! Who knows better than them how they feel/manage?* 11. Does this person really know enough about the disease/condition or are they just ticking a box based on an assumption or on a test which

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		<p>anyone can pass on a good day?? Remember, people are stressed in these situations and do not give full answers. Sometimes the answer quickly to get away from hostile environment. Terminal illness should never be included, think about people's dignity!!!!*</p> <p>12. Type of condition. Is it likely they will get cured???? A broken leg gets mended, a progressive degenerative condition won't, unless there's a miracle in science.*</p> <p>13. Explain what changes you want reported. BUT, remember some conditions fluctuate form day – day, am to pm. Will we really have to say that today Im ok, but yesterday I wasn't??? Who knows how we will be next week??*</p> <p>14. Help with understanding the gobbledegook that governments insist on using!!! gobbledegook is a sure way to put people off applying so targets are met!!*</p> <p>15. Why resort to compulsion? You know this will lead to developing a set of sanctions. You will hit those least able to help themselves.:*</p> <p>16. Some are funded by social services, if you're lucky and live in the right place. Why not give a one off payments without strings? People can get crisis loans for all sorts of rubbish.*</p> <p>17. You must remember to ask them but try not to patronise, use simple enough language but remember many are very intelligent.*</p> <p>18. Very important to continue this, publicise it really clearly and widely, sometimes it seems almost a secret that only a few have access to.: Maybe there should be targets for people getting benefit, not targets for saving money. *</p> <p>19. Isolation, lack of employment, less money, condition may deteriorate quicker, people would give up*</p> <p>20. *</p> <p>21. Some groups (ie disabled people of Asian origin) are already invisible. (partly by culture) This will encourage this to remain so.*</p> <p>22. Your proposals will place an even greater burden on the person's family, the voluntary sector, (who never have enough money/time) and will make many much more vulnerable. Is this really what the Big Society is meant to do?? This will be your legacy, is this really how you want to be remembered??*</p> <p>What do you consider to be "working age" in view of the changes to state pension age? I will be 61 before I can get mine, am I therefore classed as of working age?</p>
EM535	13-Feb-11	<p>1. Your response: I suffer with chronic general anxiety disorder, depression and anxiety. Until recently I was a public health practitioner. I am restricted to my house and its immediate environment for me sense of wellbeing. This means I need to spend proportionately more money on heating, lighting and general wear and tear, as I use my property far more than the general population. I also use my DLA for prescription payments (as I regularly take three drugs). As I live in a rural area I also have to spend proportionately more money to reach my appointments with my therapists (22 mile round trip), psychiatrist (22 mile round trip) and GP (64 mile round trip); with my local petrol station next door charging £1.36.99 per litre of unleaded. If I wanted to use and services, they're 11 miles away and thus comes at a significant fuel cost. Furthermore, this is a small settlement and with broader cuts coming this is likely to hit this community heavily. Thus, my major services will become 120 miles away. For myself, I need access to natural areas where I'm not going to meet anyone and can take my care dogs with me. Food and vet care for my two care dogs is also rocketing and as they're such a significant part of my experiencing wellbeing, my ability to have them and care for them appropriately is vital. I am also about to retrain through a literature degree, which I can do keeping myself very much to myself as and when necessary. This will only be possible because my course is being fully subsidised, and I will have access to further funds to live on; with the aim of on day, through literature, being able to be more engaged online with</p>

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		<p>the online community and add something of value to that community, as well as improve my own wellbeing.*</p> <p>2. Your response: No sure.*</p> <p>3. Your response: See question 1.*</p> <p>4. Your response:*</p> <p>5. Your response: No – but the method for the assessment needs to reflect the limitations of the individual being assessed i.e. I am disabled by social anxiety, agoraphobia and depression; having to see someone face to face is a horrendous experience for myself and those with the same or similar conditions.*</p> <p>6. Your response: What does the current research say and where does more research urgently need to be undertaken; both qualitative as well as quantitative. Can robust research methods be designed into the assessment process (qualitative and quantitative) to more accurately and meaningfully answer these questions. For me, it to be able to live a life experiencing wellbeing, physically, mentally, emotionally, spiritually and socially. These are essential areas for my everyday life, of which very few I'm currently experiencing wellbeing due to my mental disabilities.*</p> <p>7. Your response: Create a range of communications methods, including internet. A human nature challenge is when someone gains something of benefit, that if they report an improvement, they risk losing it; a different gain in its place may help address this. *</p> <p>8. Your response: No. When I didn't have access to the internet, I was hugely restricted in comparison to now. At least going online, enables me to engage still with society at some level or another, without DLA I couldn't afford this. My care dogs too ensure that I leave the house and help give me some degree of stress relief when both at home and out. It these were excluded from my assessment their vital effect would be missed, as too the costs that come with them.*</p> <p>9. Your response: Offer a range of access points, including online, with 'online live' communications to undertake the assessments.*</p> <p>10. Your response: Applicant, where relevant their carer, health care providers, social care providers, voluntary care providers, private care providers, spiritual care providers.*</p> <p>11. Your response: A huge problem for me due to my mental disability! Panic and anxiety attacks leading up to, during and after the assessment as await the outcome. Online 'live' one to one interviews I can mentally manage far easier.*</p> <p>12. Your response:*</p> <p>Should be different types of review depending on the needs of the individual and their impairment/condition*</p> <p>13. Your response: Offer a range of communications methods, examples and see question 7.*</p> <p>14. Your response: Have a website-based flow chart with questions and answers used by assessors which lead to relevant advice and information. This can be used by the general public and advocates such as CAB. It also makes the process more opaic and accountable to the general public*</p> <p>15. Your response:*</p> <p>16. Your response: Paid through initially with my salary from sick leave initially and now part-subsidised by DLA.*</p> <p>17. Your response:No comment*</p> <p>18. Your response: Website flowchart-assessment tool*</p> <p>19. Your response:*</p> <p>20. Your response:*</p> <p>21. Your response:*</p> <p>22. Your response: Please consider communications as a vital part of the process. If travel is restricted due to disproportionate fuel costs and mileage, disable people in rural areas are going to be heavily effected in relation to having their needs met. Support for telephone and IT infrastructure to enable disabled people like myself to have a lifeline into</p>

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		<p>society through the internet, although I need to pay for phone lines and internet providers, as well as hardware, it's a huge benefit to me. Some form of measurement for housing maintenance, including fuel, to enable these costs to be included.*</p> <p>Care animals factored into provision so their costs and overheads can be accounted for.*</p> <p>More academic courses provided online, with funding support for the disabled available to undertake them. This will enable us to choose courses and develop ourselves in such ways that we can contribute far more to society, as well improve our self-confidence, self-belief and overall wellbeing.</p>
EM536	13-Feb-11	<p>1. What are the problems or barriers that prevent disabled people participating in society and leading independent, full and active lives? *</p> <p>Your response: DLA is a benefit that should help disabled people participate and lead independent lives. However, in my son's case, much of the benefit is clawed back by the local authority to contribute to his care of 1.5 hours each day. The remaining benefit is welcome, but insufficient to include him in any meaningful way and has to be topped up by me simply to met his daily living costs and keep him comfortable.*</p> <p>2. Is there anything else about Disability Living Allowance (DLA) that should stay the same?*</p> <p>Your response: Yes. It should be a distinct element of a disabled person's benefit and it should be paid in addition to care costs so as to INCLUDE them in society.*</p> <p>3. What are the main extra costs that disabled people face?*</p> <p>Your response: Heating, food, domestic care beyond day-to-day such as decorating, maintenance, gardening etc., and social inclusion in the truest sense.*</p> <p>4. The new benefit will have two rates for each component:*</p> <ul style="list-style-type: none"> • 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> <p>Your response: The current benefit has rates – I don't see any major problem with this as long as it is not designed simply to reduce the numbers who can trigger the benefit.*</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 applying?*</p> <p>Your response: All those with a significant physical or learning disability from birth should automatically be entitled to benefit.*</p> <p>6. How do we prioritise support to those people least able to live full and active lives? Which activities are most essential for everyday life?*</p> <p>Your response: As a "Big Society" we should be humane and sophisticated enough not to have to ask this question!*</p> <p>7. How can we best ensure that the new assessment appropriately takes account of variable and fluctuating conditions?*</p> <p>Your response: There is enough research from the currently discredited assessment system to cover this!*</p> <p>8. Should the assessment of a disabled person's ability take into account any aids and adaptations they use?*</p> <ul style="list-style-type: none"> • 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> <p>Your response: Again, common sense would suggest that adaptations are provide to assist – but they rarely, if ever, overcome the disability. It might be helpful to suggest more efficacious adaptations, but not as an</p>

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		<p>alternative to the benefits. *</p> <p>9. How could we improve the process of applying for the benefit for individuals and make it a more positive experience? For example:*</p> <ul style="list-style-type: none"> • How could we make the claim form easier to fill in?* • How can we improve information about the new benefit so that people are clear about what it is for and who is likely to qualify?* <p>Your response: For those with a learning disability it will be essential to ensure that the form is completed by an appointee.*</p> <p>10. What supporting evidence will help provide a clear assessment of ability and who is best placed to provide this?*</p> <p>Your response: Medical, psychological and psychiatric where necessary*</p> <p>11. An important part of the new process is likely to be a face-to-face discussion with a healthcare professional.*</p> <ul style="list-style-type: none"> • What benefits or difficulties might this bring?* • Are there any circumstances in which it may be inappropriate to require a face-to-face meeting with a healthcare professional – either in an individual's own home or another location? * <p>Your response: No more helpful than any other interview that disabled people go through with the plethora of national and local government gatekeepers!*</p> <p>12. How should the reviews be carried out? For example:*</p> <ul style="list-style-type: none"> • What evidence and/or criteria should be used to set the frequency of reviews?* • Should there be different types of review depending on the needs of the individual and their impairment/condition?* <p>Your response: Physically and learning disabled people have lifelong conditions. They already have the option to request a reassessment if they think that their needs have changed....why have regular reviews?*</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> <p>Your response: Most changes in need are likely to require more support, not less. What is the point of this question?*</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: Most of the information around DLA is helpful and should be replicated.*</p> <p>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>Your response: In most cases this would be a role for the local social services department or the voluntary sector.*</p> <p>16. How do disabled people currently fund their aids and adaptations? Should there be an option to use Personal Independence Payment to meet a one-off cost?*</p> <p>Your response: Yes. As long as it is an additional payment.*</p> <p>17. What are the key differences that we should take into account when assessing children?*</p> <p>Your response:*</p> <p>18. How important or useful has DLA been at getting disabled people access to other services or entitlements? Are there things we can do to improve these passporting arrangements?*</p> <p>Your response: It is a minimum requirement for most local services – I guess it always will be.*</p> <p>19. What would be the implications for disabled people and service providers if it was not possible for Personal Independence Payment to be used as a passport to other benefits and services?*</p>

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		<p>Your response: Why would it not be? This would seem contradictory.*</p> <p>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>Your response: It could be combined with local authority Care Plans.*</p> <p>21. What impact could our proposals have on the different equality groups (our initial assessment of which is on page 28) and what else should be considered in developing the policy?*</p> <p>Your response: Too much emphasis is given to CARE and too little to INCLUSION, particularly the additional costs of being socially included and maintaining independent living.*</p> <p>22. Is there anything else you would like to tell us about the proposals in this public consultation?*</p> <p>Your response: As the father of a young adult with a learning disability who is trying to live independently in the community, I fear a double blow: a reduction in support from the local authority and a reduction in state benefits. There is already evidence that this is happening at a local level Any reduction in benefits will be the last straw and I can see many learning disabled adults returning to Care Homes.</p>
EM537	13-Feb-11	<p>I have been living with MS now for 8 years and despite my best efforts to lead as independent a life as possible there are always obstacles. I rely on my DLA to live as normal a life as I possibly can. *</p> <p>1/. I rely on my motability car – I CANNOT walk a 100 yards so public transport is a definite no. Also in the bad weather that we have been experiencing of late had it not been for my car I would have been housebound as the pavements were a deathtrap.*</p> <p>2/. My DLA also allowed me to heat my house as otherwise I would not have been able to afford heating.*</p> <p>3/. My care needs have been minimised due to an operation “Deep Brain Stimulation” to help with a tremor in my hands caused by the MS. This is a wonderful, life changing operation but the battery that controls the stimulator will run out then I will be back to square one until my battery is replaced.*</p> <p>4/. I also have to pay for physio appts as the NHS do not have an MS specialist physio.*</p> <p>*</p> <p>I appreciate the country has a mountain of debt but is that my fault for getting something that I did not ask for, did nothing to deserve and now have to live with for the rest of my life (I am only 34).*</p> <p>Please think carefully before ruining my life even further – take my DLA, take my disability too.</p>
EM538	13-Feb-11	<p>1. Your response: Other peoples responses to them, lack of knowledge, prejudice and financial hardships. They are often unable to access the things/activities, work that other people take for granted. When work is accessed it is often voluntary unpaid work. People with autism spectrum Conditions (ASC's) for example may look 'normal,' but they have an innate difficulty communicating they can easily misinterpret things and can be misunderstood. They can be and most are highly vulnerable and socially isolated.*</p> <p>2. Your response: Access to financial help for those with a disability, although this should be an easier system and less stressful for individual and their parents/carers. People with disabilities are often unable to access paid work and even then pay can be minimal. They are very susceptible to poverty*</p> <p>3. Your response: Equipment (wheel chairs, colostomy bags etc etc), extra resources eg: extra adapted rooms and furniture. Funding people to help them with every day things and getting around, helping combat social isolation. People with autism need to key into their interests (which can be expensive), to help with this isolation and help ease the stress they and their families/carers endure everyday of their lives. Social</p>

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		<p>activities are often costly but necessary to further ease this isolation. Our son has his own room downstairs as well as his bedroom upstairs, this helps him enormously, as if we did not have this room he would cut himself off in his bedroom upstairs as he often did before he had access to this room. Holiday's are important and often mean accessing the right package for their needs.*</p> <p>4. Your response: Having 2 components may make understanding better, although I am not sure until I know the format it will take* I fear that some people with hidden disabilities such as high functioning autism will get left out and will become more socially isolated and vulnerable, due to less financial assistance, being unable to key into the support and encouragement they need.*</p> <p>5. Your response: In some cases I do feel that people should get automatic benefits, especially when the condition is life-long as in autism. More unnecessary form filling and assessments cause more additional stress for the individual and their parents/carers. Also the expense of this additional red-tape is avoidable and unnecessary in these instances!*</p> <p>6. Your response: Communicating, Eating, Sleeping, keeping healthy, being able to move, access transport, access social activities, access support to those who need it, protection of the vulnerable, access to work when they are able, even if this work is unpaid, but we hope for paid work obviously!*</p> <p>7. Your response: In an initial statement by a health care specialist or social worker etc, it should be stated if the condition is life long and whether their case should be reviewed in months/years or not unless change occurs, which is most unlikely if the condition is life long or deterioration is inevitable. Cut the stress and extra finance cut the unnecessary red tape!*</p> <p>8. Your response: Aids and adaptations can mean different things to different people, and can be very costly. Adapting the environment for someone with and autism spectrum disorder, may mean an additional room, different lighting, play materials, safety glass etc. It can also mean adaptations to cater for their interests to enable they live a happy less stressful and more fulfilling lives which also impacts on the lives of their families, parents and carers. *</p> <p>9. Your response: Less questions! Which are easier to understand and non repetitive. Different form for different conditions, many questions which are relevant to someone with a physical disability are not relevant to someone with a hidden disability such as autism. If the person has a physical disability as well as a hidden disability then they should have the option of commenting at the end of the form or filling another form in if they wish. *</p> <p>Questions on diagnosis and/or needs*</p> <p>10. Your response: . A Written statement from a Social Worker, Person Centred Planner or health care professional; Doctor, Psychologist, Psychiatrist, Nurse, Health Visitor, Physiotherapist, Occupational Therapist, Speech Therapist etc.*</p> <p>11. Your response: A person with an autism spectrum condition would have great difficulties with a face to face meeting, especially with a stranger. It would not only cause great distress and anxiety to them but also for their parents/carers. I also feel that it would not be beneficial either to the interviewee or the person with autism or their carers, as autism is a communication disorder! It would be better to have a report from a professional as stated in 10 above, who knows the individual and their difficulties. Or a meeting with their parents may be accessible, although it must be understood that these people have much stress in their lives and to add to this burden is not to be thought of lightly. That is why the option of a written statement from a professional, as stated in 10 above would be I think the best option in these circumstances. Repeated form filling and assessments therefore, are not to be thought of as a necessary thing when they may be highly unnecessary and be very</p>

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		<p>anxiety provoking and expensive!*</p> <p>12. Your response: Yes most definitely every individual is different and their conditions present different needs/problems. If the condition is a 'Life Long' condition then surely it makes sense, financial and otherwise to limit these checks! Once May be enough! Please Let Common Sense Prevail!!*</p> <p>13. Your response: You could write to them at intervals and ask them about any changes they may have had or write to their parent/carer with input if deemed necessary from their health care professional, social worker.*</p> <p>14. Your response: People with disabilities and their parents/cares suffer much anxiety, they need knowledgeable supportive people at the end of a phone line (easily accessible)!! Email, letter, or face to face in some cases should they prefer, to help and support them. You Need to Supply This! Endless waiting on a costly phone call is not good. Podcasts, and booklets with help for the hearing and visually impaired. Access to advocates through citizens advice, voluntary bureau' etc could also help.*</p> <p>15. Your response: We did not claim for many years as we did not realise that help was out there. Another parent and then a social worker and the NAS (Natiional Autistic Society) helped us. *</p> <p>We were also misinformed by a person at the Citizens Advice Bureau many years ago, Therefore, correct up to date knowledge by these people is essential! *</p> <p>May be sometimes benefits should be more automatic with a chance to opt out? The health care professional concerned with the disabled individual could send an email to the DWP who could write to the person saying that because the person has these needs/diagnosis they have been alerted and forms and information could be sent to the individuals or their parents/carers.*</p> <p>16. Your response: People with disabilities use benefits such as DLA and there parents/carers often have to help through there own budgets/pay, they may have to take out loans for large products/adaptations or tap into there carers allowance. All this can make life extremely difficult and increases the burden that having a disability or a child with a disability brings (note a child remains a child for the lifetime of the parents)! *</p> <p>Only a small minority of people with an autism spectrum disorder are in paid employment.*</p> <p>Maybe a grant could be introduced for adaptations/aids.*</p> <p>17. Your response: It should be noted that just because someone reaches the age of 18 does not mean that they are able to take control, they may need someone for many years even until their death. *</p> <p>All children are expensive, but parents of disabled children should be able to access funds to help them care for their disabled child, catering for all their needs, which can mean additional expense. Often a parent has to give up work to look after the child 24/7 without an option to return to work, this can carry on throughout their child's life into adulthood.*</p> <p>18. Your response: Disabled people and their parents have to fight every step of the way. As a parent I have had to continually fight for our son from his early life. *</p> <p>Once a service is accessed it should open the door to all services which are needed by that individual.*</p> <p>The stress is unimaginable to anyone who has not gone through, or is going through it themselves! *</p> <p>In an ideal world once diagnosis or needs were initially seen, support would be there automatically for those who want it. Instead of all the battles ahead, the quagmire of people and information to find out often by chance, some services and help I am sure never knowing about. *</p> <p>It is generally other parents who pass on information about help and services!*</p> <p>I just hope that this new benefit isn't another stressful road to bear!*</p> <p>19. Your response: Please refer to 18 above, Stress, stress and more</p>

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		<p>stress! Dealing with people, paperwork, trying to find out about services, not knowing about what is out there. Repeating myself over and over, dealing with people who have no idea, asking different professionals for more evidence. Sleepless nights, worry anguish.....endless stress!*</p> <p>20. Your response: The persons diagnosis and needs, statements/reports from professionals. Form filling should stop at one if that is all that is necessary!! Initial assessment from someone who knows them, (eg their own GP, Social Worker, Person Centred Planner, Physiotherapist. Speech Therapist, Occupational Therapist, Health Visitor etc). Limit the number of reassessments to a practicable number IF they are necessary!!*</p> <p>21. Your response: There should not be any adverse affect on any gender, religion or sexual orientation. Adaptations for assessment should take the persons individual needs into consideration. *</p> <p>22. Your response: Changes should mean improvement, less red tape. A more efficient service. Without people with disabilities and their families/carers losing out on financial help to aid their lives. The anxiety and stress these individual and their families are under is very difficult to conceive for those who have not experienced it. We NEED less stress, life is stressful enough, living with a disability or with a child with a disability! We do not need more form filling and having to fight every step of the way for services that our children need (Please note our children remain our children, no matter the age)! *</p> <p>Also Importantly remember the needs of those with autism and be directed by people like the National Autistic Society for guidance in the matter of the needs of individuals with Autism Spectrum Conditions. Assessment by strangers who do not know the person with autism is highly inappropriate for this condition!*</p> <p>*</p> <p>Additionally and importantly people who are already claiming DLA and have all the relevant supporting evidence etc, why should they now go through the process again? My son's claim is being reviewed again next year, even though it is obvious that he has a diagnosis of autism spectrum disorder and learning difficulties which is life long. Hey Ho More Red Tape!</p>
EM539	13-Feb-11	<p>Dear Sirs I wish to make the following submissions to the consultation on Disability Living Allowance in answer to some of the questions posed in the public consultation document.*</p> <p>1. Mobility has to be the key issue here. Access to and the availability of public transport is limited outside big cities, so for many a private means of transport is crucial. DLA is vital for this.*</p> <p>2. It should remain payable to those living on a long term basis in care homes and hospitals. Free and convenient access to transport, whether public or private, helps disabled people to live independent lives and to participate in society on an equal basis with the rest of the population. The existing arrangement for DLA ensures that this happens. If its payment is withdrawn, those living in care homes face the risk of becoming institutionalised. *</p> <p>3. Mobility in general and transportation costs, specialised medical equipment, modifications to their homes, assistance with living independently in their own homes.*</p> <p>*</p> <p>4. • Will having two rates ... of support? No*</p> <p>• What, if any... cause? An additional layer of complexity that may require expensive adjudication. It might also appear to recipients to be a cost saving measure purely.*</p> <p>*</p> <p>5. Yes, some conditions should generate an automatic entitlement to benefit.*</p> <p>*</p> <p>6. Visiting family and friends is extremely important and for this to be</p>

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		<p>possible in the manner most of us take for granted; independently, conveniently and safely in other words; ready access to transport is crucial. Disabled people with no independent income and living in care homes will lose much of the ability to access independent transport if the payment of DLA to them is halted. Private, or even group transport is rarely if ever provided at the expense of care homes, in my experience.*</p> <p>*</p> <p>21. Diasabled people living in care homes should be treated on a par with those living independently. Receipt of DLA or PIP would help this. Yours faithfully</p>
EM540	13-Feb-11	<p>Dear Sirs/Madam, I would like to add my carefully considered response to your D.L.A. reform document.*</p> <p>There is no doubt that this allowance is subjected to some abuse, either criminally or by misunderstanding the criteria. However, having said that the DLA is a lifeline and a passport to many thousands of disabled people.*</p> <p>*</p> <p>I have been a wheelchair user all of my life, until Remploy made me redundant after 42 years service, I had never been out of work for one day. This was in part due to the DLA that supported me financially. Being severely disabled is very expensive, there is always a heavy mark up, with excuses like, specialist knowledge costs! Small production runs cost more, higher quality specifications, etc etc. in the end, the disabled person wanting and needing to live a 'normal' lifestyle pays, sometimes through the nose! I refer to myself, because everyone is an expert on oneself, However, the above, to a more or less degree affect many thousands of disabled people throughout the country.*</p> <p>*</p> <p>I now intend to go through the Questions (5) of your document, keeping my responses as concise as possible.*</p> <p>*</p> <ol style="list-style-type: none"> 1. People, Tradition and the fact we live in an old country.* 2. Most of the DLA should remain the same. What should change is a more in depth genuine initial check and updates carried out on a regular basis. I believe genuine clients would not be opposed to this.* 3. Everything from clothing, special foods, transport, specialist equipment not covered by NHS, specialist care, extra costs of holidays. The list is as diverse as the disability of each person.* 4. Within the two rates of each component will there be diversity and flexibility, to accommodate the many types of disability coupled with the individuals needs and location differential.* 5. Obviously there should be an automatic base line for some health conditions or impairments, however these should be tempered and adjusted on an individual basis. ie someone living in the country may receive a higher reward for accessibility than someone living in a well served town or city.* 6. Priorities must be based on the pyramid of existence. 1. adequate shelter. 2. Sufficient and appropriate food and water. 3. Heat and light. 4. Appropriate health care. 5. Access to suitable employment. 6. The ability to reproduce. 7. The ability if possible to support oneself and family, with help if required. 8.The ability to have a social life.* 7. Use professionals from all walks of life, including a very high percentage of disabled people, who have to live with problems that quite frankly non disabled people, however well meaning do not even think about. (How high is the kerb outside your house?) Many non disabled people would not know, why should they? but someone in a wheelchair MUST know.* 8. Yes, because aids and adaption's can be very expensive to purchase and to maintain and they do wear out. All aids and adaption's should be included. They all should assist in leading a standard life. Assessment of aids and adaption's should be ongoing. Disabilities

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		<p>change, circumstances change, life changes, we are human, nothing ever stays the same.*</p> <p>The average target age for form filling and information gathering in this country is unbelievably 11. Therefore, multiple choice answers, high visibility highly coloured questions with as many mono syllable directions within the questions may be useful.*</p> <p>9. I am very wary of so called professionals, standards of professionalism vary so*</p> <p>10. much. The long suffering family doctor will probably be used, although he/she will only know the disabled person usually in times of stress and illness. Social services are also so overstretched genuine assessment is in my view almost impossible. My social services do not even know I exist.*</p> <p>11. Face to face discussions are good but we are back to who is a good healthcare professional? Language these days can be a real barrier, as can communication with some types of disability.*</p> <p>12. Reviews should vary according to the individual, unfortunately time, which is always in short supply, seems the only way the fairest assessment's can be reached.*</p> <p>13. Usually the personal approach and observations are the most appropriate forms of assessment. In this day and age an expensive luxury. A system of spot checks, with little notice, (well published) may help in keeping the system fair.*</p> <p>14. The P.I.P. will need to be explained carefully, simply and using the age target as above.*</p> <p>15. The average person is frightened/worried about change. A poster campaign in public buildings and post offices would be appropriate. A television campaign would also be useful.*</p> <p>16. One off costs rarely remain as a one off cost. Items wear out, technology improves, spares become unavailable. The status of disability changes within the individual.*</p> <p>17. Children do or unfortunately do not have parents, this makes the divide great. Individual assessment of the child and its environment are essential. I believe this is where most examples of systems abuse occur.*</p> <p>18. Using DLA as a passport to other services, is cost saving, the criteria's in my view are always similar. The system perhaps needs upgrading but never the less should continue.*</p> <p>19. Expensive, time consuming, duplication of workload, creating unnecessary work load. In this day and age of computers 'talking' to each other, what would be the point?*</p> <p>20. If the disabled client is genuine and information gathering is protected why not share relevant information! It must be cost effective which must be beneficial to everyone.*</p> <p>21. If the change over is carried out in a ham fisted manner, many people who rely on DLA will without doubt unfairly suffer. All groups of clients will suffer equally.*</p> <p>22. We are all aware that reform of the DLA is a financial exercise and this is not a bad thing, however, great sensitivity and understanding is required at all levels, to weed out criminality, make sure the most needy are treated fairly and to use the resource effectively and economically by the use of modern technology and the reduction of expensive staff where inappropriate.*</p> <p>*</p> <p>I hope my understanding of your document is correct and that my observations as a disabled person are useful.*</p> <p>If I can be of any further assistance, please do not hesitate to contact me.</p> <p>I remain, Yours truly,</p>
EM541	13-Feb-11	<p>My wife has lost her good health and Independence because of Multiple Sclerosis 23 years ago has relied on me to live at home caring 24 7 in a wheelchair. I have lost my career and £800,000.00 in lost salary. If you make it any harder than it is now I and many carers like me will put the</p>

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		<p>burden of care to back to local government which will cost you a lot more than you will save with your irresponsible cuts in care and allowances. You are pushing too far now.*</p> <p>*</p> <p>I am currently seeking lost income from role as a carer and for 23 years of loss of quality of life for both my wife and myself. Since you do not value the cheap care that we have given you will suffer from your attacks on vulnerable people. That's a promise. The public have had enough. Yes there may be scroungers around. A lot of them work in government. My wife and I have not had a holiday since 1997. There are genuinely ill people with carers who are struggling to make ends meet now. You need to be careful what you do. As I said enough is enough. I expect a 25% increase in my wife's DLA and my carers allowance must be based on a minimum of £16.00 per hour with immediate effect without penalty.</p>
EM542	13-Feb-11	<p>I wish to respond to the DLA Reform Consultation: Some of the reform seems sensible, but much is worrying. *</p> <p>*</p> <p>I have MS, a condition that varies greatly. As a result I would be very concerned about the need to be assessed whenever there is a change in my condition. I have been receiving DLA for only a few months, but before that I had a period of a year where I would have huge problems for a couple of months, then improve for a month, then went into a significant relapse which lasted six months. I then improved slightly, enough so I could work. Had I been receiving the new DLA then would I have had to be assessed at every change in circumstance? *</p> <p>*</p> <p>As for DLA being a barrier to work, I find it to be completely the opposite. With MS I suffer from fatigue and there is only so much I can do in any one week. I currently manage to work 3 days a week, but doing this work means there are regular household jobs that I cannot do, e.g. cleaning or ironing. I use my DLA care allowance to pay a lady to come in and do those jobs for me. This allows me to retain energy for work and ensures I do not burn out. If it were not for the DLA then I would face the choice of having to do all the household jobs and work and then burn myself out, or stop working so I could do all my * household jobs. *</p> <p>*</p> <p>I think there could certainly be some improvement to the way DLA applications are made. The fact that the two types of award are "proxies" to help look at likely additional costs is not made clear at all. The claim form makes it sounds like only someone who needs a full time carer could qualify for any of it. *</p> <p>*</p> <p>I also think that reading through the documents on the website and the comments from government ministers, there is a real misunderstanding of how a genuinely disabled person would approach getting the benefit. It is not easy for someone * of working age to admit they need so much help with everyday activities. Personally I have a real tendency to play down my needs and just try to make do. Any assessments the government does should make sure that people claiming should feel able to be completely honest about the barriers they face to living life.</p>
EM543	13-Feb-11	<p>1. Your response: social attitudes*</p> <p>2. Your response: I feel that the DLA works perfectly well and that no reform is needed.*</p> <p>3. Your response: transport, medicines, day-to-day living expenses.*</p> <p>4. Your response: I think that the existing system works perfectly well and there is no need to change it.*</p> <p>5. Your response: Based on individual need.*</p> <p>6. Your response: Those that require the most support should be</p>

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		<p>prioritised; but all claimants have good and bad days.*</p> <p>7. Your response: Judge claimants on how they manage on their worst days.*</p> <p>8. Your response: All aids and adaptations should be considered. If a disabled person does not have what they need, then funds should be provided for them to receive those aids or adaptations.*</p> <p>9. Your response: Don't close the citizens advice bureaus (as is proposed) Provide funding for disabled organisations to help disabled people fill in the DLA forms.*</p> <p>10. Your response: Medical records. Support workers, specialists, CPNs etc.*</p> <p>11. Your response: Expensive; not necessary – trust the medical diagnosis.*</p> <p>12. Your response: A 3 yearly review might be necessary; but if a person's condition is medically unlikely to change then a 5 or 10 yearly review might be more appropriate.*</p> <p>13. Your response: Generate trust – not the current fear that funds will be taken away from disabled people.*</p> <p>14. Your response: support groups and self-advocacy.*</p> <p>15. Your response: work in partnership with Disabled Peoples Organisations. Listen to what Disabled People have to say and avoid putting words into our mouths.*</p> <p>16. Your response: They don't : masses of disabled people live in poverty. Of course funds for equipment should be available.*</p> <p>17. Your response: Children are likely to meet higher funding needs as their needs change more rapidly.*</p> <p>18. Your response: DLA is very helpful but doesn't tell you about other entitlements eg. Health certificates.*</p> <p>19. Your response: The DLA does not need replacing with PIP. *</p> <p>20. Your response: One assessment is enough – for DLA and Incapacity benefit.*</p> <p>21. Your response: Work in partnership with equality group organisations.*</p> <p>22. Your response: There is nothing fundamentally wrong with DLA. The cost of replacing it with PIP is unnecessary and a waste of money. Disabled people are frightened that the little that is already given to them will also be taken away. Most disabled people live in poverty. Do not take away this benefit that we have become used to.</p>
EM544	13-Feb-11	<p>Hi there - Here is my input for the consultation. I respond as a carer for my husband (currently in receipt of DLA) and also my parents (my mother is also disabled and gets AA). We have discussed the document at great length.*</p> <p>*</p> <p>If you have any questions or would like clarification on any of my points, do let me know, and I would also gladly be of further assistance with the next steps. Regards*</p> <p>*</p> <p><u>Context</u> - I am responding as a carer for my husband, who is significantly impaired following an aortic dissection and cerebral infarcts seven years ago. I am also using my knowledge and experience of my parents' situation – my mother has MS and is now in a care home as she requires full time care; my father has been her carer for many years and to an extent still is.*</p> <p><u>Question 1</u> This is really two separate questions. The first part – what prevents people from participating in society – is largely down to attitude – a combination of understanding, acceptance and willingness to help the disabled. The second part – leading independent, full and active lives – is highly subjective. Many disabled people will never be able to do this, no matter how much support they receive. The problems and barriers are often highly specific to individual situations. Generally speaking, gadgets that make the basics easier help, so access to these would solve</p>

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		<p>a part of the problem. Things like washing, dressing, using the toilet and so on take a lot longer and are often exhausting. Eating a meal or having a drink come into the same category. Getting about is complex, difficult and potentially dangerous, inside the home as well as outside it.*</p> <p><u>Question 2</u> No comment!*</p> <p><u>Question 3</u> The main extra costs borne by my husband relate to gadgets and medical/alternative treatment or therapies not provided by the NHS. Transport is another. My mother was paying the care home until her savings ran out last year.*</p> <p><u>Question 4</u> I'm not convinced two rates for the mobility component would be sufficient to recognize the degree of variation. For example, both my husband and my mother get the full mobility component, he of DLA and she of AA. My husband would not be able to walk 50 metres without help; my mother cannot eat without someone feeding her and needs to be moved using a hoist and a wheelchair. Although it would make it simpler!! *</p> <p><u>Question 5</u> Are you really going to assess 3.2 million people individually? I don't think so, so I'd answer 'yes' purely from a practical perspective. *</p> <p><u>Your paragraph 21</u> needs an injection of reality. If an individual is in hospital and has issues besides the one being treated, these are largely ignored. The quality of personal care received in hospital is poor in comparison with that given by the carer at home. The acute medical condition may be treated very well, but patients do not receive the level or quality of care they do at home. Carers are also put under more pressure trying to keep the home running whilst also visiting/caring for the individual in hospital or similar. For example, my father visits the care home where my mother is every day to feed her her lunch. To give another example, whilst my husband was in hospital following a broken hip due to a fall, I visited him each day, often twice, and made sure he had access to a bottle to pee in when he needed it, had access to food he could eat (he only has one functioning hand) and drinks within reach. On more than one occasion I ended up fetching and carrying for the other patients on the ward, including replacing one man's bandages.*</p> <p><u>Question 6</u> No comment*</p> <p><u>Question 7</u> Let the individual choose when and where they are assessed. Accept their carer's and other medical professionals' input on the degree of their disability, nature of variance from day to day and so on. There is no foolproof way to do this.*</p> <p><u>Question 8</u> Bear in mind people may well have paid for these themselves. You might consider taking as a baseline from what the NHS can provide, its suitability/effectiveness and speed of delivery. *</p> <p><u>Question 9</u> Make the claim form shorter and simpler. Link with PCTs, GPs and so on to improve signposting.*</p> <p><u>Question 10</u> You need to take input from all sources, not just those provided by the state and not just medical professionals. Include the carer!*</p> <p><u>Question 11</u> Given the scale, I think you might have difficulty recruiting the people to do it! It would be inappropriate to do this with the terminally ill.*</p> <p><u>Question 12</u> Get GP input on any further medical events; there probably should be different types of review. From a practical perspective, I can't think of anything better than having the individual drive the review process (I am assuming this is after the first assessment) although this is clearly open to abuse. *</p> <p><u>Question 13</u> I think some of my response to Question 12 answers this point. People should be reporting changes under the current system, but they don't. It needs to be made very clear at the outset, maybe with an annual reminder to be signed and countersigned by the GP or nominated consultant..*</p> <p><u>Linking people to support – Questions 14 and 15</u> Navigating sources of support and expertise is an expert task, and there is a massive amount</p>

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		<p>out there. Basically, yes, it would be helpful to provide help with this, but I am concerned about the practicalities of avoiding a sudden overload, or signposting to inappropriate sources.*</p> <p><u>Question 16</u> Disabled people fund these things with their own money! Surely you can use the current DLA to fund one-off expenses – you just need to save up?? Not sure I understand the point of the question.*</p> <p><u>Question 17</u> Acknowledge and value the parents' input on a par with others.*</p> <p><u>Over 65s</u> I have never understood the logic behind DLA and AA being separate, as disability doesn't change as a result of reaching pensionable age. Neither are linked to earnings. If you kept people DLA and got rid of AA you would save lots!*</p> <p><u>Questions 18 and 19</u> This is very important. To us, more so than the money. As a result of DLA, my husband has a blue badge, which has made an immense difference to life outside the house – in fact, as a result, he has a life outside the house. This is because we can park near the places he wants to go to, and because we can guarantee being able to open the car door wide enough for him to be able to get in and out safely.*</p> <p>Other things that have helped are the Radar Key system and concessions/accessibility at public places and events. *</p> <p>Without this the implications are immense. There would be more work for service providers who would have to carry out their own assessments. Our lives would be much harder if we did not have the blue badge – either I wouldn't take my husband to a lot of the places we visit, or we would have to pay for specialist transport, or he would end up using a wheelchair which he does not want to do. And I would end up pushing him, which I don't really want to do either...not exactly helping the independent life you are pushing.*</p> <p><u>Sharing information</u> This is a great idea as long as the individual consents. I have lost count of the number of times I have explained the same things over and over again! Or the number of times my input has been dismissed.*</p> <p><u>Question 20</u> The way I would approach this is to research what is currently provided that is linked to DLA, understand the processes behind these and look for ways to streamline them. Then I would look for what else is offered that is similar in concept to any of these things, and go through the same process again, looking for ways to add them in. So as a first step you improve the efficiency of what you currently have, and then as a second, give added value by incorporating anything else that is appropriate.</p>
EM545	13-Feb-11	<p>Dear Sir, I am the carer for my husband [REDACTED] as he is partially sighted, I need to be with him when he is out and about to cross roads etc, only yesterday he walked out in front of a car he didn't see. He receives DLA at the lowest rate, I do not get anything as a carer. [REDACTED] is also now my carer as I have had major life saving surgery, he does not get anything as my carer, neither of us is complaining on that score, rather we are grateful for the little amount of DLA [REDACTED] receives.*</p> <p>*</p> <p>There are many carers who do get allowances, as I understand it those people whom God has entrusted our less able (or is it differently abled these days, it is difficult to keep up with the changes in terminology) companions care to save the country £87,000,000,000 (eighty seven thousand million pounds).*</p> <p>*</p> <p>[REDACTED] has been registered partially sighted for more than twenty years, has a bus pass, a rail pass and receives blind persons tax relief, a medical examination seems like you have loaded the outcome against him to save money, like our friend treated for asthma for decades but not recognised as having it until after he retired so that his employer, whose actions brought about the condition didn't have to pay him.*</p>

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		<p>* [REDACTED] has only a part time job now and while he is doing some cataloguing in the remaining time it doesn't make his money very much, I have state pension and a very small work pension which is taxed, any reduction in our income or rise in our outgoings is difficult to cope with.* *</p> <p>The financial situation was caused, I beleive, by greedy high earners, I cannot fathom why those least able to look after them selves, those least likely to earn good salaries and those who care for them, saving the country money as they do, should be asked to pay back in place of those who were at fault, except of course that such people are easy targets and least able to fight back.* *</p> <p>That those who may still get allowances may then have the indignity of a medical exam so that another expert can agree (or otherwise) with the Doctors who are treating them and encouraged them to get registered in the first place.Anyhow, please think carefully about your decision on this. Yours sincerely</p>
EM546	13-Feb-11	<p>1. Your response: Mobility to get around, home care, belonging, and somewhere disabled people can go and meet their peers, warmth, and good medical facilities' close by *</p> <p>2. Your response: The ability to have someone care for you, helps you gain freedom of fear ,it doesn't matter if it's your wife/husband or relative .But when you are unable to read your drugs, or you fall over, it's good to know you have help there at all time's especially at night . * it also means you don't have to call out doctors act as your carer all ready has all ready done a first aid course and knows you ,it allows you freedom without having to ask local government for extra funds to help, it also allows partners to work part time if they can ,which means they pay tax and put back some of the cost ,but if you say they can only have one option ,work or care , then work will lose out ,and we will all lose out as work can be the only break the carer can get from the patient and can help them afford to life without state hand outs . Obviously some disabled people only need care at night ,when they take high doses of drugs act ,while others need all day care, while other disabled people need specials care before going to work them self's, and others need 24 hour care ,but if you remove any of these components, then the cost of caring will go higher, as people will have to take life changing decisions on a ad hock basis, as to whether they can continue to care for the disabled ,and that would be very expensive for both councils, government ,patients ,and carers. It's a lose, lose, option. Professional may think outside the box, but social experiments in my experience inevitably fail, and end up hurting the weakest and costing more. *</p> <p>3. Your response: All forms of Transport, buses trains ,taxi .The only way someone in a rural area can escapes by car, and those costs include , Petrol, Tax .and the general Upkeep and wear and tear of a vehicle but is the only transport available ,unless you have a carer or friend , especially if you want to attend hospitals which are now 10 miles away ,and doctors surgeries ,which are several miles away from home's. the other things are electric and gas heating as disabled pay more than anybody else per % of income ,and most conditions react to the cold, therefore disabled people have no alternative than accept the pain and suffering they go through if they don't get the heat ,mind that is a cheaper option . *</p> <p>4. Your response: You will lose the flexibility you have now to move someone from one grade to another, and that will cost money over time, no matter what size of payments are made. for instance a small payment now can make a difference ,a family who have to travel home at lunch time to ensure a disabled person is okay and gets something to eat and drink for them in this age of Austerity cost's money , remove it, and it could impact on the family as a whole .If you remove their crutch so to</p>

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		<p> speak then it will open you up to more costs ,as more people will start to appeal against your decision to with draw help ,or they will stop working all together, if that's what they have to-do to qualify for help ,illness is not something you can price like you do at a butchers ,l/E liver 60p a pound per week ,lost leg £31 for a whole leg, or £15 for half a leg per week , Diviticular disease ,(that's intestines) 30P a week ,cancer £5 per lb of growth, or madness, not sellable a brick cell for them then . Act...act* </p> <p> 5. Your response: Depends on how the government are going to enforce the new conditions ,and the criteria, .If people are under constant financial strain, then they cannot cope with their disability and things will get worse, not better .for instance you might be able to walk one week, but it doesn't mean you're able to do the same the following week, but it's likely in order to walk you will end up confined to bed in agony for several days after that's a decision disabled people have to make every day of their lives' .But if there seen they should not lose that help based on one visit from a government doctor, who is only guided by how much money he can earn himself by signing off disabled people. Many disabled can be forced into doing many things around the house, because they have no all tentative, they will put up with pain act for a very short time period in order to do things they cannot afford... So if you are going to penalise the disabled for trying to help their families just because they are in remission, then that will become counter predictive for all concerned. Especially if their condition is long term, and especially if you say they have to start the whole process again and it will show how little this government actually understands long term illnesses, and disabled people, it also shows this government is prepared to infringe the human rights of disabled people, by including law they would not use against able bodied people with in this legislation. If a Doctor says a condition will never get better, then the government must respect that decision, and not go down the armed forces root, where they make up their own rules regarding disability. An Example of the MODs madness, is tinnitus ,the MOD will not recognised the condition unless you have lost more than 50% of your hearing in both ears, but if you have lost 100% of hearing in one ear, it means you still don't qualify for help or compensation, as you have only lost 50% of your over all hearing ,that also means you can't have tinnitus in their view ,as tinnitus according to them only happens when you have lost over 51% of your hearing, That is against all known medical knowledge, but it's there law and it's mad.* </p> <p> If this government intend bringing in such stupid rules as the MOD have, then this is not about disability, but more about how they can avoid helping disabled people .As for the term of disability, that should only change if new medication or advances in medication, or surgery have found a way forward to help disabled people get better, or the person recover's, and that should be decided by the patient's own team of doctors. And the NHS should be compelled to offer any new products to the disabled first ,in those cases It they should be reviewed every 3-5 years by their own GP, as they have a full history of the patient, not by some paid hack of the government ,who will only do what the governments wants them to do ,after all they need money to live as well ,so they will do what the government asks ,and return patients to work If this action is taken, then I also believe, those hacks must be accountable to the law, and the patient ,and the patient should be able to take that individual doctor ,or company ,plus the government to court, if something happens to the patient once they have been forced back to work ,which could be shown as negligence by the state ,especially where it can be proved they inflicted unnecessary pain and suffering on them ,which is contra to the human rights convention ,and is a save guard against corrupt doctors or government officials this could save money, plus it allows security for the patient, and removes fear.* </p> <p> 6. Your response: By supporting their families, and by offering good back up care run by doctors, but not by local councils, charities, or private </p>

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		<p>companies.*</p> <p>7. Your response: By asking the patients Doctors and specialists care team, how the long term illness /,disability affects the individual over a period of time „rather than making a condition / disease, fit a specific profile set by a government think tank .*</p> <p>8. Your response: It doesn't follow ,that a disabled person is better off , it doesn't take away the pain in fact it can increase the pain, but it may allow that person to get about, if an adaption is used ,but they can also course further damage especially where there are joints are concerned ,their fore it should be down to the individual what aids he wants to use ,again the duty of care should be to the patient, plus the patient should be able to claim compensation if their condition gets worse, if forced to use something they don't want to use .*</p> <p>If the adaption is to the home, then the present system is adequate ,provided the cost is specific to the adaption required by the disabled person ,I/E if an occupational therapist says they need a walk in shower ,then that person should get it ,according to the families/ individual means and income ,but they should not get a shower they cannot use , this happens in councils housing ,because the council have the right to say yes or no to any adaption on cost grounds .*</p> <p>9. Your response: By using plain English.*</p> <p>10. Your response: By using the GP of the patient, or a hospital specialist, who knows the patient, I/E Occupational therapist, physio, or Consultant they know the individual person and his problems. But please don't use retired GOVERNMENT HACKS. *</p> <p>11. Your response: Many will not know the full history of the patient, unless you intend any old Hack, or private company from obtaining private and confidential files? There is also the problem regarding time and convenience if other people are all so required to attend such as carers ,and will the government pay the cost's ?*</p> <p>12. Your response: This depends on the condition, if the condition is known to get worse with age such as Arthritis, Spondylosis, M.E Parkinson's, and other such diseases, then their GP or hospital specialist should be ask may be after two years for an update .as these people deterrent over time will require further help, this would also show up those who don't.*</p> <p>13. Your response: If people do send info to the DPW, it would be helpful if they did not reply by saying they don't need the info sent regarding the condition, or if they actually acknowledged recite.*</p> <p>Dialog goes' along way.*</p> <p>14. Your response: Not sure what this question is about. *</p> <p>15. Your response: Again I'm not sure what you are asking for here. Are you talking about the Built access environment, or community access, electronic access or access to all within the general term?*</p> <p>16. Your response: Prescription, or from the Hospital .unless you're talking about the built adaption, then it's through government or council .Which are all direct payments *</p> <p>17. Your response: Take the Mothers and families financial passion into consideration, and see how they react to your suggestions and again trust the local GP and Specialists. *</p> <p>18. Your response: Not really, as the DLA all ready opens doors we would not have known about *</p> <p>19. Your response: Nothing, the present system doe's that very well *</p> <p>20. Your response: All medical notes as I understand it are private and confidential by law, and this must remain so. *</p> <p>.Private companies or charities' should ever be given access to patients note's, unless they have taken the medical Hippocratic oath , nor should other departments have access for any reason, unless the patient agrees in advance they can ,and then the disabled patient should be sent a copy first ,so he/she can ensure the truth has been told . Therefore the present procedure should be less bureaucratic than anything that could</p>

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		<p>replace it ,as only 3 people /dept need have access if used correctly I/E my GP, your dept, and the patient . *</p> <p>21. Your response: Little. As there is no guarantee regarding the security of care of the individual or of privacy, and there is no view regarding the government's duty of care for the disabled through monitory help. This government are discarding their duty to disabled people and those with long term illnesses to the private and volunteer sector .rather than care for the individual and his personal information, which should will be kept within the confines of the government and the GP as is required by law. This is a social experiment in cutting costs only. 22. Your response:</p>
EM547	13-Feb-11	<p>1. Your response: One of the main problems is transport. If I lost my DLA Mobility component I would not be able to get out at all. I would not be able to see my family, I would not be able to have any kind of social life and I might as well not exist. *</p> <p>2. Your response: The care component allows me to get the care that I need. My husband is unable to work because I could not manage on my own. He claims no benefit because he has a pension that takes him slightly over the limit.*</p> <p>3. Your response: During the winter ,especially we need extra heating. When you cannot move about, you feel the cold much more than people who are mobile and able to get about on their own. Because of the type of medication I have to take I have digestive problems and have to eat properly. The extra cash from DLA helps me to do that. I would find this difficult to do this on the income I have from IB. I have to have shopping and other items delivered because I cannot get around the shops. This costs extra money. If I need to go anywhere in the car , and I need to go everywhere in the car, the costs of petrol mean extra cash to do anything.*</p> <p>4. Your response We have two rates for mobility component at the moment. You can either walk or you cannot. It depends very much on the clarity of the criteria. With DLA at the moment its very hard to understand the criteria for the care component. I apparently am on the cusp of lower and middle care component but receive the lower rate even though I believe I should receive the middle rate .The reason people need help and advisors to claim these benefits is because of the complications of the criteria. So having two rates of benefit for the care component should certainly make things easier to understand whether or not it works is another matter.*</p> <p>5. Your response: I believe that it should be based on the needs of the people applying, however, I do not believe it should be income assessed as most disabled people want to work and DLA helps with this ambition.*</p> <p>6. Your response: Being able to get out and about is most important to me . Seeing my family and being able to have a bit of a social life comes as a joint first. Whilst saying that .people need help and support to allow them to do these things. They need to have the money to pay for these little extras which are an essential to human life. We don't all of us go on foreign holidays. Most of us are very lucky to get a holiday at all.*</p> <p>7. Your response: I don't understand whether you can do this or not. I the case of a disability that does fluctuate then the emphasis should always be on the "worst Day" scenario. Most disabled people would be perfectly happy to have an annual assessment, I am sure however that there will always be people who receive benefit who are not entitled to it.*</p> <p>8. Your response: Aids and adaption should not be taken into account. I cases like a stair lift for example, the person only gets the use of that in their own home and nowhere else. To take this into account is like penalising a disabled person for having to use an aid. A lot of people don't find it so easy to get an aid or adaption that they need. This would be the government's opinion. I personally could do with a downstairs toilet but can't afford it. Will the government pay for it.*</p> <p>9. Your response: You could shorten the form. It really intimidates people just to look at the form and it seems that you are trying to trip us up by</p>

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		<p>asking the same question in a different way. *</p> <p>There presently exists an inch thick document of rules and regulations for DLA care component. Most of the entitlement statutes lie in law so simplify this. If people are not clear in their forms or don't have up to date evidence then send them for an assessment. Peoples GP's know about their condition. Write to GP's privately and allow them to give their opinions of their patients condition.*</p> <p>10. Your response: The patients own GP is best placed to provide supporting evidence however, it should be given to the DWP not to the patient , if the GP wishes it.*</p> <p>11. Your response: People do not trust government Health Care professionals. They believe that their only job is to put people off benefits and not to help them. *</p> <p>I know of a friend of my parents who had cancer and had a bladder fomed out of a piece of bowel who was refused sickness benefit by a "Health Care Professional". This woman was very ill and I fail to understand how this was even a possibility. She got benefit after appeal but this meant months of worry which failed to help her recovery.*</p> <p>As you can no doubt see "Health Care Professionals" do not have a good reputations among disabled people.*</p> <p>12. Your response: The patients own GP shold be filling in a form with room for comment and opinion of patients condition. The patients GP knows the condition of the patient and the GP's opinion should be the main Health Care professional involved. If the GP's report is full enough there should be no doubt and no need for different types of review. The GP can also take into account any hospital or physiotherapy reports etc.*</p> <p>Frequency of review should depend on the patients condition and whether it is ongoing such as arthritis.*</p> <p>13. Your response: Again that should be down to yearly or two yearly assessments .*</p> <p>You are never going to get people to report changes if it means they lose benefit. DWP can only keep doing what they are doing and ensure that penalties are more severe.*</p> <p>14. Your response: They need to know if they are entitled to this benefit and of course it would be helpful. Its bad enough trying to find details and entitlements to benefits as it is.*</p> <p>15. Your response: It might help but remember you are dealing with disabled people here. Its not always easy for them to get about so there would be a need for such advisors to be mobile and expected to visit people to help. It would also be necessary for them to be independent and not government employees in a case where personal information would be required to be disclosed.*</p> <p>It could not be seen to be another step on the ladder to whether people received benefit or not.*</p> <p>16. Your response: They buy their own. If they can't afford it they don't get it.A bit of help is available but not a lot especially with the council cuts beginning to come into affect.*</p> <p>17. Your response:*</p> <p>18. Your response: The only thing I have is my blue badge. I don't know about any other services I would be entitled to.*</p> <p>19. Your response:*</p> <p>I do not know but I am sure it could be catastrophic to some people.*</p> <p>20. Your response: This question horrifies me. Information about people should not be shared out willy nilly. I would hope that this would be a matter that would require a lot of consultation with the people concerned.*</p> <p>21. Your response:*</p> <p>22. Your response: This is the 13th of February and I have only just heard about the consultation.*</p> <p>I want you to know that , if I lost my car and my benefits, I lose my independence and I might as well not exist or be here at all. I am not rich but I manage. I am careful with money and I manage to live relatively</p>

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		comfortably. To the millionaires in the cabinet this may seem to be OTT but if you don't have the money to live like a human being there is no point in being here at all. I would like government ministers to remember that its human beings you are dealing with. Not all of us are scroungers.
EM548	13-Feb-11	<p>Hello, Attached is my response to your consultation on DLA reform. I have filled this out as a private individual but have drawn upon my experience as a trustee responsible for SEN and Disability with Education Otherwise as well as owner and moderator of [REDACTED] Please feel free to contact me if you require any further information. Best Wishes,*</p> <p>*</p> <p>1. Much of the equipment for disabled people is very expensive. Companies charge more than it costs for many things as they seem to believe that funding is available from the NHS or other government areas therefore it doesn't matter how much they charge. Also some equipment is available in other countries but not in the UK because it is not worth importing something that is not supplied by the NHS. We are currently trying to find a suitable wheelchair for my son which will be small enough to fit on an Intercity train but will also be suitable for off road or rough terrain as we live in the countryside. There is nothing suitable on the NHS so we are having to get something privately, but there is a very limited choice and everything is very expensive. This means that we are now virtually housebound. Many say that with a social model of disability you just have to change people's attitude but that doesn't always work. There needs to be a mixture of the social and medical model. In fact it is the adherence to a social model of disability that we find is a barrier to leading a full and independent life. My son is different due to his Autistic Condition. Trying to make him conform to someone else's ideal society only ends up making him feel more different. In fact it has been found that the once sector of society that has become more isolated rather than less since the introduction of integration is those with emotional and behavioural problems. Part of the social model of disability states that ramps should be built for wheelchairs. The problem is that people thought that that was all they had to do, so there has been almost no research and development into new and more comfortable wheelchairs that can go on all terrains,*</p> <p>can fit into the small shops and houses we have in the UK not to mention trains. Although the biopsychosocial model isn't usually applied to disabilities as such, that or some other combination of the medical and social model of disability would actually start to remove many of the barriers to disabled people. By rejecting the medical model there is less emphasis on physiotherapy, speech therapy, and equipment development all of which would make my son's life better. We are not looking to cure him, just taking an intrinsic responsibility for his disability rather than expecting society to deal with it. *</p> <p>2. The "passport to services" is almost as valuable as the money itself. For instance single parents are exempt from seeking full-time work if they have a child on middle rate or higher DLA. If this was removed it would cause a lot of hardship in that area. At the moment things like this can be restricted to certain levels of DLA. What would be better is a register of disabled people that would enable them to access further and more informal passported services regardless as to the level of payments.*</p> <p>3. Although the greatest cost is for equipment, personal care is also expensive. Sometimes though a small amount of equipment or care is the difference between independence and isolation. For instance something as simple as a an assistant for trips out shopping will make a huge difference to someone who is normally self contained at home. This wouldn't cost much if the assistant was only needed occasionally, but could make a huge difference to the person's life. Sometimes the main extra costs are not financial in nature. *</p> <p>4. • Will having two rates ... support? Having just two rates per component will make it simpler, but will also remove some flexibility. •</p>

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		<p>What, if any, ... cause? At the moment with only two rates of mobility, a lot of people don't get increased mobility* allowance for their children as they are not deemed to be disabled enough for the higher rate of mobility allowance. They often comment that there should be a middle level of mobility for those that need more help than the basic level but don't have the severe limitations required of the high level.*</p> <p>A personal example is my son who has hypermobility syndrome. This means that he has pain when walking relatively short distances but he can walk. When we go out shopping or for other leisure reasons we have been using a buggy so that when he can he can walk a short distance but as soon as he is in pain he can sit down and be pushed. However he has now grown* out of the buggy and at age [REDACTED] he needs a wheelchair which is significantly more expensive. This is not reflected in his DLA though, as he is still deemed to be of low impairment of mobility because he can walk short distances. The result has been that we have become increasingly isolated to the point that we no longer go out. A middle rate of mobility would mean that we could better afford a wheelchair.*</p> <p>So it would be just as simple to match mobility and care and increase the levels of mobility to three.*</p> <p>As for disadvantages of reducing the care rate to two levels, this will leave out many people who struggle during the day with their children a lot more than at just the basic care, but don't have the problems at night that would result in high rate of care. Some disabled people sleep well at night but have huge care needs during the day, so if the care rates were dropped to two levels only, then they would have to take both night and day into a single consideration, rather than having the distinction of day and night care required for high level, so that those that currently get middle rate due to high levels of care required in the day won't miss out on the extra money just because they have no care needs at night. *</p> <p>5. All claims should be based on the needs and circumstances of the individual. I am concerned about the six month requirement. It is often not possible to predict how some people will recover from things such as strokes. While some recover quickly, they can be profoundly disabled in the first 6 months, and that is when they will need the equipment the most.*</p> <p>A personal example of this is a friend who had a stroke at age 39. As a young woman she was expected to recover quickly. She was profoundly disabled in the first 6 months and could not get out at all. She started to suffer from depression. Eventually they fought and received a wheelchair, but by then she had started to get better. When she really needed the extra help was in the first six months when all help, support and DLA was refused. However her recovery was not as rapid as they expected, so again it wasn't until after she had been ill for a year that they started to get appropriate support by paying for things when she finally received DLA. By then she was severely depressed and this has made her recovery even longer. As soon as someone becomes disabled they should qualify providing it is expected that they will be disabled for six months to come. There shouldn't be the initial six month waiting time. *</p> <p>6. Which activities should be assessed will depend on individual people. For instance some people are happy putting a packet of convenience food into a microwave but others either prefer to cook from scratch or have to because of allergies. For those people the test of making food is a lot more difficult and they will need more support or even someone to cook for them but someone with the same disability who couldn't care less if their food was fresh wouldn't need someone to cook for them. Likewise a mother who is disabled will have a greater need for help with cooking for the family than if they were single.*</p> <p>Another example of how each person is different is in socialising. Some people on the autistic spectrum don't like to socialise at all and therefore</p>

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		<p>for them having someone take them out window shopping is a waste of time for them. But they may need more expensive computer equipment and internet connections so that they can keep in contact with people online.*</p> <p>Alternately another person may really miss social contact and require transport and care to get them to a day centre several times a week. You can't say that one or the other is more or less disabled; in each case they are severely disabled, just disabled very differently. Each person should be assessed as individuals.*</p> <p>7. At the moment the form is filled out using the worst day scenario. This can be very depressing, especially for parents who constantly try to dwell on the best of things, not the worst things. We often arrange for parents to have extra emotional support when filling out DLA forms as dwelling on the worst day is very depression. However, if you dwell on the average or even best day then many people will end up with no help at all. The frequency of difficult days may not be high, but on* a difficult day they can be 100% disabled. With the new interview regime it is possible that the interview will take place on a good day and it will appear that the person is only slightly disabled. Therefore it will have to be taken on trust or evidence from other people who work or live with the person will have to be taken into consideration. There will be no getting away from thinking about the 'worst day'.*</p> <p>8. • What aids ..? All aids and adaptations should be included. Just because something is useful to one person but not another doesn't mean that it shouldn't be included. There may be situations where a disabled person has come up with something that suits them but is not used by anyone else. But I am gravely concerned about the suggest that they might consider an individual's ability to get around in a wheelchair might mean that they are considered able to get around and therefore not qualify for the mobility component. Wheelchairs and similar are very expensive. The one we are considering for our son is £3,000. Yes, he will be able to get around better in one and therefore have less mobility problems, and may even be considered to not be disabled at all in his ability to get around, but that doesn't mean that he has less cost. How the person meets their disability is just as important and just because the social model of disability says that he is no longer disabled, doesn't take his disability away. • Should the assessment ...obtain? Assessment should also take into consideration aids and adaptations that have not been taken up yet. Otherwise how will the person afford these? If someone is not in a particular* wheelchair because they don't have DLA yet, and when assessed they are assess on what they have now, then they will never be able to afford any equipment. It is also possible that some people will have no idea of what is out there to help them until they are in a financial situation to explore what is available.*</p> <p>9. • How could ... fill in? When I filled out my first form I played a little game of rewriting it. I got it down from 40 pages* to 6. It would be much better to have open questions such as how does your disability affect you, rather than having closed questions that are often irrelevant to the person's situation. For instance many home educated children's families find it almost impossible to fill out the form because it isn't suitable for emotional and behavioural problems such as Autistic Spectrum disorders, and it assumes certain lifestyle situations which include school. It would also be great if you would ask* the people themselves what levels of care and mobility they think they are entitled to and why.*</p> <p>• How can we ...qualify? There has to be training for all Health Care Professionals, schools, and voluntary groups.*</p> <p>The voluntary organisations in particular have to be seen as partners rather than the enemy as they are at the moment.*</p> <p>10. It seems wrong that a healthcare professional that has never met the</p>

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		<p>person before and doesn't know them well will be expected to decide whether they qualify. It reminds me of the paediatric textbook from the 1970s that stated that a doctor should never believe anything a parent says but should base their assessment on their clinical observations only. They have now thankfully recognised that parents who are with their children all day and all night are actually in a better position to observe their child, and not only that, that children can react very differently from one place or time of day to another. I really can't see how a short meeting with a stranger will suffice to assess someone's needs. By all means have an independent interview but the majority of the information used to assess the person should come from themselves and their carers or parents. Their carers are in a far better position to assess how much care they need. There is also the situation with adults and children on the autistic spectrum who will really suffer greatly when meeting a stranger and will therefore any assessment based on that meeting will not be a true assessment.*</p> <p>There will also be cases where there will be very few other health professionals involved. As a parent of an otherwise healthy teenage with Asperger's Syndrome and Hypermobility Syndrome, we have had very little contact with health professionals. He has been to the GP once in the last 10 years, there is no support for Asperger's Syndrome in our area and I deal with the county physiotherapist over the telephone as they don't have enough people to see us face to face. For us our lack of contact with HealthCare Professionals doesn't mean that my son's disability is any less. If anything we are saving the government money by not taking up their precious resources. But that would now fall prey to new rules if they depended on people that we don't see regularly. Supporting evidence should be gathered from the carers and the people themselves.*</p> <p>11.. • What benefits .. bring? If this went hand in hand with shortened forms this could be useful, but only if you get away* from the tickbox one size fits all. If you still have that then all you are doing is shifting the form filling from the disabled person themselves to the person interviewing them. • Are there any ... location? It may well not be appropriate to meet with children generally and specifically with those on the Autistic Spectrum. Children, especially those that have already had extensive interaction with healthcare professionals, may well react very badly to having yet one more interview with a stranger. ASD children and adults may well not cope with being interviewed by a stranger and the healthcare professional may well misinterpret any behaviours such as lack of eye contact, stimming, or aggression incorrectly.*</p> <p>12. • What evidence .. reviews? To be fair the reviews should be the same for all. Either a set number of years for adults or* a milestone years for children. • Should ...condition? At most there should be two categories, one for permanent disability such as amputees (I have yet to hear of legs growing back) and another for conditions that vary such as Autism. That*</p> <p>way a review for a permanent disability could be of the nature of making sure that there are no additional needs, and the review for the variable ones more comprehensive to make sure that it is still needed.*</p> <p>13. It can be hard to recognise changes in one's self. With the best will in the world some get worse but don't bother to claim until their next renewal (that happened to my son) because of the difficulty in making changes. It is complicated, and can sometimes have a knock on effect of affecting other benefits which seem to be stripped away at point of enquiry rather than after reassessment.*</p> <p>Trust will go a long way. The more we trust people the more trust worthy they become. If it is simple to report changes, and we trust that people will, then they will. If we don't trust people they will start to resent the government and will be less likely to willing report changes. *</p> <p>14. Advice and support should come from organisations independent of</p>

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		<p>the government. They may need advice such as how to hire a carer, how to access appropriate equipment, day centre, sheltered workshops and support for the carers should also be offered. Advice from the same people that are paying out a benefit could be seen as a conflict of interest.*</p> <p>15. There would need to be a safeguard to make sure that refusal of government supplied support would not stop the benefit. Some families find that their severely disabled children when they have been traumatised by attending a special school, no longer trust people in authority and prefer to have nothing to do with them. If the child is happier without input that has been evaluated and rejected by the parents then they should not be penalised by removal of benefit or further pressure being put on them to accept something that they know is not suitable. Perhaps something along the lines of the NICE guidance whereby they say that if a family has made an informed choice and can explain how they came to their decision, they should be left alone and not pressurised or penalised in any way.*</p> <p>16. Currently I am having to save DLA payments in order to buy expensive equipment which means there can be a delay between needing something and being able to afford it. It would be better if an advance could be made for expensive items. Or even better once the underlying benefit, say mobility, has been granted, specific recommendations could be made. In my case I would be able to buy an appropriate wheelchair upfront and have enough money for three first class train journeys to York a year to see his best friend, and I would not require any further mobility money. The following year I would need only the amount to make the train journeys and maintenance for the chair, but not the extra for the wheelchair. In the long run this may be cheaper, but at the same time it could be more expensive to administer.*</p> <p>17. Although children need extensive support, the type of support they need is very different and is traditionally given by family members unless 24 hour nursing care is required. The traditional items for discussion with disabled adults such as getting a drink or snack, preparing a meal and mobility are very different for a child and in some cases inappropriate. I know that the emphasis is on what adults can do rather than what they can't do, but for children it is still more about what they cannot do, as by definition children already can't do much of what adults do regardless as to disability. The emphasis at the moment is that the child needs more care than other children at the same age and that is a very far and useful assessment. This will take into consideration most disabilities.*</p> <p>It is also important to remember that information about the children will come from different types of sources than for adults. For instance with home educated children the parents normally do all their therapy, so there would not necessarily be physio or occupational or even speech therapists involved in the child's education as there are in schools. At the same time there may be an increased number of lay people involved such as other parents or leaders at home education groups, private tutors, sports coaches, or other friends of the family. These should be taken equally as evidence as the evidence from teachers and other health professionals. It would also make sense to take into consideration the child's support needs if they are being met at school. Many home educators say how unfair it feels that parents whose children are in school all day get the same rate of DLA as parents who home educate their children and therefore have them at home for an extra six hours a day. Either those with children at school should get less money or those with children who are home educated should get more.*</p> <p>18. Passports to further services and benefits are hugely important and should not be underestimated. There are the more formal things such as the county registers of disabled children and the leisure services provided that way, and motability schemes, to more informal situations like carers getting in free to privately run functions, places like Legoland, cinemas,</p>

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		<p>housebound facilities at libraries, extra help at educational establishments. But so much of that is a postcode lottery. Generally though the extra services and support that is gained from outside the government run areas are better, faster, and more respectful. I don't feel qualified to comment on other means tested benefits, but I have greatly appreciated things like the Warm Front grant. It wasn't just that I got free insulation, it was that it was installed by someone that understood that we had a disabled child in the house.*</p> <p>19. There are a lot of very valuable government services that would be withdrawn such as Blue Badge Scheme and so on which would result in genuine hardship, but my experience in the private sector is that when I say my child is disabled they believe me and act accordingly and don't seem to need a special letter to prove it. Again, I guess it is all about trust. As I was told at one museum that they wouldn't want to ask for proof of disability as they couldn't imagine anyone actually pretending their child was disabled when they weren't.*</p> <p>20. I feel that details don't need to be shared, it should be enough to say that someone is disabled and to what level.*</p> <p>21. I cannot think of anything.*</p> <p>22. I am very concerned that children and young people that are home educated will end up being discriminated against as they have a lifestyle that is different to those that go to school. Nearly half of all children that are withdrawn from schools today do so because their SEN or disabled needs are not being met, and yet many government officials doesn't even realise that home education is legal, let alone popular with families with disabled children. In reforming the system I feel that this is a great opportunity to take into consideration a minority of children and young people who are disabled but have been discriminated against because they are not at school. I trust that the government will consult with members of he-special or Education Otherwise in this area. I would be happy to assist in any way that I can.</p>
EM549	13-Feb-11	<p>1 A: • Attitudinal (recent report published by EHRC revealed that around three quarters of people viewed disabled people as needing some kind of care; a lower, but nevertheless significant number, also thought negatively about disabled people's ability to contribute to life, particularly with regard to employment)*</p> <ul style="list-style-type: none"> • Structural or procedural – inflexible working conditions, for example; over-zealous health and safety concerns with lack of reasonable adjustments* • Physical – steps, door widths, turning circles, lack of accessible toilet provision, accessible parking etc* <p>2 A: Different bands; even so, it is always difficult to slot people into boxes.*</p> <p>3 A:• Adaptations to home*</p> <ul style="list-style-type: none"> • Care/support aids (eg commode, seating)* • Care/support assistance (from high level care to put people to bed and get them up in the morning, etc, through to home and garden maintenance, general domestic help right down to getting someone to change a light bulb!)* • Mobility aids (clearly, if someone needs a mobility aid, they are unlikely to be able to walk well so I do not understand the implied difficulty with the current definition of mobility concentrating “on an individual's ability to walk”. If that person subsequently becomes “enabled” through using a walking aid – from a stick through to a motorised scooter or wheelchair – this is great, but there are costs involved, not only with the initial purchase but, potentially, with the ensuing accessibility issues)* • Transport – accessible taxis, in some areas, charge a premium (in York, for example, there is a £10 minimum fare, making short rides unnecessarily expensive). People who are not sufficiently mobility impaired as to warrant using a wheelchair but, nevertheless, depend on a motorised aid for their mobility in the form of a mobility scooter, frequently

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		<p>face difficulties in accessing public transport, increasing a reliance on taxis*</p> <p>• Premiums for DDA/Equality Act approved accommodation.*</p> <p>Will having two ... support? A: It may be more onerous to administer, but it is not feasible to categorise all disabled people into one group.*</p> <p>What, if any, ... cause? A: People may not fit comfortably into either category!*</p> <p>5 A: In the majority of cases it should be down to individual need with circumstances playing no more than a minor part (eg, if a disabled person lives with a partner – or an adult child – the needs of that person [carer] with regard to employment and mental wellbeing need to be considered when assuming support with the disabled person's support needs). *</p> <p>I am not a healthcare professional and have limited knowledge of other conditions and impairments but if people, for example, are diagnosed as para/tetra/quadruplegic it would appear that they would be automatically entitled. It is also hard to see that someone being diagnosed with a horribly progressive condition – like Motor Neurone Disease – should not be automatically entitled. Other progressive conditions, such as, for example, Parkinson's, Multiple Sclerosis (MS) might have little impact in the early stages and/or if the condition is controlled by drugs.*</p> <p>The proposed six month qualifying period is worrying because this is the time frame when many newly diagnosed disabled people find they need most help.*</p> <p>6 A: If we are to think in terms of the eminent psychologist, Abraham Maslow, the activities most essential for everyday life are those connected with the physiological aspects of survival: food, drink, shelter followed by the protection (safety) of these of which employment forms a significant aspect in that it is hoped that the ensuing remuneration will cover the cost, at least, of basic needs. However, whilst not necessarily being essential, love and belonging, self-esteem right through to self-actualisation (at the top of Maslow's hierarchy of need) all play a vital, albeit indeterminable – with anecdotal rather than scientific evidence – role in a person's wellbeing. In other words, only setting out to ensure only the most essential, and basic, needs of disabled people does little to empower us and facilitate any meaningful contribution to society either paid or, as part of the "Big Society", voluntary, or within the family unit. It is generally essential that we should have access to the same range of opportunities as non-disabled people. *</p> <p>7 A: This is potentially tricky. However, healthcare professionals, along with societies that support many such conditions are well-placed to advise.*</p> <p>8 What aids ...? A: None, unless such really do, in effect, serve to remove the effects of the impairment without incurring subsequent costs (eg in respect of access), with low initial cost and little or no maintenance costs. Initial thoughts consider the apparent ability of many to become largely able-bodied through the use of a simple walking stick might fit the category of an inclusive aid. The ability to use a rollator or a wheelchair/scooter should not be included.*</p> <p>• Should the ... obtain? A: Only if they fit the thinking in the response to the first part of the question.*</p> <p>9 How could ... fill in? A: No form is going to be easy for everybody so perhaps signposting to assistance is the best option.*</p> <p>• How can we ... qualify? A: This is difficult to answer without knowing exactly what the new benefit is going to look like. Process flow-charts can often be helpful; an "easy-read" version is essential with guidance in a Q&A format – all in an accessible (large non-serif) font.*</p> <p>10 A: Clearly what is required is an understanding of how the condition affects the individual. Having had numerous assessments (in pursuit of grants, and in respect of employment [Access to Work]) I find that occupational therapists or physiotherapists – familiar with working with people with similar conditions – are likely to be best placed.*</p>

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		<p>11 What benefits ... bring? A: The main difficulty might be in co-ordinating this followed by the possibility of involving a healthcare professional who might not be the best person in respect of the individual concerned. *</p> <p>• Are there any ... location? A: I, personally, cannot think of any but cases must be considered on merit and with professional guidance.*</p> <p>12 What ... reviews? A: This will have to go on evidence and a prognosis supplied by a qualified and specialist practitioner.*</p> <p>• Should there ... condition? A: Yes. As someone living with MS, my condition is never going to get better. It might, just conceivably, not get significantly worse, but the overall prognosis is that it will decline further. It would, in these circumstances, seem a waste of resources to keep doing reviews to check eligibility for the benefit (unless, of course, it was to consider increasing the amount due by moving to a higher band!) and there are many people living with many different conditions and impairments who would fall into this category. On the other hand, someone diagnosed with, for example, cancer, may stand a very good chance of becoming quite well again so a regular review would be pertinent. (NB regular reviews should be carried out sympathetically and not intrusively.)*</p> <p>It should also be noted that claimants in work may well have higher support needs than someone identically placed who does not have paid employment.*</p> <p>13 A: Other than well advertised sanctions for what is tantamount to false claiming, I have no idea!*</p> <p>14 A: Disabled people may require all manner of advice and information and any signposting is useful, but it will not work if it is perceived as a means to cut or reduce benefit.*</p> <p>15 A: The way this question, and supporting information, is couched, suggests that the motivation behind it is, in fact, one designed to reduce the amount of benefit paid out.*</p> <p>On a personal level, if it were accepted that I cannot, even with a stick, walk more than 15 metres on a good day, without stopping and without considerable labour, the implication seems to be that I could be referred to my local mobility showroom with a view to obtaining a mobility scooter. Would the subsequent acquisition of a scooter be deemed to make me mobile and not in need of a benefit? Mobility scooters cost money and need maintaining and, as previously mentioned, place further demands on access.</p> <p>I already have a mobility scooter (two, in fact, in case one breaks down) with a combined cost of around £3k. Making my home accessible for it has resulted in additional expenditure approaching £15K. In terms of getting about, certain transport is still denied to me, as a scooter user, and – despite legislation – access to shops and places of interest remains patchy.*</p> <p>Were I not already convinced as to the merits of owning a mobility scooter I would, undoubtedly, be pleased at being directed where to go for help with this, but I cannot see how whether choosing to follow this up or not should affect my claim. In fact, it could be argued, that regaining some level of independence increases expectations and need and, with these, costs.*</p> <p>16 A: I think many people might find this useful provided it did not preclude them from applying for subsequent “one-off” costs as their needs might change.*</p> <p>Common ways of funding aids and adaptations are:*</p> <ul style="list-style-type: none"> • traditional ways through savings, bank loans etc* • saving DLA* • grants* <p>17 A: No comment on this as the subject is outside my experience but I would have thought that many of the same rules apply just as much to children as they do to adults.*</p>

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		<p>18 A:Speaking only for myself, here, I can only say that DLA has enabled me to get a blue badge amazingly promptly. It also means I do not have to justify myself when applying for things like bus passes, disabled person's railcard and obtaining the (few) concessions that might be available. It was also useful recently in the process of applying for grants and, indeed, when challenging potential cases of potential disability discrimination.*</p> <p>19 A:The implication would be a lot of time spent in collecting the same old information and getting hold of up-to-date medical reports etc. This would also tie up the time of health professionals who might otherwise be better employed diagnosing and curing rather than doing reports in respect of on-going (and, therefore, non-urgent) cases.*</p> <p>20 A:Given the Government's keenness to encourage disabled people to seek employment, I believe a lot could be done to link the two particularly around Access to Work assessments. They could even be linked with Motability assessments.*</p> <p>*</p> <p>To give an example from my own experience: Fortunately, I was already in work when I was diagnosed with MS although, having said this, because the recommended reasonable adjustments were not implemented it took a period of 18 months, two grievances, an appeal and a claim to the Employment Tribunal Service, to get back to work – all the while undergoing a series of relapses (doubtless exacerbated by the stress) and being actively encouraged to “medically retire” (whatever the term is). However, I did get back to work but, having regained my confidence after a few months, I was unable to progress (the limits on my ability had been imposed without my assent). So, I started applying for new jobs and, in this process I was heartened by the fact that being in work with adjustments I was able to state my access requirements quite clearly and assertively. In other words, if I have x, y and z, I can do the job.*</p> <p>Imagine, not being in work to start off though. How can anyone definitively say “If I have etc etc ...” because they may have no idea what might be available to help? Furthermore, with the new restrictions on what Access to Work will fund, employers are likely to be much less willing to employ a disabled person, particularly where there might be a need for expensive structural adaptations to premises which are no longer eligible for support through the Access to Work scheme.*</p> <p>Imagine how it will be for a disabled person at interview to say “Well, I might be able to get this, or that ...” Such considerations will weigh heavily on small businesses in particular, although my difficulties relate to a large public sector employer! *</p> <p>Additionally, on the issue of Access to Work assessments, even without the cuts – or, rather, reapportioning of the budget – there are great difficulties around disabled people finding a job if they are not already in work for assessments cannot take place unless you are in work or within six weeks of a confirmed start date.*</p> <p>I was lucky in that I eventually secured a new post and a fair amount of support funding through Access to Work based on previous and new assessments. However, I also needed a vehicle and so applied for a car under the Motability scheme. Based on a driver's assessment the previous year, I was told that I needed a vehicle with an automatic gearbox, an integral lumbar support and a hoist to lift my scooter. Although ordered on 1st July last year, it took months to arrive and I only collected it on 27th December. In the few weeks I have been using the vehicle, it has quickly transpired that the hoist is not suitable for me, resulting in considerable back pain and an inability to use my scooter in conjunction with the car. *</p> <p>Accordingly, I now have a car which is more disabling than enabling as I have had painful episodes in my lower back necessitating trips to the Osteopath and acupuncture. It has now transpired that I should have had</p>

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		<p>a hoist assessment but no one ever suggested this (I thought a hoist was a hoist ...) although a chance chat with my Social Services Occupational Therapist directed me to the [REDACTED] assessment centre in Leeds. I rang them but while they invited me over this was not possible as I needed to take my scooter with me and, with no car then, I had no means of getting to the centre as the local train operating company refused to carry my scooter!*</p> <p>At the time of writing, I am due to go there tomorrow, 14th February, for an assessment but it is likely that I shall need a new hoist which will, in turn, necessitate a change of vehicle with all the ensuing extra cost, inconvenience, and general impact on my effectiveness in the workplace.*</p> <p>To sum up, there is, simply, no joined-up thinking around the wider issues of disability, particularly – but not exclusively – where matters of mobility are concerned.*</p> <p>The whole topic of the employability of disabled people does not just affect me personally as a private individual but professionally as well. My job is to provide education, training and employment opportunities for disabled people. It is hard enough for the able-bodied to secure employment in the current economic climate and it has always been harder for disabled people. How much harder will it be with the reduction of support from Access to Work particularly when more support is needed in terms of a pre-employment (at the job-search stage) assessment to help identify the kind of opportunities that might be realistic with the inclusion of certain aids and/or adaptations.*</p> <p>21 A: Thought definitely needs to be given to how people aged 65+ should be treated. *</p> <p>Policy developers should examine how this – and other areas – affect Government policy to encourage disabled people to work, as well as the wishes of many disabled people who want – or who are desperate – to work. *</p> <p>22 A: What consideration, if any, has been given to the cost of all these reassessments planned for current claimants? What is the estimated cost? Whilst I accept that there are, undoubtedly, many people claiming DLA falsely or erroneously, is it really appropriate to re-assess all existing claimants?*</p> <p>Who will be doing these assessments? Atos Healthcare, perhaps? The same people who, reportedly, with one hat assess someone as being unfit for work one day of the week and, on another, with a different hat, assess the self-same person as being fit for work. No wonder many legitimately claiming disabled people are feeling anxious, and anxiety never did anyone any good, least of all anyone with an impairment or long term health condition.</p>
EM550	13-Feb-11	<p>Dear Sir / Madam, Despite Kenneth Clarke's assertion that most people are unaware of the extent of the cuts required in public spending, I believe most people recognise the need to reduce expenditure on benefits. Indeed, there have been several prominent programmes on recently aimed at that subject. It is unfortunate that the general gist of the programmes seemed to imply that most people were claiming benefit fraudulently but this must surely have focussed the general public's attention on the need to discuss reductions in benefit.*</p> <p>Given the above, it is extremely disappointing that the government has not felt the need to inform recipients of benefit of forthcoming reviews such as the one you are currently conducting into Disability Living Allowance. I am on this allowance and note that, while the Benefits Agency can waste six pages of paper and postage for same telling me I'm going to get the usual tenner each Christmas, not a drop of ink was used to inform me about this review.*</p> <p>It smacks of deceit and evasion to hide the review and dress it up as anything other than a cost cutting exercise. Given it's current public image, the government should be at pains to be open about the problems</p>

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		<p>we face. It is less than truthful to suggest (as the preface seems to do) that people with disabilities no longer need the support they did because they now have the protection of, frankly, the weakest bit of legislation ever to go through the Commons (the DDA and its successors). *</p> <p>A simple paragraph only is required, along the lines of "The benefits we once enjoyed are no longer available because the public budget cannot afford them. So we must make cuts while ensuring those who need it most get help."*</p> <p>Having learnt about the review, I would like to contribute a few thoughts. *</p> <p>Firstly, is the benefit system itself being managed as effectively as it should be? Is payment and assignment of benefit being done by as few Civil Servants as possible?*</p> <p>Additionally, is sufficient use of current technology being made? Given the number of people on email these days (including the elderly), sending out notices such as those for the Christmas Bonus electronically might save more than a few Pounds. Rather than the usual multi-page monstrosities that allow access to benefits, perhaps one single form could be produced stating the help being requested? Said form to be put on a single government web site.*</p> <p>Better yet, rather than having loads of people processing forms, perhaps interviews could be held by someone from local council to assess what help someone needs (rather than what benefit corresponds to their entitlement)? In many cases, having met someone it becomes self evident what help and support they are likely to need.*</p> <p>Ultimately, disabled people need money. This bring independence and freedom. As I see it, the money can be provided by the government. Better still, the government can provide assistance so that disabled people can get it themselves. Too often, however, the government lays down regulations which run contrary to this aim and can ultimately cause people with disabilities to break those rules and criminalise themselves. *</p> <p>For an example of the above, after recovering from severe depression (which a large number of people with spina bifida appear to have), I attempted to get off Incapacity Benefit and return to work through the Therapeutic Work scheme. Although this proved a first step, my employer and I were frustrated because the limit on the number of hours imposed. I gained confidence and wanted to work more but could not for fear of losing my benefits. I note the limit remains sixteen hours. *</p> <p>Given that different businesses work different lengths of time, this period is very arbitrary. It would be better to say 'no more than three day's work per week' before someone is transferred to work-return assistance. Such a period is clearly understood and allows for times when an employer needs a worker to work into their lunch hour or come in a bit earlier or later. It does little for employment prospects to be constantly checking how many hours or half hours you have done! The alternative is, by trying to achieve independence and employment, you end up breaking ludicrous and ill thought out rules. *</p> <p>Likewise, I recall that one of the tests to measure disability (ie your ability to get a job) was whether you could walk a number of steps. I must say I have worked in a number of places and done many different jobs in radio, office managment and now PR, but never one where the requirement was to walk a number of steps.*</p> <p>Please, in the new benefit's regulations (whether they be related to work ability or degree of disability) please can 'real world' examples be made use of? *</p> <p>Rather than the ability to walk so many steps (which with me varies daily), perhaps people could be assessed on their ability to achieve real world tasks on a daily basis such as to get to a bus stop, to queue at the bus stop, to get on the bus, to stand on the bus (when no-one offers them a seat!), to get to a specific place by a specific time, to withstand being jostled by a large and moving crowd. These are, I feel, better tests of a person's degree of mobility/independence than if they can walk a set</p>

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		<p>number of paces. Although I can achieve some of these tasks, they are done with a considerable degree of pain and certainly not on a daily basis. *</p> <p>Sadly, pain is one of the few things which cannot be measured accurately or scientifically. Research by the government into this would be very welcome both by myself (spina bifida/hydrocephalus) and my mother (vasculitis)!*</p> <p>Mobility is clearly not just a question of steps walked. It is also clearly vital to most forms of employment. The government has stated its desire to get disabled people into work but I fear that removing people's access to transport will destroy that goal. In a recent case, a man who, having an artificial leg was deemed to be mobile and not in need of a Motability car. He now says he may well lose his job! My great grandfather got his leg shot off in the First World War. While he could get about, he was in constant pain and certainly wouldn't have won any races. So I am at a loss as to how anyone can see one and a half legs as equal to two good ones. The belief by some parts of government that one and a half equals two may go some way to explaining our current financial crisis.*</p> <p>Given our financial crisis, I believe that it is the government's duty to make sure money is well spent. I question whether this is the case with Motability. *</p> <p>Motability is an organisation (possibly listed as a charity) linking car manufacturers and the Benefits Agency. This organisation has a practical monopoly on money from Disability Living Allowance. There are, to my knowledge, no other schemes where a car can be rented for three years in exchange for benefits money. As a result, Motability has around half a million of the cars currently on the road. I believe the government (and whatever replaces Disability Living Allowance) need to establish some kind of competition to Motability so that those handing over benefits money in exchange for transport know that they are getting the most competitive deal. *</p> <p>Given how few of the cars within the Motability scheme (as a percentage) are automatics and that someone with a mobility problem is highly likely to need an automatic, I have to question Motability's fitness for purpose. Unfortunately, I realise that an investigation by MPs would be politically unpopular. As the cars would appear to be unfit for the use of the disabled person, I suspect that they are in fact often being rented by the family of the disabled person. *</p> <p>I believe family use of the vehicle, particularly where there is only one car in the family, is both frequently occurring and entirely reasonable. Despite this, I note that the rules surrounding the Motability car's use state that it is solely to be used for the needs of the disabled person. Again, going back to my point about ill thought out and unrealistic legislation, this must invariably criminalise the disabled person through no fault of their own. I can only hope that this is a situation which is addressed by the new benefit and related legislation.*</p> <p>As a final point, I would like to highlight that loss of the current Disability Allowance benefit has a 'knock-on' effect not only on other benefits and access to a car but on access to other benefits such as a Disabled Person's Railcard, Blue Badge, etc. Possession of the last one itself permitting access to further mobility-related benefits such as easy parking within Europe (excepting London) and free travel through (but not parking) the London Congestion Zone.*</p> <p>The loss of any of these may seriously restrict a person's mobility, independence and ultimately employment. Could I suggest therefore where the government does not feel it appropriate or possible to provide someone with the new benefit because of the money, they might indicate that a person is entitled to the benefits of having the new benefit other than the money? For example, paperwork could be provided stating a person's eligibility to have a Blue Badge, etc. but not to receive payment of the benefit. *</p>

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		<p>*</p> <p>Apologies for the length of this missive, but there are a number of ideas I felt needed to be highlighted. I am copying this to Mr Paice, my local MP, in the hope that he can help make the proposed new benefit fit with the government's stated aims on disabled access and employment. Best wishes</p>
EM551	13-Feb-11	<p>1.Your response: My wife has MS (Multiple Sclerosis) and can only walk slowly and for short distances. To go further she is completely dependant on her car fitted with hand controls. (Difficulties in dressing and starting the day mean that it is normally mid- morning before she is able to go out.) Having the car (costs supported by DLA) enables her to visit and care for her 87 yr old mother (still in her own home) and also to give support to our daughter who is partially sighted and has 7-month-old twins. Thus my wife's DLA enables her to remain active in the family, amongst friends, and do valuable community work.*</p> <p>2.Your response: It should continue to be paid to those living in a care home to enable them to have some independence and the opportunity to go out on visits and trips – which are always charged as extras – not included in basic fees.*</p> <p>3.Your response: Transport and mobility aids - Adaptations to the home - Additional washing of clothes due to incontinence accidents (also more clothes needed for the same reason) - Incontinence pads and other non-prescription medicines or items from the chemist. Paying cleaners or care workers to assist in running the home Replacement of crockery and other essential items following accidents – which happen more frequently due to MS Induced clumsiness.*</p> <p>Additional fuel / power costs for powering essential aids (e,g tumble dryer, recharging scooter battery etc) and heating the house to a necessarily warmer temperature for longer periods.*</p> <p>4.Your response: Having two rates is very arbitrary. The rate given should be determined by need, which does not fall into two convenient categories. There will be many people who need and deserve an intermediate award, of varying amount.*</p> <p>5.Your response: Automatic entitlement would save significant administration costs for the Government and reduce the considerable stress always arising when faced with an assessment. (For MS and some other conditions such stress can directly lead to relapses and worsening of the illness)*</p> <p>6.Your response: Being able to move about – around the home first and then to be able to get out and interact with other people.*</p> <p>7.Your response: Rely upon and trust the assessment of the specialist who cares for the disabled person. That specialist will have knowledge of and records of past fluctuations and their intensity and will be able to assess the probability and likely intensity of future fluctuations or relapses. Many GP's and non-specialist medical personnel do not have an adequate understanding of the less familiar causes of disability (e.g.) neurological conditions.*</p> <p>8.Your response: In determining the eligibility for DLA, the only reason for enquiring into aids and adaptations would be to confirm evidence already given in another part of the application. The report from the consultant should be adequate and so the question becomes unnecessary.*</p> <p>For most disabled people aids and adaptations are necessary but they are capital items and it is not reasonable to expect DLA to cover the cost.*</p> <p>9.Your response: The current form is appalling and deceitful in the way it seeks the same information in different ways. The task of completing this form is nearly always left to an 'expert form filler' because it is beyond the capability of ordinary people who are unwell. Why not consider accepting a video presentation or photographic evidence to support statements, verified by a third party like a passport photo? If the various cut-off points (or hurdles) were then stated briefly and clearly, the</p>

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		<p>applicant could simply sign against each applicable one and have this confirmed by an appropriate third party – like a passport photo. *</p> <p>10.Your response: Video or photographic – see above. The applicant or their carer could provide this and have the doctor or another professional sign confirmation – just like a passport photo.*</p> <p>11.Your response: A face-to-face 'interview' would be disastrous for many disabled people, particularly those with neurological conditions because the inevitable stress involved could trigger a relapse and make them ill for some time. Other forms of disability can also have psychological consequences, which could cause an interview to be counterproductive. It would be far better to have confirmation of a condition from a reliable professional who knows the applicant personally.*</p> <p>12.Your response: Some cases may require review but in many cases a review would not be helpful to either party, particularly when the condition is known to be irreversible. A review is only truly justified if there is prior evidence or significant suspicion of mis-claiming.*</p> <p>13.Your response: By being polite, positive and above all fair. It should not be necessary to have to complete the whole process as if starting afresh. The applicant needs to have complete confidence that a different civil servant is not going to remove from them components of PIP that they still need and have previously been adjudged to be entitled to. *</p> <p>14.Your response: Clarity! State the hurdles or trigger points that have been set and what evidence is suitable to support a claim against it.*</p> <p>15.Your response: Why should bureaucrats be needed to fill in forms for people!? Make the process straightforward and transparent and then the majority of applicants or their families could cope. If they can't, the process is over complex.*</p> <p>16.Your response: No. There should be a separate fund to give assistance with the capital costs of aids etc.*</p> <p>17.Your response: *</p> <p>18.Your response: The DLA award letter is useful for blue parking badges, train concessions etc. This should continue.*</p> <p>19.Your response: It would cause a lot of stress filling in more forms with the same information and potentially repeated invasions of privacy. It would discourage many claimants to apply for other benefits. The objective should be to have an effective passport for all entitlements – perhaps a certificate included with the award letter.*</p> <p>20.Your response: See above*</p> <p>21.Your response:*</p> <p>22.Your response:</p>
EM552	13-Feb-11	<p>Individual Response to DLA consultation from [REDACTED] (disabled wheelchair user)*</p> <p>1. Lack of mobility, lack of transport facilities, societal negative attitudes towards people with disabilities. Employers not adhering to the DDA now Equality Act and instead simply ticking boxes to satisfy audit returns – it's all pretence they don't want disabled people in the workplace they tolerate them because they have to. I will however continue to work for as long as I can even though I face discriminatory comments on a daily basis.*</p> <p>2. Regular payments so that some stability is maintained. Please keep Motability as I would be isolated completely without this help.*</p> <p>3. Heating, purchasing aids and adaptations, servicing of aids and adaptations, transportation costs, cost of therapies – I use oxygen therapy and see a chiropractor to keep me going but these are extra costs not on NHS provision. *</p> <p>4. • Will having two ...? No it will make it more confusing, more stressful – it's hard enough already – don't make it intolerable. • What, if any, ...? Confusion, unnecessary complications, worry, stress, creates paper work mountains, increases administration costs.*</p> <p>5. People with diagnosed incurable long-term conditions should not be</p>

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		<p>put through continual stress so yes automatic entitlement for this category is recommended. If the DVLA can categorise significant disabilities then surely the DWP can do the same. I have MS and the symptoms fluctuate but my mobility doesn't and I'm confined to a wheelchair – it's a long term incurable and debilitating illness with no chance of a reprieve. *</p> <p>6. Provide finances for them to obtain the services they deem they require. For example as well as other costs I have extra costs in term of laundry as I have continence problems which I need to cater for especially as I want to continue to work for as long as I can. Integration into society, transport to get to work or just to get outside the house to the shops, feeling a sense of belonging, accessing facilities, accessing hobbies. I live in an isolated village and without motability provision life simply would not be worth living. *</p> <p>7. Even with fluctuating conditions some symptoms persist – they come and go but that doesn't mean they do not still require support as employers are not amenable to flexi-time or time off for disability leave they count it as sick leave and the question capability and then make you take early retirement on ill health grounds – they hound you out of employment, of earning power and out of society - they would rather not see us in the workplace.*</p> <p>8. Yes for example because I work I could not get any help towards the costs of aids and adaptations. I work full time but when I first became disabled I was in hospital for a lengthy period and then had another lengthy period trying to get well at home and had to pay for carers to come in and help me at £16 an hour times 4 times a day for 6 weeks. My diagnosis meant that I was left with a progressive debilitating disability with major mobility problems. I was off work for 6 months which meant I was put onto half pay. So this affected my ability to pay my mortgage, to pay for the carers I needed, to pay my children's university costs, to pay for heating and it left me without the ability to buy aids and adaptations. Even when I pointed all this out to social services I was still turned down for any support because I worked and my earnings were considered to be over the amount where any financial help could be offered! I'm part of that middle class bracket who pay Taxes etc but miss out when trying to get any help – I'm not sure where the government thinks this extra money comes from as I certainly have no savings and I've worked hard since I was 15 years old. I was desperate as I needed adaptations to help get my live back on track and get back to work. A disability charity told me about DLA and I applied and it literally saved my life as although it is a limited amount of money it helped alongside having to sell off some of my belonging I was able to get a motability adapted car, a second hand wheelchair, a second hand stair lift and a second hand ramp to get into and out of my house – and I was free again. Until I got the award I had contemplated suicide as I've always been a workaholic and the thought of never getting back into my employment left me devastated – the DLA award saved my life.*</p> <p>• What aids ...? This is different for different people and dependent upon the severity of the disability - I needed an adapted car, a stair lift, a wheelchair, a ramp. I would also have liked help adapting my bathroom so that I could get into and out of a bath. I would have liked help with my increased heating bills, with obtaining a Zimmer frame, walking sticks, hand rails. Being disabled has financially drained me.*</p> <p>• Should the assessment ... ? The problem is that some adaptations require servicing especially when you can only afford to buy them second hand so it is not simply about the purchase costs it is about the maintenance as well. This is an on-going concern for me as all by aids and adaptations are second hand (apart from the motability car). I'm not sure if they are electrically sound but what else could I do I couldn't afford to buy new and can't afford to get an electrician to check them for me – risks and benefits have to be balanced so I take risks to survive.*</p>

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		<p>9. Allocate someone to help fill out the forms as from my experience I found it extremely difficult filling out a lengthy form at the same time as trying to come to terms with my disability and inability to walk. I felt abandoned by a system I had paid into all my life as it seemed as if because I worked and earned a good salary I was being penalised. *</p> <p>• How could we make the claim form easier to fill in? This was a strange experience for me because even though I had suffered a critical incident I didn't want to label myself as disabled so when filling out the form I was trying to prove that I could do more than I actually could. I wanted to put down how I was on my best days but even my best days were hopeless – my legs just wouldn't work and although I tried desperately to walk I kept falling and injuring myself. Plus although I am an intelligent person (with a doctorate) my mind couldn't fully appreciate my body's altered state – I simply didn't want to accept the new limitations being placed on my life and liberty. I didn't know how to fill the form out, I've never been on benefits of any kind before. I couldn't face the length of the questionnaire but I needed help and that's when an occupational therapist put me in touch with the disability charity and a kind volunteer said that I had to "tell it like it is".*</p> <p>• How can we improve ..? I don't just want leaflets, I don't want patronising health and social care professionals, I want someone who really knows and understands what it is like to be disabled – someone who has empathy and can "tell it like it is" in the same way as the disability volunteer advised me.*</p> <p>10. The best information comes from the person with the disability or their carer. I'd fail any meaningful daily living activity criteria and yet I have now been back to work full time for two year without any further time off. But it is extremely difficult and although access to work help in reasonable adjustments – this is interpreted differently by my employer – they tick boxes but supply little and make life intolerable at times. I apologise if this seems negative but it is my experience of disability. I'm not keen on having young seemingly uncaring health and social care professionals or older jaded health and social care professionals offering cognitive behaviour therapy to promote positivity as this is not going to repair the damage to my spine to help me walk again. The voluntary organisation staff, in my opinion, were the ones who helped me most but as their funding has been cut these might no longer be available to help in assessments. Alternately a hospital consults report or a GP report on the condition should suffice. *</p> <p>11. NO definitely not • What benefits ..? I did not experience any benefits from healthcare professionals I experienced patronising, uncaring, stereotyping attitudes for example when I asked for help with a stair lift I was inform by one professional that they don't recommend stair lifts as it was dangerous for people with my condition – well let me tell you crawling up and down the stairs is much more dangerous and made me wonder what had happened to the concept of personalised care rather than being slotted into a homogeneous grouping.*</p> <p>• Are there any ...? YES I have no faith in their ability or their care provision and I don't want them coming to my home to TELL ME WHAT TO DO or WHAT I SHOULD BEING DOING and WHAT I SHOULDN'T BE DOING. If I need help I want to go to their workplace I don't want them in my home telling me I'd be better off in intermediate care and then telling me that because I earn a salary it will cost me £250 per week – NEVER AGAIN – II felt abused by them - I'll go to Switzerland before I'll face that rubbish again.*</p> <p>12. • What evidence ..? This depends upon the condition for example my condition is going to become increasingly debilitating with no opportunity of any significant recovery – this is a fact as there is no known cure. So this being the case I can see no reason to being subjected to continual reviews that are going to say the same thing as I'm not going to get better I'm going to get worse. So unless the reviews are based on my changing</p>

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		<p>needs and the adaptations and aids I need then I see no point of these. For others where their condition may be more temporary or where there is a chance of improvement or recovery then they can be assessed at regular interval ranging from 3 months to a year.*</p> <p>• Should there be different ..? Yes long-term conditions mean little chance of full recovery and indicate people who need support.*</p> <p>13. This is difficult if the changes are more debilitating. For those who have not been diagnosed with a long-term condition reviews can be undertaken at regular intervals to assess progression or remission or recovery so the personal independence payments can be adjusted accordingly.*</p> <p>14. "Tell it like it is" plain non-jargonised language which is short and snappy rather than long and complicated.*</p> <p>15. No smacks of a big brother mentality If so, what would ..? Avoid this paternalistic approach.*</p> <p>16. I sold off my belongings – sad letting go of treasured possessions – but it was the only way for me to buy my second hand aids and adaptations, I received a one off payment for a ramp but it was a mere fraction of the cost I had to pay out – (causing me to sell more of my belongings) but I guess something is better than nothing.*</p> <p>17. The differences as I see them are the need to take into account the child's viewpoint, if possible, and not simply the parents or the carers viewpoints – that way the children have a say in what happens to them - some control over their lives. But there are also transport costs, laundry costs, activity costs, fashion costs so that they fit in with friends and trends, if true engagement and inclusivity is going to become any kind of reality.*</p> <p>18. It helped me get an adapted car, a road tax disc, a blue badge, an exemption certificate for medications (even though I can't actually get the disease modifying drugs I need as it is age based even though the professionals say it's not someone should do some research on how many people over 50 actually gain access to these), a disability train travel card, a reduction in council tax, and help from Access to Work.*</p> <p>Are there things we can do to improve these passporting arrangements?*</p> <p>I obtained all the above with great difficulty as nobody tells you what is available you have to do the groundwork yourself and it is an exhausting experience. So I suggest this information is supplied to people who have been successful in being awarded DLA PIP.*</p> <p>19. Devastating as some of these services help to maintain a presence in society and promote independence, autonomy and self management.*</p> <p>20. Simplify the process by only undertaking reviews on people not diagnosed with a long-term debilitating conditions.*</p> <p>21. Not sure yet as it is still an emerging area.*</p> <p>22. I like many other disabled people want to continue to exist within society but to do this we need some help. The government needs to tighten up on reasonable adjustments as they are not always interpreted in the best interests of the disabled person. There is a lot of face value work being undertaken, but the reality for disabled people remains difficult and everyday becomes a battle which I consider to be an unhelpful way to live life.</p>
EM553	13-Feb-11	<p>1. Your response: An almost total lack of money for respite care. Only ILF funding as enabled us, the abused carer, to buy desperately needed care. So I hope this seemingly unnecessary reform will not in any way effect ILF funding(our handicapped sons only glimmer of light at the end of a very dark tunnel)*</p> <p>2. Your response: DLA seems to a well targeted benefit for the genuinely disabled or handicapped. Except for mobility that does not consider that handicapped people are incapable accessing public transport(can't get on/off at correct stop, read destinations and numbers. No road sense), even if they can walk!*</p> <p>3. Your response: My son is severely mentally handicapped. Therefore, he cannot earn money. He needs 24 hour care, provided by us(his</p>

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		<p>parents) so that he can participate in society, and lead an independent, full, and active live. I imagine that the only disabled/handicapped people that have full and active lives have it provided by their friends and family. I dare say there will be a lot less of them after these changes have made them poorer.*</p> <p>4. Your response: It will be very very difficult to qualify for the top rate. So many people that need the top rate won't get it.*</p> <p>5. Your response: Yes some health conditions should automatically qualify. And people that have been assessed as severely handicapped for live should have to suffer the humility of reassessment.*</p> <p>6. Your response: 1. Warmth, food and water like everyone*</p> <p>2. Care and attention like everyone*</p> <p>7. Your response: Sympathetic assessment of the varying conditions.*</p> <p>8. Your response: Take them into consideration*</p> <p>9. Your response: Most people that apply for benefits think that the person on the other side of the desk is there to disallow their application. This situation will be exasipated by the knowledge that this is a cost cutting exercise. *</p> <p>10. Your response: GPs written assessment. Government employed assessors are deeply and justifiable distrusted.*</p> <p>11. Your response: In the case of the mentally handicapped it is essential to consult with workplace care workers and GPs. It should also be remembered that successive governments have handed the care of these people to friends and family. These people are therefore the only true experts on the problems and extent of their condition. Social workers and healthcare professionals are novices.*</p> <p>12. Your response: If the condition is permanent. Obviously, no reassessment is required.*</p> <p>13. Your response: reassess conditions that are likely to change*</p> <p>14. Your response: Provide a citizens advice professional to help these vulnerable people with their application.*</p> <p>15. Your response: See 14. But apply before it closes.*</p> <p>16. Your response: Yes*</p> <p>17. Your response: Read the last 2 years reports, and be nice.*</p> <p>18. Your response: Its been very important. Seems a shame to abandon all that knowledge, and swap it for the inevitable 2 years of chaos and incompetence.*</p> <p>19. Your response: People will lose essential benefits. In our case the only thing that as partly provided, your visionary independent, full and active live for our son has been ILF funding.*</p> <p>20. Your response: Consult people closest to the claimant. Give more weight to their opinion. They know.*</p> <p>21. Your response: Carers should not be abused.*</p> <p>22. Your response: People need to be assured that this is not just a cost cutting exercise, and that some good could possible come out of it!!</p>
EM554	13-Feb-11	<p>Please find attached suggested answers to consultation questions. With thanks,*</p> <p>1. Your response: Because of progressive multiple sclerosis I am now virtually housebound and confined to a wheelchair. Contact with the outside world is limited and my hearing and brain are not up to long conversations. This condition must apply to many in my circustances. In my case MS was diagnosed in 1996, 15 years ago.*</p> <p>2. Your response: I rely on DLA for financial assistance for independent living at home alone; it allows me to have personal carers, to have help in the home and in the garden. I live in a remote rural area so travelling costs are expensive. I should be devastated by any loss or diminution of DLA. It is very important to my independence and morale. Progressive MS is a cruel, debilitating illness and I am thankful to DLA for the financial help which deters a bad stuation from being worse.*</p> <p>3. Your response: High costs of adapting the home and garden to disabled and wheelchair access; cost of wheelchairs and their</p>

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		<p>maintenance; installation of bathroom and toilet facilities; transport to and from home; cost of payment for care, domestic and garden services which we are unable to do because of MS. I shop and communicate online and it is crucial that my computer is maintained, renewed or repaired quickly so additional costs are necessary. Those MS patients without online facilities will have other costs to get their shopping and communicate.*</p> <p>4. Your response: I have been grateful for receiving the two rates for the care and mobility components. Loss or diminution of either would be severe.*</p> <p>5. Your response: Progressive MS should mean an automatic entitlement to the benefit because there are so many implicit additional costs. . *</p> <p>6. Your response: Support in permitting people to lead independent lives with dignity, if possible in their own home. To me the most essential activities are exercise, eating, reading, communication and sleeping. Heartfelt thanks to my GP, district nurses and NHS for welcome help and advice always available.*</p> <p>7. Your response: By recognition that conditions are variable and fluctuating and that in the case of MS 'improvement' may be only temporary followed by relapses.*</p> <p>8. Your response: Yes. See response in 3 above. Aids and adaptations are updating continually, as are the needs of patients with a progressive illness such as MS. *</p> <p>9. Your response: Forms should be multilingual and the benefit widely publicised in appropriate media and places. Filling in the DLA forms was long-winded and complicated and, if similar need to be filled in again, help should be offered unless they are clarified and easier to understand.*</p> <p>10. Your response: Length of time of disability and its progression. Probably one's GP or appropriate specialist*</p> <p>11. Your response: Ability to communicate between professional and patient.*</p> <p>12. Your response: If a new treatment were found for an 'incurable' condition reviews of need/suitability would be highly desirable.*</p> <p>13. Your response: See response 7 above. Changes of circumstances should be reported as requested at present for DLA*</p> <p>14. Your response: The best advice would be notification that patients with existing DLA are exempt from need to complete Personal Independence Payment forms.*</p> <p>15. Your response: Good publicity.*</p> <p>16. Your response: In my case, by DLA, other grants, Social Services, personal expenditure.*</p> <p>17. Your response: I don't know*</p> <p>18. Your response: Yes, very helpful in enabling and advising further assistance*</p> <p>19. Your response: The implications would be unfortunate in that help available might not be known about.*</p> <p>20. Your response: As many as possible without prejudicing patient confidentiality *</p> <p>21. Your response: don't know*</p> <p>22. Your response: not at present</p>
EM555	13-Feb-11	<p>Dear Maria Miller, *</p> <p>I am writing to you both as the recipient of higher Mobility and middle rate Care components of DLA because I am permanently in a wheelchair due to M.S. and also as a Disability Qualified Panel Member of The Appeals Service for DLA and AA cases. Consequently, I have both my own experience of being wheelchair-bound for over 15 years and that gained by my long involvement with tribunals since the inception of DLA in 1992. I would agree from both points of view that the present system is not perfect but it does have some definite advantages over previous</p>

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		<p>methods of assessment by its consideration of the "social" model of disability as well as "medical" one. For the first time, assessment was based on the effects of the disabling condition on the individual rather than on the medical condition itself, as is reinforced by the inclusion of DQPMs like myself on appeals tribunals. In my opinion, the result is a much fairer approach to disability needs and benefits and I am extremely worried that your emphasis seems to be very much on saving money rather than being "fair" with regard to attempting to create the "level playing field" for which DLA was originally intended. *</p> <p>To me, the consultation period seems rather short for something that is so very important to a large number of people with disabilities (please note that this is the usual term used by the disability movement to emphasise that you are dealing with people, who happen to have a disability). Has there been any attempt to contact every single person on any level of either component of DLA to ask their opinions? Given the huge database held by the DWP, this should be relatively easy and would certainly give everyone a chance to participate. It needs to be borne in mind that many long-term recipients may not have had sufficient educational opportunities because of historically insufficient provision before the days of the Disability Discrimination Act to argue their case adequately and it should certainly not be assumed that everyone can afford computers to respond by e-mail. It just so happens that in my previous life I was an English teacher but had to take early retirement on health grounds when at the height of my career, as Head of English at a large comprehensive in South London. However, if the "consultation" period was longer and <u>all</u> benefit recipients were approached, it would counter the impression given that this process is at best an unseemly rush and at worst sham democracy.*</p> <p>What exactly do you mean by "a realism" with regard to input from people with disabilities? The only reality that most will understand is how it compensates to some extent for the negative impact of their condition(s) on their quality of life. The way in which the term is used by you is clearly financial and ties in with the openly stated target of saving 20% of this benefit, presumably from those who will no longer qualify under the new system. Apart from the further reference to the amount of money involved ("one of the largest benefits that's paid in the UK"), I am concerned about the comment that there is a need to make sure "it's getting to the people who need it most". In other words, it is clearly assumed that a significant number of those currently in receipt of DLA would lose entitlement under the new system as there is certainly no intention to increase the money available. If the Disability Alliance's estimate of 380,000 recipients taken off benefit (quoted in the BBC news article of the 8th of January 2011) is anywhere near the truth, this is by any standards a huge number. Neither should you assume that the number of applicants for DLA is finite: although medical treatments are constantly improving, we are also seeing an increase in diagnoses of some major disabilities which would appear to have a possible environmental explanation, e.g. autism. *</p> <p>However, there is absolutely nothing to explain how your 20% figure is reached and it certainly doesn't include the not insignificant amount lost by DWP errors, largely due (again in my opinion, as I would not presume to talk for other tribunal members) to the extreme pressure put upon Decision Makers to make decisions quickly. As I said previously, I am sure that most DLA recipients would agree that this benefit is not perfect but in many ways it for the first time tried to see people with disabilities as human beings rather than statistics. If you wish to save money, the first port of call has to be inefficiencies in the DWP itself. All too often in my experience the tribunal finds for the appellant because the initial decision has been made in ignorance of material facts which could have easily been avoided if the Decision Maker had the time required to seek further medical evidence rather than have to rely on leaps of faith from the</p>

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		<p>Benefits Agency Medical Services or more recently the private Atos agency, both of whom frequently seem to me to be very aware of who pays their salaries. I am convinced that a good deal of money could be saved by allowing Decision Makers more time on each case (or, heaven forfend, by employing more of them!) and looking again at the effectiveness of medical "advice" from third parties, especially when expensive contracts are involved.*</p> <p>Finally, in the December 2010 interview with Able Magazine you talk of the "very subjective" nature of the DLA assessment system. To me, this sounds as if you are thinking of going over to the sort of system used in Incapacity Benefit claims, i.e. based solely on a formulaic box-ticking questionnaire "examination" that doesn't really allow for variation in conditions and is frequently not even administered by a qualified doctor! This of course would mean the removal of the input from people with knowledge of disabilities, thus ignoring the social as opposed to the medical model of disability. I imagine it would also logically extend to the removal of the DQPM in appeals, who were included precisely to bring in a different way of looking at disability, according to my District Judge. The further reference to the lack of any "very good system of reassessment within the present process" would suggest built-in regular reassessments along similar lines with all the resultant appeals and very real financial worries and stress for those claimants involved on top of having to deal with all the problems caused by their disabilities. All in all, I can't really see how you are so sure that you could save 20% of the cost of this benefit: I might be able to understand if I knew the basis on which you have reached your conclusions.*</p> <p>I make no apologies for the length and complexity of this submission as your decision could have a seriously adverse effect on my standard of living and that of my many acquaintances in a similar position. For the sake of everybody involved in this matter, please give more time and thought to your approach here as I doubt that any disabled people were involved in formulating these proposals: I believe even Iain Duncan Smith in his hunt for the elusive Universal benefit did not think that DLA would change in any way. People without the specific disabilities in question cannot possibly understand the wider ramifications of these conditions: indeed, when talking to someone with M. S. in a tribunal, I always explain to them that I also have the disease but know enough about it to realise that no two sufferers have the same experiences. It also crossed my mind that you might have wondered how someone on such a high level of benefit was able to produce such a lengthy piece of writing. However, I have to use a voice recognition system because of limited typing ability and this has actually taken me 4 days to complete! If you feel that I could produce further useful input, please do not hesitate to contact me by e-mail. Thank you for taking the time to read this.</p>
EM556	13-Feb-11	<p>1. Your response: there are several both physical and mental issues that prevent disabled people participating in society, as due to the nature of their disability every day is a challenge to them. With mental difficulties the changing world around them is a challenge each and every day. Ensuring the right support and care that disabled people get is the key to them having full and active lives. Each disabled person is an individual who needs more or less support on different days.*</p> <p>2. Your response: The current system works well but the forms for people with mental issues should be reviewed, as they may not look on paper as needy as a person with physical needs, but even the slightest change in their surroundings can cause great distress.*</p> <p>3. Your response: Every disabled person incurs extra costs, as this can be regular more frequent trips to the hospital for appointments, equipment needed to support them in their daily lives, help and support from carers etc.*</p> <p>4. Your response: 2 rates will be fine if administered correctly. But you need to consider that a person with a long term illness may have good</p>

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		<p>days and bad days. A person with mental issues may be able to move around well, but have great difficulties in other ways. I.e. problems when going outside with the changes around them, but they can walk perfectly well.*</p> <p>5. Your response: Some health conditions should mean you are entitled to an automatic entitlement. If a person has been diagnosed with a condition or impairment, a process of consultation with a specialist will have taken place prior to the diagnosis been made, and in my experience a specialist does not give a diagnosis of a condition without further investigations over a period of time.*</p> <p>6. Your response: This is a difficult question to answer as each disabled person is an individual and see's the definition of a full and active life differently. However, the basic things such as been able to feed yourself, wash yourself and dress in my view are the most important.*</p> <p>7. Your response: A person with a variable and fluctuating condition will always have good days and bad days and the way an individual copes with their individual condition could be very different. If a person manages their condition well they should not be punished for this with a reduced level, against a person who doesn't manage their condition well.*</p> <p>8. Your response: Any aids should be considered as the funding would have been found at some point to provide the person with their aids. Care must be taken to ensure people do not get greedy and apply for more than they actually need.*</p> <p>9. Your response: I think the current claim form and information is fine. As I have stated earlier a lot of emphasis is put on physical actions i.e. walking etc.*</p> <p>10. Your response: The person who carers or supports the disabled person would be a good starting point for a clear assessment and a very real day to day view.*</p> <p>11. Your response: This could be difficult with some peoples conditions, as if they have a mental issue and they are in a good phase the outcome of the meeting would be very different to if they met with them on a bad day, and the same for people with fluctuating conditions.*</p> <p>12. Your response: If someone has a diagnosed condition, a specialist has been involved to ensure the correct diagnosis has been made. If this is for a long term condition the frequency of review could be reduced. If a person has a fluctuating condition this could be looked at on a more regular basis, or any changes to be updated by the individual.*</p> <p>13. Your response: Other than frequent reviews, I am unsure how you could* improve this, as you will always have this situation as it is down to individuals to respond.*</p> <p>14. Your response: If changes are made to any benefits or process people should be informed and included as part of the process.*</p> <p>15. Your response: At the point of diagnosis of a condition a person could be informed of what they are entitled to. All of the services and support available are greatly over stretch today and any help or advice is useful in these circumstances.*</p> <p>16. Your response: Unsure as I have not had to use this process before.*</p> <p>17. Your response: Children need a lot of support from carers and people around them. If they have mental issues they may be able to walk well, but need support when outside etc.*</p> <p>The support provided for a child with special needs in a main stream school is a lot less than that provided in a special school, and is not sufficient to have a full and positive impact on the individual needs, without extra support at home and via out side providers. I.e. I use my son's allowance to pay for a private tutor out of school hours to support and help him with his learning difficulties. Without this he will not have improved and would now be in a special school.*</p> <p>This would be a far greater cost than the current allowance that I receive for him to support his difficulties.*</p>

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		<p>18. Your response: DLA have been good up to now. A sign posting service could be useful, so that people are made aware of other areas of support they can access when faced with a disability.*</p> <p>19. Your response: The correct support that is needed across the board to support a disabled person on a daily basis may be lost due to the lack of continuity. The current process works well and ensures the correct support can be obtained and with minimum stress of filling out forms and applying for several different benefits.*</p> <p>20. Your response: The current service involves completing one form which is shared with the relevant areas i.e.: individual and carers allowance. Any other services are informed with the current system.*</p> <p>21. Your response:*</p> <p>22. Your response: The benefit should still stay non-mean tested and as cash benefit, as it is important to ensure that those who can or do work are not penalised for this even though they cope on a day to day basis with a disability. Consideration should be given when breaking down and looking at the benefits for children, as the help and support they get as a child will in turn have an impact on how independent they will be as adults.</p>
EM557	13-Feb-11	<p>1. Your response: There are many problems from the simple and obvious to the complicated and individual - such as access to buildings; access to public transport; lack of specialist equipment; to the more financial things such as inability to get life insurance and expensive equipment. The everyday barriers for me are adaption's to building that are treated as one size fits all, lifts that do not fit heavy electric wheelchairs such as mine, the extra cost of having a disabled member of the family, paying for heating, extra washing of soiled clothes. *</p> <p>This question is far too general as each person who has a disability will different need help and will want to achieve different things in life. One size does not fit all.*</p> <p>2. Your response: Why on earth would you want to reassess people who have a terminal genetic condition? My award would have to be reassessed but my genetic condition will not change. I object to more tests, more form filling and more doctors, god if life isn't hard enough as it is.*</p> <p>3. Your response: High heating with limited mobility, lighting, washing of clothes, personal carers, special diets, transport and adapted vehicles, adaptations to the house, extra maintenance to the house due to damage from electric wheelchairs, maintenance of specialist equipment, extra equipment, replacement of worn equipment and so on...*</p> <p>4. Your response: I can't see that it will make any difference as DLA already has different rates.*</p> <p>5. Your response: All should be individual as the severity of some genetic conditions varies widely. Mine is severe others who have this have only a mild form. Consult the professionals before making a judgement.*</p> <p>6. Your response: This is two questions; prioritise support (1) and essentials for everyday life (2).*</p> <p>(1) Good question how do you prioritise support? Answer – through a nationwide system and not a local authority system. If I move house to another council district I am not guaranteed the same support I receive now. I am trapped and unable to move out of this area for the fear of lack of support and no organisations to turn too.*</p> <p>(2) Essential everyday life is a wide combination of many things, from good emotional support to good health support, carers who can and will do the wide varied tasks that we need help with. Access to physiotherapy and occupational therapy all the time and not just a few weeks then send you away to fend by yourself. This country treats the mentally handicapped persons far better that the normal intelligence physically disabled persons. If should be services for all not just for some.*</p> <p>7. Your response: There is always difficulty in finding happy mediums</p>

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		<p>with this, I can only see only way forward and is to continually assess.*</p> <p>8. Your response: Absolutely not, my wheelchair beaks downs, my equipment breaks and my adaptations become obsolete as my condition deteriorates. How can you reduce my financial support because I have a toilet frame or wheelchair, or and adapted car. This would amount to penalising me for having equipment that not only allows me to participate in general society but sustains me living in my own home. Without my aids I would need 24 hour care. It would people off seeking adaptations if they felt they were going to be financially penalised for doing so.*</p> <p>9. Your response: Applications could be made with the help of advisors at centres or they come to the house. I go no help; these forms are long and complicated. Online applications could help and information on the internet.*</p> <p>10. Your response: I believe that it should be consultant lead or a doctor who is not your general practitioner. I have no problems at be reassessed and neither would any genuine claimant. No self diagnosis.*</p> <p>11. Your response: So long as the healthcare professional has experience of the area of your medical condition then it shouldn't be a problem. Like I said before a genuine claimant would not object to face-to-face meetings, however there could be difficulties with someone who may have serious mental health problems.*</p> <p>It would be inappropriate to make people travel long distance to be assessed.*</p> <p>12. Your response: The frequency should directly relate to the severity of the condition and its' known outcomes/prognosis. The reviews should be fair and as individual as a care plan.*</p> <p>13. Your response: Constant reviews for conditions where people could recover or significantly improve.*</p> <p>14. Your response: Information on the time scales and what is expected should be standard. Possible outcomes of certain conditions etc should be provided. A helpline to ask questions about the questionnaire etc.*</p> <p>15. Your response: One assumes this is about people who either no longer need the claim or have deteriorated and need more help. A telephone service should be available, avoiding long form filling and having some system in place such as an amnesty for people who know they should not be receiving these benefits.*</p> <p>16. Your response: Interesting question. Funding of aids and adaptations is so varied throughout the country that we truly live in a postcode lottery. We have to save every spare penny to buy things, my partner has had to make specialise equipment, charities have provided assistance with repairs when manufacturers stop production or refuse to repair their own equipment; NHS and social services provide equipment and I've even borrow equipment from a care home. Most disable people do without some aids and adaptations as they cost so much and often fail to useful. Manufacturers charge such high premiums for specialist equipment that broken equipment is almost impossible to get repaired at reasonable cost. One off payments are of little use to the majority of us who need equipment maintained all the time. One off payments for the initial aid does not help when it breaks or needs servicing or no long meets my needs.*</p> <p>17. Your response: I don't feel in a position to answer this.*</p> <p>18. Your response: You could actually write to us and tell us what else we are entitled to other than my blue badge and a few home insulation things. Heating allowance would be nice.*</p> <p>19. Your response: More problems more form filling in, but hey what are we entitled to? *</p> <p>20. Your response: I was under the impression that DWP, DLA, Job seekers etc was under the same umbrella anyway. Maybe a register from doctors to help with conditions but what exactly do you want?*</p> <p>21. Your response: It doesn't seem too bad as it is*</p> <p>22. Your response: My serious concern it that it could be perceived the</p>

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		<p>more you struggle to more you get and that if someone who uses adaptations or aids will not be entitled to the same because these artificial item assists them in living with dignity. *</p> <p>Should someone who uses and electric wheelchair to get about be penalised for not using a manual wheelchair? What about being able to transfer without a hoist, are you going to penalise for that?*</p> <p>Just because someone has the use of life changing equipment should not disqualify them from the same financial benefits as someone who does not have the equipment or chooses not to use it (and believe me I have met people who choose not to use equipment).</p>
EM558	13-Feb-11	<p>Preamble We are responding as individuals with a grown-up disabled daughter, living independently. We also have personal knowledge of a number of disabled children and young people, and the problems encountered by their parents.*</p> <p>Comments about the Reform Process Although it is understood that there is a perception that there are many 'fit' people claiming Disability Benefit, and that the current profusion of benefits is confusing and inefficient, it must also be understood that there are many genuinely disabled people who are now seriously concerned that their benefit will be cut. In order to re-assure such people and assist reform implementation, it is important that the reform process be implemented sympathetically.*</p> <p>It must be noted that current benefit level payments have been arrived at over a period of many years, allowing many of the less obvious effects of disability (e.g., sensitivity to cold, periods of intense fatigue) to be taken into account. *</p> <p>It is totally unrealistic to expect that all such effects of a disability can be picked up by one assessor with a tick box form.*</p> <p>Therefore:*</p> <p>The revised assessment process should start with new claimants.*</p> <p>Implementation of the new system should be on a 'step-by-step' basis. The starting point should be based on the current 'specific entitlement' but with plus/minus factors based on the new review process. This process should be such that for existing claimants, where benefits are to be decreased the onus of proof should lie with the assessor, not with the claimant. Also, there should not be a single assessor; the claimant should be able to call on his/her GP and other specialists before there are any financial changes. This transition process would decrease the possibility of major mistakes (along with attendant publicity) and re-assure claimants that they would not be subject to an erroneous and distressing change in income.*</p> <p>*</p> <p>1. Problems and Barriers.*</p> <p>Every disabled person is different and cannot be categorised meaningfully, e.g., some wheelchair users are almost immobile, whereas others are able to compete in the Paralympic Games. Also, local conditions have to be allowed for, e.g., closeness to shops, availability of drop curbs, hills/ slight inclines. Many disabled people suffer from fatigue and disturbed sleep patterns caused by pain and decreased stamina.*</p> <p>2. Which aspects of DLA should stay the same.*</p> <p>People who live in care homes still need an allowance in order to finance individual needs, e.g., aids that are not provided by the state, and funding for a social life outside the care home.*</p> <p>It should also be possible for someone to claim both carers allowance and DLA. The theory is that a disabled person cannot also be a carer. In practice many are, and need the extra finance to be able to cope without both having to move to care homes.*</p> <p>What are the main extra costs that disabled people face?*</p> <p>Domestic help (cleaners, carers) Cost can be very high.*</p> <p>Specialised wheelchairs and other aids and ongoing maintenance.*</p> <p>Heating of home*</p> <p>Transport e.g., Special Taxis, Specialised personal vehicles, where</p>

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		<p>buses are not accessible (cannot get to bus stop, cannot get on bus)* The New benefit will have two rate.....*</p> <p>4.a I don't know the answer so cannot comment.* 4.b Disadvantages to having two rates. If the new process results in a decrease of income hardship will result.* Should some health conditions ... mean an automatic entitlement to the benefit.* Where the health condition is sufficiently disabling benefit should be automatic as it does not make sense to go down to the detail of needs and circumstances.* How do we prioritise support.....* Independence is important but so is support, which will vary according to need.* Assessment must be based on 'average ability' and not what the claimant appears capable of on a 'good day'* *</p> <p>How can we best ensure that the new assessment ...takes account of variable and fluctuating conditions.* The 'best' way is for the claimant to stay in an assessment centre for several days. This will be costly and not a true representation of what goes on in the claimant's home. Alternatively the assessor could stay in the claimant's home for several days....????* Ultimately the assessor will need to be sensitive and sympathetic to the claimant's needs, and not be trying to meet cost cutting targets. Input from the GP and other medical professionals who know the claimant's limitations are important.* Should the assessment..... take into account any aids and adaptations.....* Yes, but it must be understood that obtaining and maintaining aids requires funding. It must also take into account the limitations of such aids in the claimant's environment, e.g., provision of drop curbs for a wheelchair user.* How could we improve the process of applying.....* We have no suggestions on this question.* 10. What supporting evidence.....and who is best placed to provide this?*</p> <p>Family G.P., other healthcare professionals, (Physiotherapist etc) , teachers/school staff, family, friends.* 11. An important part..... face to face discussions with healthcare professional.....* Benefits are that such discussions will give the assessor an additional dimension on the problems the claimant has to face but it is imperative that the healthcare professionals involved have personal, long term knowledge of the claimant's problems. * Difficulties are that this whole process will put additional stress on people who have already had a struggle to reach some sort of steady state in coping with their disabilities in daily life. * A quick interview with a stranger who has no knowledge of the claimant or his/her disabilities will be pointless unless the only objective is to save money regardless of need.* 12.How should the reviews be carried out?*</p> <p>- what evidence ...should be used to set the frequency of reviews* This depends on the disability. Review period should be set based on the recommendation of the claimant's GP.* should there be different types of review depending on the needs of the individual....* Definitely. The review for dementia and other mental disorders needs to be very different to physical disabilities * 13. The system.... How can we encourage people to report changes in circumstance.* By issuing a reminder letter at a time related to the next review (e.g., 80%</p>

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		<p>of the way through) which includes a S.A.E and questionnaire. However, the original assessment needs to take account of the nature of the reminder. Someone with a mental disorder (e.g Alzheimer's) may well simply ignore the reminder.*</p> <p>14. What types of advice ... are people applying for P.I.P likely to need.* Currently it is unclear to which agency someone needs to apply to get a particular type of assistance, e.g., walking aids (via physio.), wheelchair (via GP), Carers Support, Age UK for advice and information etc. It would be helpful if claimants could be signposted to appropriate agency.*</p> <p>15. Could some sort of requirement...* Don't really understand the question. It is surely self evident that claimants be helped to make best use of all resources at their disposal.*</p> <p>16. How do disabled people currently fund....* Currently waiting time and financial support for claimants needing assistance vary greatly depending on Local Authority, Local Health Service etc. This should be made more consistent. If using PIP for one-off costs would help, then let's do it!*</p> <p>17 What are the key differences that we should take into account when assessing children.* Key differences are the need to listen carefully to parents, and in particular, to recognise the perhaps unspoken need for parents to have respite, to spend time with each other and devote their attention to their other children.*</p> <p>18. How important or useful has the DLA been at getting.... Access to other services and entitlements? Are there things we can do to improve...?*</p> <p>Important but not fully effective.* Answers to questions 14, 15, 16 and 18 all highlight the need for joined up thinking to enable disabled people to access help available to them in a consistent way, similarly for the various support agencies to provide that help in an efficient and cost-effective manner.*</p> <p>19. What would be the implications for disabled people and service providers if it were not possible for Personal Independence Payment to be used as a passport to other benefits and services?*</p> <p>This would be a major problem for both. Disabled people would have additional forms to fill in, duplicating information already provided, thereby wasting time and increasing stress. Service providers would likewise have to set up their own assessment process, duplicating sections of the PIP process, thereby wasting their resources and funds. A 'lose/lose' situation.*</p> <p>20. What different assessments.....could be combined.....minimise bureaucracy and duplication.* We don't have a fully comprehensive view of all the agencies and assessment processes involved so cannot give a definitive answer, but 'joined up thinking' is vital to minimise bureaucracy and take cost out of the system without adversely affecting those who the system is in place to assist. *</p> <p>21. What impact could our proposals..... different equality groups. No obvious impact.*</p> <p>22. Is there anything else you would like to tell us about the proposals in this public consultation?*</p> <p>We are aware of considerable concern amongst people currently claiming DLA that they will lose their benefit and are at a loss to know how they will cope on a reduced income.*</p> <p>The revised assessment process should start with new claimants.* Implementation of the new system should be on a 'step-by-step' basis. The starting point should be based on the current 'specific entitlement' but with plus/minus factors based on the new review process. This process should be such that for existing claimants, where benefits are to be decreased the onus of proof should lie with the assessor, not with the claimant. Also, there should not be a single assessor; the claimant should</p>

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		be able to call on his/her GP and other specialists before there are any financial changes. This transition process would decrease the possibility of major mistakes (along with attendant publicity) and re-assure claimants that they would not be subject to an erroneous and distressing change in income.*
EM559	13-Feb-11	<p>Dear Sirs, I am a mother and carer for my son who has a learning disability. I am concerned about all the reported changes that are being discussed at the moment for people with disabilities and their carer's. If either of the benefits that we receive, DLA for my son and carers allowance for my self, are lost this would have a profound effect on my son's quality of life as it would most other families who care for a family member with a disability. Families like ours already live with a lot of stress, when we read reports of benefits to which we are entitled are to be cut by 1 billion pounds this causes a lot of anxiety about what the future holds. We voted for the conservatives believing that they understood the pressures that families with vulnerable members in their care have and that they would be protected against cuts. *</p> <p>PLEASE PROTECT VULNERABLE PEOPLE AND THEIR CARER'S FROM CUTS TO BENEFITS.</p>
EM560	13-Feb-11	<p>1. Your response: the society of "I cant do", to many people are taking the easy way out!! Everyone is able to something to an extent, yes disabled people struggle to do normal everyday tasks, but there are always ways to do things. As a disabled person and having fantastic parents who made me try everything as a child and did not treat me any different to my other siblings I have the strive to try everything in life, *</p> <p>2. Your response: *</p> <p>3. Your response: the main extra cost I have our things like grab handles, adapted kitchen equipment, extra things to help me do every day tasks. My car us a major extra cost – I have very expensive adaptations in my car which is essential for independent living *</p> <p>4. Your response: I think having two rates is a better system, it gives everyone a simpler system to follow. *</p> <p>5. Your response: I think certain disabilities that won't get better should be automatically entitled to the benefit, it should look at the individual needs but be given a basic benefit. Disabilities such as VI, spinal injuries or Cerebral palsy should automatically qualify. *</p> <p>6. Your response: take into account what they can do but how they do it. They may have different ways of doing things and may need different and more adaptations, than normal – down to the smallest of things. the essentials for everyday living are to get around, preparing food, general care issues. *</p> <p>7. Your response: regular contact with the person, talking to their GP, health workers as for reports over a number of days, weeks. *</p> <p>8. Your response: yes as long as it is taken into account that they use the adaptations. All aids should be included no matter how small they are – they are all their to assist a disabled person in life. As a disabled person I am finding out about my own adaptations by myself, so if I had someone to turn to advise me that would be good. Anything to make my life easier would be good! *</p> <p>9. Your response: I had no problem with filling in the forms, could be useful if someone could advise and offer support but this is normally from the CAB. Detailed information on the new benefit would be good in the form of a flow chart and several examples for different disabilities. *</p> <p>10. Your response: GP, some disabled people don't have care workers or links to social services so asking them for this information is not the best way. I think just asking the GP to write this (making sure they know who the person they are writing the report for) *</p> <p>11. Your response: this would benefit people that don't have links to such people. Some people do try to hide how they are not coping, so this could help them. I think if the person applying states a disability such as Spinal</p>

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		<p>injury or Cerebral Palsy, and the GP backs this up, is there a need for a meeting? I think when a person mental disability then I think a face to face meeting would benefit both parties. *</p> <p>12. Your response: I think that a face to face meeting and application form would be good if a review is needed. I think there should be different types of reviews for different types of disabilities. *</p> <p>13. Your response: stop the benefit straight away. The letters already ask if your circumstances have changed so the responsibility should be on the individual. *</p> <p>14. Your response: what the new benefit is. What it should be used for. What is the process and how long will it take (there is nothing major that needs to be changed in what the proposal are)*</p> <p>15. Your response: as a person that does not access any advice and support I think this would be good. I know there are many things I am missing out on – in terms of support and advice and would be good. I have no idea on the key features as I don't know what is already available. *</p> <p>16. Your response: I save up my DLA (as I am on no other benefit) and use this to buy things I need. There are several expensive things that would help me, but it takes to long to save up for them and in the meantime I need other things to assist my living I tend to struggle and do without so I on off payment would be good, *</p> <p>17. Your response: none all treated equally. *</p> <p>18. Your response: I have never been offered access to support or other services. This would be good if I could have access to thses services. *</p> <p>19. Your response: I have no comment to make on this issue *</p> <p>20. Your response: I don't know as I don't claim other benefits *</p> <p>21. Your response: as long as it supports the long term disabled it will be fair *</p> <p>22. Your response: overall I think it's a good idea as I know many people more able them myself who receive DLA. All I want to say is make sure it helps the people with a long term disability and supports them to lead a full and active life (including them working for a living if they can!!)</p>
EM561	13-Feb-11	<p>1. Your response: Increased financial costs e.g. living expenses, equipment costs. Physical barriers e.g. increasing lack of public toilets, access to the environment whether buildings or open space. It always seems that it is the individual's responsibility to research and claim a benefit or grant; central & local Government does not fully engage with the public about their welfare rights or help them to claim.*</p> <p>2. Your response: That it should remain a payment to help with the additional costs of disability.*</p> <p>3. Your response: In my case higher transport and heating costs. Funding of equipment etc. to make life more bearable e.g. wheelchair. *</p> <p>4. Your response: The existing DLA split did not cause me a problem*</p> <p>5. Your response: The payment should be for the extra costs caused by the disability. It would seem illogical to reduce a payment because the recipient had purchased an electric wheelchair which had reduced the need for a taxi to the shops.*</p> <p>6. Your response: By measuring and auditing how your proposals will improve 1) Health, 2) Personal Welfare, 3) Social Inclusion. These are the major concerns for the disabled person*</p> <p>7. Your response: The existing DLA already has a regular reminder to notify of a change in circumstances. To this could be added a random sample called in for more detailed examination. In addition any benefit under claimed should be backdated to when the situation changed.*</p> <p>8. Your response: No. How do you design a non-means tested allowance that allows for the wide disparity in costs and benefits of equipment and adaptations and the different individual purchasing power? *</p> <p>9. Your response: It always seems that it is the individual's responsibility to research and claim a benefit or grant; central & local Government does not fully engage with the public about their welfare rights or help them to</p>

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		<p>claim.*</p> <p>10. Your response: The medical team in the PCT and the Consultants used.*</p> <p>11. Your response: Another discussion is another cost to the Taxpayer. Sometimes it is difficult to find even healthcare professionals with experience of your disability. Probably this exercise will be put out to tender. However a private company will not employ specialists if there are insufficient cases to generate an adequate income stream. Will this mean that if you have a less "popular" disability you will have to travel further for your "discussion" i.e. centralised assessment? Bear in mind that attending existing surgery and hospital appointments is extremely tiring and stressful - Can you park? Is there an accessible toilet? Is there room in the waiting area for wheelchairs? etc. etc. Adding another layer of bureaucracy to this is not in the best interests of the disabled person. *</p> <p>12. Your response: Reviews should be by random sample unless there is evidence of fraud. The primary aim of the review is to see what further help can be given. To reduce costs those cases with static or degenerative conditions need not be reviewed. *</p> <p>13. Your response: Once again, random sample assessment. Increase liaison between all parts of the medical and social sectors. *</p> <p>14. Your response: Provide advocates to help in the process. Ensure they work for the claimant's benefit and not the Department's. *</p> <p>15. Your response: Yes. It must be free, accessible and impartial.*</p> <p>16. Your response: The benefit is paid to help us cope with the disability. Treat people as adults and the vast majority will act responsibly. Leave them to decide where best to spend the money.*</p> <p>17. Your response: n/a*</p> <p>18. Your response: DLA is a passport to a very limited range of benefits e.g. V.E.D. exemption. It seems strange that this does not include costs such as prescriptions and dental work.*</p> <p>19. Your response: Once again increasing their costs and reducing their social inclusion.*</p> <p>20. Your response: Increase the passport arrangements. Whilst receiving DLA your NI number should be "flagged" accordingly. This should be sufficient evidence for all private and public sector bodies to recognise your eligibility for access to their disability arrangements, grants and benefits. *</p> <p>21. Your response: no comment*</p> <p>22. Your response: I am worried that people in residential care will have their DLA cut. Are they now to be left just the option of sitting in a wheelchair and watching TV? The DLA is not a barrier to employment. Where did this idea come from? In fact it can act as a subsidy to the costs of getting to work. In conclusion I believe whether a person is disabled, less able or differently abled is not the point. There are costs to the individual over which they have no choice. Until now the taxpayer has made some contribution towards these costs. The PIP system proposed is a lot more bureaucratic than the existing DLA. I suspect that any projected net exchequer benefit of PIP will not be attained. If the benefits to the disabled are to be reduced, the Government will have to live with the social and legal consequences of their actions. Indeed, in cases where the State played a part in causing disability e.g. polio, compromised blood products, these proposals will be particularly noxious. It seems, yet again, we taxpayers will have to pick up the bill for another Government failure to use some "joined up" thinking.</p>
EM562	13-Feb-11	<p>On 11 February 2011, 45 Deaf people who communicate through British Sign Language and who are currently in receipt of DLA, met in the Derby Deaf Club to consider the proposed reform of DLA. Their views, comments, experiences and suggestions are summarized in the responses to the questions listed below.*</p> <p>1. the communication barriers between hearing people who speak but cannot sign and Deaf people who need to communicate through British</p>

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		<p>Sign Language • the attitude of hearing people to the communication barriers presented*</p> <ul style="list-style-type: none"> • the communication barriers produced in a society that presents information and services in written English and requires responses in written English and Deaf people who are not confident in written English and cannot receive and respond in written English• the communication barriers produced in a society that is now increasingly providing services through telephone and internet methods and which Deaf people cannot access• the communication barriers are frequent and daily , occurring every day in every day living tasks eg: shopping, traveling, at work, in education and leisure as well as in more formal situations such as medical appointments, making significant purchases, and dealing with crises.* • continual exposure to the barriers and the struggle to deal with them leads to frustration, unresolved anger, despair, unemployment, extremes of anxiety, ill health, lack of dignity, lack of privacy, loneliness, embarrassment, humiliation and patronization. • expectations in some hearing people and institutions that the provisions of the DDA and Access to Work have reduced these barriers. This has not been the general experience of the people at this meeting where the limitations of the provisions were acutely felt.* <p>2. • people who are over 65 years of age now, are in receipt of DLA for conditions that cannot change (such as being born Deaf), and have made their financial planning for their retirement as they had been granted DLA 'for life', should be allowed to continue to receive DLA.*</p> <p>3. • Sign language interpreting• Communication support where information, explanation, advice and advocacy is required as well as sign language interpreting• Having to travel for face to face meetings which hearing people can deal with by telephone or internet• Having to travel to meet people who can sign to avoid isolation• Having to travel to participate in sporting and leisure activities without communication barriers• Purchasing of equipment when technical developments take place prior to these becoming mainstream or cheaper should that happen eg: subtitling recording equipment, video conferencing, door entry systems with CCTV• Utility costs of running equipment – including cost of minicom calls• Communication barriers reduce choice, 'best buys ', bargains, shopping around and switching, prey to being unable to understand the small print and hidden costs, *</p> <p>4. • there is not enough information here to comment easily• some people will have more essential needs than others• it depends if the English used is clear and not open to different interpretations• our experiences have shown that the decision makers have themselves made different interpretations that have required the House of Lords and independent tribunals to clarify• our experiences have also shown that people with similar needs are today on different rates and that decision makers often do not understand disability. • If the rates are not linked to 'impairment' – eg: profound deaf ness – but to expressed needs there will always be difficulties in interpretations. Linking rate to impairment would save bureaucracy and paperwork*</p> <p>5. • there should be automatic entitlement for people who have conditions that will not change and which so obviously lead to extreme needs such as Deafblindness• there should also be an automatic entitlement for people who have conditions that will not change such as being Deaf and communicating through British sign Language as these present with very similar needs• these permanent conditions can be evidenced at the beginning of a claim thus making the process more efficient and economic. • automatic entitlement in these cases will save considerable money as well as reducing the ordeals and protracted battles which people have previously faced when applying and on review. Reviews are expensive and are unnecessary where people have conditions that will not change.*</p>

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		<p>6. • if an activity is essential – it is essential and cannot be prioritized. • of course it is essential to eat and drink – but it also essential to communicate about eating and drinking. • it is essential to keep safe – and this requires communication – eg: when traveling, calling for help, responding to alarms, getting access to information, being alert, knowing what is written about medication, being able to participate in societies activities, complete financial declarations.*</p> <p>• it is essential to be able to have social interaction – and this requires communication • it is essential to achieve – and this requires communication. • from our perspective therefore – the priority is communication*</p> <p>7. • we were born profoundly deaf or became profoundly deaf when very young and our deafness does not vary or fluctuate • the assessment should make a clear distinction between conditions which do and do not vary so that people with constant conditions are not inappropriately dealt with.*</p> <p>8. • no • how will the decision be made that any equipment is meeting a person's needs rather than ameliorating them? • people with similar needs can find that equipment varies in effectiveness • vulnerable people may not be able to cope with equipment • equipment varies in price and reliability • equipment needs maintaining, repairing and replacing and may have running costs and never solves the problem, it may assist but usually brings other problems with it.*</p> <p>9. • provide regional BSL versions / guides / road shows – with regional signs and at different language registers so that communication is comfortable and not stressful • provide independent communication support to complete the forms and make sure this is paid for and that there are appointments readily available for this face to face / one to one service • provide this face to face service with communication support workers / advisors who can communicate in British Sign Language themselves so that this is not done through interpreting requiring a third person • make sure that contact does not require telephone communication • make sure that plain english is used for those with some english skills – but that not only one 'easy read' version is available as this can be experienced as patronising.*</p> <p>10. and 11 • supporting evidence needs to be provided by people who can communicate directly with a Deaf person in British Sign Language and only when communication has taken place. We have experience of travelling to appointments when interpreters have not been booked and the interviewer has made up their own view without communication taking place. *</p> <p>• audiograms from National Health Service audiologists will give evidence of deafness*</p> <p>• registration with the local authority as a Deaf person will give evidence of deafness*</p> <p>• all professionals giving evidence need to be trained and be competent*</p> <p>• our experiences of previous medical assessments by approved Departmental doctors has been extremely poor. It is also expensive to use Doctors who are trained in medical assessments and not social assessments. These assessors are not going to provide a free service.*</p> <p>• occupational Therapists are not appropriate to assess the needs of Deaf people*</p> <p>• using healthcare professionals to make assessments of our abilities is going back to the old days when they concentrated on hearing aids*</p> <p>• we prefer assessments to be made by social care staff*</p> <p>• there is considerable emotional stress in insisting in face to face situations with people in authority who cannot communicate. This is a very stressful, bad idea and discriminatory and patronizing.*</p> <p>12. • Reviews are not necessary for profoundly Deaf people as our needs do not change and therefore such reviews are a waste of money and resources*</p>

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		<ul style="list-style-type: none"> • If, on grounds of fairness, reviews need to be held – a date 10 years ahead could be considered and could then be a simple declaration by an independent person – such as an audiologist – that the person remains a Deaf person.* 13. • this does not apply to Deaf people as their condition does not change* 14. • see response to question 9* 15. • it may be advisable for people to access advice and support if it is available but this cannot be compulsory* • the important thing is to make very good advice and support readily available* 16. • our current aids and adaptations are provided without cost by the local authority or the health service* • aids and adaptations are never on a One-off cost – see response to question 8* • DLA (and presumeably PIP) does not at present cover the costs of sign language interpreting so how can it stretch to equipment – the PIP would have to be a very large amount.* 17. • we feel this needs a different consultation process which will also include children, young people and families.* 18. • it has been very useful, saving many other assessments and intrusion – for eg; Housing Benefit, Council Tax Benefit, Working Tax Credit, Income Support, Bus passes, some charitable sources of support.* • we would wish this to be kept* 19. • each provider would then have to make their own assessment – with possibly different criteria – very intrusive and confusing, expensive and time consuming* • the disabled person may not know they could have an assessment for assistance and therefore could have a much lower income than could be available – Deaf people already are more often than not in low paid work or find it difficult to obtain work and their incomes are relatively low.* 20. • permission to share should always be sought and confirmed in writing and controlled by the disabled person• sensitive data should not be shared – only relevant data• the data to be shared should be fully understood by the disabled person • we are concerned about the sharing of data and whetherr organisations will fully obey the Data Protection Act and Human Rights Acts• we would like the information that we are Deaf to be passed on and responded to appropriately.* 21. • To change DLA to a PIP is a very important change for us. • Deaf people’s communication needs have to be taken into account right from the start. • No resources have been made available so that we can understand and participate in this consultation process. • We have had to rely on volunteers to do this. • No communication has been sent to us as people in receipt of DLA that this change was coming. • The timescales for the consultation have been very short – especially with the bad December weather and Christmas and New Year coming in the middle of it.* • It does not appear that the communication barriers we are faced with have been understood by the organizers of this consultation process.* 22. See the response to question 21
EM563	13-Feb-11	<p>I am responding on behalf of my brother who has learning difficulties as well as mobility problems which have become worse since he suffered a stroke in 2007. He relies on his disability allowance to pay the cost of taxis so that he can get out to mix with other people and have meals that he cannot cope with in the home environment. The papers outlining the changes are well beyond his grasp and must also be for many other people. Perhaps that is the idea so people do not know what is happening there needs to be a better system and not one that penalises applicants because they are not sure what is meant by all the terms used.</p> <p>Yours sincerely [REDACTED]</p>

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EM564	13-Feb-11	<p>I am the parent of a young man (19 years old) with Asperger's syndrome who has been receiving DLA since he was 13 and I have received Carer's Allowance. These benefits have made it possible for me work fewer hours and to give my son the support he needs and have covered additional expenses.*</p> <p>* Now he is 19, other financial help will come to an end – Child Tax Credit and Child Benefit. Our son will not be able to work and DLA and Carer's Allowance have become even more important to us and to our son as other benefits have gone. *</p> <p>It is very important that any new kind of assessment takes into account individuals at the more able end of the autistic spectrum. The full extent of the difficulties that these individuals have can often be missed by trained professionals and may well be missed by others carrying out assessments for benefits. Many adults with autism rely on their families to a very large extent to cope with daily life and will need some sort of financial support throughout life. As far as we can tell, our son will be living at home with us and will be dependent on us for the rest of our lives and we have also have the worry of what will happen to him when we are not here.*</p> <p>How will the change in the benefit system affect carers who receive Carer's Allowance and often work fewer hours to carry out caring responsibilities and rely on Carer's Allowance to make ends meet?</p>
EM565	13-Feb-11	<p>1. Your response:*</p> <p>2. Your response: Whilst it is perfectly reasonable for people in hospital, care homes and schools not to receive the care component when they are not at home it is perfectly unreasonable to take away the mobility component if they are in care homes or schools as this would effectively lock them into one institution and mean that they would no longer be able to even try to become a more 'normal' member of society. For example, my daughter currently attends a residential school but the school wants her to come home every other weekend for various reasons linked to her development both mental and social. We have a motability car which we honestly only have to have for the purpose of getting her to and from school at weekends and giving her the chance to come on holiday with us. I do not need the car for work. Her school is not accessible by public transport and there is every possibility that the local authority would have to fund expensive taxi journeys every two weeks to take her to and fro which they may well be unwilling to do in the current climate. Does she lose out because of this change?*</p> <p>3. Transport, adaptations and special needs which the state or local authority does not currently fund.*</p> <p>4. Your response: 5. Your response: 6. Your response: 7. Your response: 8. Your response: 9. Your response: 10. Your response: 11. Your response: 12. Your response: 13. Your response: 14. Your response: 15. Your response: 16. Your response:*</p> <p>17. Your response: 18. Your response: *</p> <p>19. Your response: Se answer to question 2. 20. Your response: 21. Your response: 22. Your response:</p>
EM566	13-Feb-11	<p>Dear Sir/Madam, I have attached the completed form for the dla consultation. I look forward to reading what others have said when the consultation results are published. Yours faithfully,*</p> <p>* 1. Lack of support, knowledge, equipment and finance can be significant barriers that may prevent people with impairments participating within society. *</p> <p>2. Any individual that is entitled to DLA should still receive the same level of support without worry that their rate will be changed and their level of independence will be reduced as a result.*</p> <p>3. As a parent of a disabled child we have had to purchase specialist</p>

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		<p>equipment that is not provided by the NHS. We have had to pay for our home to be adapted as the Staying Put grant did not cover all the cost. We pay for extra incontinence nappies as we are not supplied with enough each month. We have had to get a wheelchair accessible vehicle and even though we have got it through Motability we still had to find a large advance payment. We also have the cost of petrol as the frequent medical and therapy appointments are 20-30 miles away. We need to pay for home support to help provide care to take my daughter out to socialise and join in with activities outside the home and also to help with the 24 hour care that she requires. *</p> <p>4. I think that having two rates would make it easier to administer. However the people currently awarded the low/middle/high rate will need to be guaranteed that they will still be entitled to the benefit and it is not just cancelled because the rates have changed.*</p> <p>5. I believe that people with lifelong and complex needs should receive an automatic entitlement as it is unlikely that their care and mobility needs will change and they will need the highest level of support and will have the most barriers to overcome.*</p> <p>6. Support should be provided to anyone that needs help with living a full life. Any activity that the individual wants in their lives should be able to be accessed; from assistance with getting up and dressed, to going to work, on holiday, to the local pub, to the supermarket - anything that is a barrier without additional support.*</p> <p>7. By using medically trained people for all assessments - whether it is the people already involved with the individual - perhaps they will be required to provide a report - and by encouraging these practitioners to report significant changes after appointments.*</p> <p>8. No, just because an aid can help someone manage their impairment it does not mean that this should be used against them. You would be penalising people for using an aid to overcome society's barriers if they want to have an independent life. If you are referring to the social model then the barriers are caused by all sorts of external factors and that is not the responsibility of the individual to fix or to feel as though they are at a disadvantage if they use any aids. *</p> <p>9. Have a simple, straightforward form without a repeat every 3 years. Have a clear information leaflet and offer a helpline service.*</p> <p>10. Supporting evidence needs to come from consultants, doctors, physiotherapists and key health professionals involved in the individual's life.*</p> <p>11. This would depend on who the healthcare professional will be, what are their qualifications, and to whom are they accountable? The wait for an appointment could be a long time if there are a lot of people that need to be accessed and this could hold up the award being given. It is also not always convenient for someone with an impairment to be able to travel to an appointment so I believe a home visit should be an option. * I think for people with complex needs especially communication difficulties or behavioural issues or individuals under 16 the experience may be very stressful.*</p> <p>12. If the individual has a lifelong condition or complex needs then the reviews every 10 years or so, with any significant changes being reported immediately. If the condition is likely to change with age, then perhaps a shorter interval. For individuals who depend on a Motability car the term for the lease should be taken into account when setting review dates.* I think that there should be different types of review, especially for children and those with complex needs.*</p> <p>13. An annual letter to the individual asking them for any changes to their situation. Also stressing that therapists and medical people involved have a duty to report changes. *</p> <p>14. There should be clear and concise information about what is expected and how long the process will take. An explanation about how mobility, learning, sensory and mental health problems all fit into the</p>

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		<p>equation would be helpful, as would suggestions of who to contact locally for help. Other useful information would be a guide to related benefits, eg Carers Allowance, and a Motability leaflet. There should also be a support helpline for people completing the forms/attending reviews etc.*</p> <p>15. I think as long as the individual has been made aware of their entitlement then it does lie with them and/or their support network to decide whether or not to use this benefit. Some people may not want to or need to, just as long as they are aware it is there at any time.*</p> <p>16. Personally we have increased our mortgage, I have taken two part-time jobs, we have applied to charities and we have done fundraising to get equipment that will give our daughter a better quality of life. However we are older parents and this should not be the way that aids and adaptations are funded. If there was a central grant that could be applied to for equipment, without having a negative impact on the PIP benefit, then that would be great, but I think that is unlikely.*</p> <p>17. The needs of many disabled children can change very quickly and increase as they grow older. For wheelchair users they will need adapted vehicles and hoists, other children may have more challenging behaviour especially around puberty and beyond. The stress on families can and does result in marriage breakdown, resulting in serious financial need. Children are invariably known by numerous professionals who can vouch for the genuine nature of their needs therefore the face-to-face interview and reviews wouldn't be necessary. Perhaps at the time of change to adult social care then it would be assessed then.*</p> <p>18. DLA is extremely useful as a passport to other services. The arrangements could be improved by having a central record of everyone's DLA entitlement which could then be accessed by other bodies, with the person's permission. For example, instead of having to send in a photocopy of the DLA award with a blue badge application, it could be possible to put a password on the application which could be used to view that person's DLA award. This would save time for both claimants and administrators. *</p> <p>19. Other services may be missed if the claimant is not already aware of them, which would mean they could actually be achieving more within their day-to-day life.*</p> <p>20. Blue Badge, council tax reduction, road tax, carer's allowance.*</p> <p>21. I do not have an answer to this question.*</p> <p>22. When looking at saving money and improving a service it is important to look at the whole picture. Having a disabled child or having a disability yourself can put a huge financial burden on yourself and your family. With so many cuts in so many areas there will be a point when the least advantaged people in society will be left behind financially and with the great achievements that have been made within the disabled sector of society it would be atrocious if we were to start regressing through social acceptance and visibility.</p>
EM567	13-Feb-11	<p>Dear DLA reform team, I am responding as an individual, I have attached my response. Regards,*</p> <p>Question 1 A lack of wheelchair accessible transport, worried about incontinence, extra costs for taxis as underground is mostly inaccessible and buses often don't have ramps or they are broken.*</p> <p>Question 2*</p> <p>Question 3 Having to keep the heating on because you don't generate as much warmth on your own due to a lack of mobility. Having to pay for taxis to cope with the lack of accessible transport – or the cost of running an adapted car if you can drive. Medical supplies such as gloves, incontinence pads and medication. Wheelchair purchase and maintenance. Walking sticks. Extra laundry due to incontinence. Personal care assistants *</p> <p>Question 4 • Will having two ...? I don't think it will cover the full spectrum of disabilities. Even people with similar disabilities are affected in different ways.*</p>

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		<p>• What ,If any,...? Lack of being able to tailor the benefit to the person.*</p> <p>Question 5 All claims should be based on individual needs however with a fast track system that allows for people with problems such as terminal illness, and severe communication difficulties *</p> <p>Question 6 People who are more impeded to carry out everyday activities should get priority.*</p> <p>Being able to eat and drink, cook and access food and fluids.*</p> <p>Accessing essential medication *</p> <p>Washing, cleansing and dressing *</p> <p>Toileting*</p> <p>Mobility – getting out of bed, getting around the house. Accessing outside of home/ community.*</p> <p>Communication – phone, writing Internet access*</p> <p>Managing health needs – going to bed when tired, medication, checking skin, avoiding seizures, eating at certain times etc*</p> <p>Question 7 People with fluctuating conditions should inform you of any changes.*</p> <p>Question 8 Should the ...? Yes – But should also take into account the expense of purchasing and maintaining them. The aids don't necessarily make the persons life easier, but create a whole new set of problems. i.e. Wheelchair – accessing areas/steps/ public transport etc is harder and wear and tear is very expensive. *</p> <p>• What aids ...? All Aids and adaption's that the person uses should be included.*</p> <p>• Should the assessment ..? The assessment should be based on what they have at the time. This is because adaption's can take months and months to actually happen and aids don't always turn out to the right one or useful for the person so to base an assessment on something that 'might' happen or that 'might help is flawed.*</p> <p>Question 9: • How could ..? Less systematic in the sense of less tick boxes (which wont cover every individuals case) and more of an option for the person to describe in their own words what there problems are and how it affects them. Obviously for people with communication problems then there should be an independent advocate that can assist with this. Braille forms, online forms.*</p> <p>• How can we improve ..? TV and leaflet campaign which also includes speaking with groups such as MS society, RNIB, SIA etc to ensure they are informing their members. Proper training for GPs / relevant healthcare professionals so that they will be fully informed to recognize people that might be entitled and to tell them how to go about applying.*</p> <p>Question 10 Supporting evidence from the individuals GP and/or hospital consultant. Evidence from the person themselves is most important. However a family member/ advocate for those with communication / complex needs.*</p> <p>Question 11 • What benefits ...? Benefits -Its easier to describe your own problems face to face with someone. Difficulties – you might forget to mention certain things that you had planned to say. You might run out of time. You might feel intimidated/scared by the process.*</p> <p>• Are there any ...? Someone with severe communication/cognitive/ mental health problems. Accessing another location.*</p> <p>Question 12 • What evidence ..? The assessor and individual should discuss a mutually agreeable review time frame. Any new evidence whether from the individual or GP Hospital Consultant about change in circumstance should trigger a new review. *</p> <p>• Should there be ...? Reviews should be tailored to each person and therefore reviewed at a mutually agreeable time.*</p> <p>Question 13 Financial incentives to report changes. Vouchers etc*</p> <p>Question 14 How the process works, time frame of the process i.e. when applying for a CRB you can go online and track what is happening. Keeping people informed of decisions and reasons for decisions and also how to appeal.*</p>

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		<p>Question 15 You would need to avoid 'making' someone access support i.e. telling someone with MS they 'HAVE' to access MS society when they may not actually get any personal benefit from it.*</p> <p>Question 16 Lots of people have to self fund for aids and adaption's or seek grants from charities etc however this can be a stressful process and they might not get any money at the end of it. The PIP should cover the ongoing costs accumulated of maintaining equipment/aids. It should take into account the high prices that specialist 'disabled' manufacturers /shops charge. *</p> <p>Some people have more than a one off cost, i.e. wheelchairs every 5 years.*</p> <p>Question 17 Don't know.*</p> <p>Question 18 This is a crucial part of my life. I would not be able to get around my community without my taxi card and freedom pass. The government has to make sure that when DLA finishes there is correct dissemination of information to all companies/ agencies that assist Disabled people to ensure that they can carry on using these services. I.e. Taxi Company is aware that DLA is now PIP and that my Taxi card still applies and I can still use it.*</p> <p>Question 19 This would be terrible because people would not be able to access the community as they might have previously. Service providers will not be able to provide a service if people cannot access it. It is also important for people who use a blue badge.*</p> <p>Question 20 Don't know*</p> <p>Question 21 People over the age of 65 will miss out, if they have been disabled for a long period of their life then suddenly at 65 they lose a lot of benefits. DLA stops and they therefore are not able to access things as they used to. People are living longer and 65 is no longer considered to be that old. Many able-bodied 65 year olds are very active and still want employment. The same should be for someone who is 65 and disabled.*</p> <p>22. I live off DLA and income support at the moment it is just about enough to live on. I am concerned that the new changes to PIP would mean that I would receive less money as the government is trying to cut everything else. I'm concerned that the more I try and live an independent and active life the more I will be penalized for it. I understand it has to be a fair assessment but I see it as the government's way of taking more money away from the truly vulnerable people of society that actually need it. Being able to interact with my community, visit friends and family is an essential part of who I am and what I do. Without DLA I would be confined to my flat and I would really struggle to pay the bills. This isn't about doing fancy things like going to the Theatre or Cinema and nights out its about basic mobility and being part of my community and adding to my community. I don't waste my DLA money it is all used for bills and meaningful activities, which improve my life and that of my family around me.</p>
EM568	13-Feb-11	<p>To: Maria Miller and department I should like to respond to your consultation document on DLA.*</p> <p>I have been diagnosed schizophrenic and receive DLA plus disability premiums on IS. I am surprised there is no specific mention of benefit recipients with long-term mental health problems in the document. Our circumstances and needs may be different from those of other disabled people. The last time I filled in a DLA form it had the same lack of specificity, so that filling it in for mental health problems required a social worker to explain the necessary code.*</p> <p>I am very concerned that you intend to pay less attention to (presumably diagnosed) conditions. People with serious mental health problems often have conditions that recur, with periods in between acute episodes that are considered remission by doctors. If these periods of remission are not seen for what they are, a person with mental health problems could be reclassified, from disability to simple unemployment. This might have two effects: a loss of disability benefit, and being pushed towards jobs that</p>

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		<p>don't exist for people who are fragile and have long been out of employment (and who may suffer discrimination). Catastrophic loss of benefit is likely to have very negative impact on people's mental health, as it undermines the capacity of people with long-term problems to function in society. What we need is support in supporting ourselves, not punishment for our success in avoiding symptoms and hospitalisation.*</p> <p>I am also unhappy about the proposition that disability benefit should no longer be a passport to disability premiums on means-tested benefits. The loss of income would be serious. And what happens about free prescriptions, dentistry, eye tests? How far will this process go? I think there needs to be some sense of the reality of the lives of people with long-term problems, for this to be reform rather than crude cutting.*</p> <p>I think people diagnosed with severe mental health problems need as much as anyone does, what Hobhouse called the "civic minimum" of welfare provision, which has recently been interpreted as being "understood generously, not simply as biological subsistence, but as a minimum necessary for someone to participate meaningfully in society" ('Soundings' issue 46 p.21). The mental health system in the NHS is inadequate; the best part of it is the link with generous benefits. I can only call on you to maintain that link.</p>
EM569	13-Feb-11	<p>Please find attached my response to the consultation. As a disabled person I would be happy to take part in any focus groups etc surrounding this. Regards*</p> <p>1. Your response: A lack of money if a disabled person requires equipment that needs to be paid for by the disabled person, i.e: wheelchairs, adapting a home, using public transport, which is mostly inaccessible to anyone with a large electric wheelchair. Money for petrol for Motability car.*</p> <p>Disabled people have higher costs than non disabled people for the above reasons. The lack of access in buildings, where there is no lift, or wider doors for wheelchair access. Lack of accessible public transport. Negative attitudes to disability.*</p> <p>2. Your response: I do not consider that DLA needs reforming. It identifies the mobility and care needs of disabled people and pays them benefit accordingly. The only problem with DLA is that it is a self assessment benefit, which has resulted in some people being on the benefit who should not be. This could be addressed simply by medically assessing all claimants. There is no need to completely replace the benefit.*</p> <p>The mobility component, which gives eligibility to the motability scheme is essential. It should not be considered that someone's independence and lifeline (i.e: motability car) should be taken off them if they are for example, in hospital for a long period of time and/or in a care home. These cars are a lifeline for people. Please consider that if a car is taken away from someone in hospital, then as soon as this person is able to drive again, another car will need to be sought and more, costly adaptations made. This is not cost effective.*</p> <p>3. Your response: 1. Having to buy specially made clothing, *</p> <p>2. Having a home adapted, especially if you move in with a partner, then this person is expected to pay, this can run into thousands of pounds.*</p> <p>3. Buying equipment such as hoists, wheelchairs, wheelchair accessories such as waterproof covers etc.*</p> <p>4. Travelling, whether this be by train or bus (if accessible) upgraded seating is expensive and can be costly, preventing disabled people having a quality of life.*</p> <p>4. Your response: As long as it is clear what needs entitle a person to each level of care I see no problem with 3 rates. If having 2 rates means the lowest rate of care will be removed and those previously entitled to this rate will not be entitled to the middle rate, you are simply taking benefit away from those who were deemed to need it previously and this seems morally wrong. As the original benefit pre DLA had only 2 rates of</p>

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		<p>care it seems like a step backwards.*</p> <p>5.Your response: Those with terminal illness should automatically qualify.*</p> <p>Those on kidney dialysis should automatically get middle rate care.*</p> <p>6.Your response: Recognise the extent of people's disabilities, what affect this has on their lives and the amount of care they need accordingly. *</p> <p>1. Having suitable transport and money to pay for petrol.*</p> <p>2. To be able to get out and enjoy the outdoors.*</p> <p>3. To be able to get up, wash, dress, go to the toilet and eat.*</p> <p>4. To enjoy holidays like the average person, makes life worth living.*</p> <p>7. Your response: Through medical assessment from a qualified individual (doctor) or by a medical report from a doctor who knows the disabled person or through self assessment once a doctor has confirmed the disability and the disabled person reports a deterioration.*</p> <p>8.Your response: No, for example, if a person uses a wheelchair, this does not replace the ability to walk. The fact they use a wheelchair means they will incur additional costs. If they could walk a reasonable distance they would not have any additional mobility costs. Therefore, using a wheelchair should not be taken into account, as a person using a wheelchair would still have increased costs, which you state is the purpose of the proposed Personal Independence Payment.*</p> <p>If a person needs to use aids and adaptations, this proves they have a disability and the fact that they use an aid does not make their disability any less. Just because someone values their independence and tries their best to do things for themselves they should not be penalised.</p> <p>Using an aid or adaption may mean a disabled person can do more for themselves, but it may take them, for example 30 mins, rather than 5 mins for an able-bodied person. Therefore, although a disabled person could use aids or adaptations, paying a carer to help them would make life easier and disabled people should not be left to struggle unnecessarily.*</p> <p>9.Your response: Make the form available online, as it is often difficult for disabled people to get out to post the form, which may result in a delay. Remove duplication on the form. For example, ask about day and night needs in one question, e.g: 'does this person need help to go to the toilet', day (yes-no) night (yes-no) rather than splitting it into separate sections.*</p> <p>10.Your response: A medical report from a doctor or consultant who knows the disabled person and has seen them recently. However, in many cases the medical professional would not know what a disabled person could and could not do without asking them. *</p> <p>Please bear in mind it can be a great physical effort for many disabled people to attend a medical assessment and if it is clear from evidence the person is genuinely disabled there should be no need to make this person attend a medical assessment in person.*</p> <p>11.Your response: Difficulties of getting to the assessment. I think it would be inappropriate if a person has been diagnosed with a terminal illness.*</p> <p>12.Your response: A common sense approach should be adopted – e.g. if someone is paraplegic they are (unfortunately) not going to get better.* Maybe tailor the review to the condition e.g. if someone's only disability is deafness don't ask them about their physical walking ability.*</p> <p>13.Your response: Make it clear to people that if they fail to report a deterioration they may miss out on extra benefit. Also, if they fail to notify the department of an improvement in their condition or of an admission to hospital etc they could be prosecuted.*</p> <p>14.Your response: Yes, leaflets on help with adapting properties, care services available, Motability, Wheelchair Services.*</p> <p>15.Your response: Not clear on what is being asked here – if you are talking about organisations that can help individuals claim these already exist e.g. Citizens Advice.*</p>

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		<p>16.Your response: It depends on their circumstances, low income people may get (certain) adaptations free through their Occupational Therapist, others may have to pay. In the case of home adaptations, Housing Associations/Councils may not have the budget to make essential adaptations. Therefore yes it should be an option when other options exhausted.*</p> <p>17.Your response: No response.*</p> <p>18.Your response: Extremely important – it entitles a disabled person to a motability car and free road tax- It entitles a disabled person to a disabled badge- It results in extra premiums on Income Support*</p> <p>19.Your response: Severely negative implications resulting in a severe reduction in the quality of a disabled persons' life, resulting in loss of an adapted vehicle and the blue badge, plus less money to have a quality of life*</p> <p>20.Your response: Incapacity Benefit and Severe Disability Allowance customers are now starting to migrate over to ESA, which will result in an assessment. Surely it would make sense to assess these people for DLA at the same time. This would be a saving to the government as well as more convenient to the disabled person, meaning they only have to attend one assessment. This info could also be used when Universal Credit comes in, to prevent further assessment at this time. If information is to be shared it must be held and moved securely as data relating to disabilities is particularly sensitive.*</p> <p>21.Your response: In could result in an inequality between disabled and non disabled people. With regard to what to consider when developing Policy consider the cost of implementing a whole new benefit when the intention is to make a 20% saving. See answer to question 22 for further info.*</p> <p>22.Your response: DLA is an essential benefit for many disabled people and is critical in them having a quality of life. Throughout the consultation it states that the government is committed to helping vulnerable, disabled people. However, the intention to stop mobility after 4 weeks in a home will result in (according to government estimates) 80,000 people losing income and 12,000 people losing Motability Cars. The majority of these are likely to be severely disabled people who cannot live at home and a member of the family uses the Motability Car to take the disabled person out. Without it the disabled person will lose the ability to go out with their family. This is NOT an area in which the government should be looking to make cuts. This will have a negative effect on the most vulnerable people in our society and this should not be allowed to happen.*</p> <p>This all comes down to the need for the government to make a 20% saving. However, the way to do this is not to introduce a whole new benefit and cause unnecessary stress and worry to millions of disabled people. The costs to bring in a whole new benefit must be massive. Legislation has to be drafted, involving lawyers and a Project Team set up and paid for, new Decision Maker Guides will have to be written and all Decision Makers retrained, computer systems will have to be altered to administer the new benefit and all documentation referring to DLA will have to be changed. This will cost the government a significant amount of money. The answer is to simply medically assess everyone on DLA and stop it being a self assessment benefit. This is likely to result in a significant saving, with only the cost of assessing people to be offset against any savings. If the assessment is combined with other assessments, such as for those migrating to ESA and the change to Universal Credit, this will result in further savings.*</p> <p>It is unreasonable to change the qualifying period from 3 months to 6. For example if someone has lost a leg, this is a permanent, long term disability and they should therefore get paid immediately and not have to wait. *</p> <p>In excess of 25 Disability groups have already expressed concerns about the proposed changes to DLA, especially the removal of the mobility</p>

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		<p>component for those in homes and the affect on Motability cars for both those in homes and hospitals more than 28 days. As a result, it is clear the government needs to take time to understand the effects of the proposed changes and ensure they do not make any changes that result in the most vulnerable in our society ending up being negatively affected, resulting in a reduced quality of life.</p>
EM570	13-Feb-11	<p>1. Your response: The "rights" provided to disabled people under the Disability Discrimination Act are too easy to avoid, thus making the Act toothless. It is far too easy for businesses to say that it is too expensive for them to, for example, provide step free access for wheelchair users. Business can say that changes they need to make fall outside of "reasonable adjustments" because of the cost of them, or because of the age or layout of their building etc. By way of example, in our local shops, around half of the shops and businesses are inaccessible to wheelchair users because they have no step free access.*</p> <p>Also disabled people find it more difficult to obtain employment. Lots of employers premises are inaccessible in various ways to people with various types of impairment. Even if employers are accessible, employers are often reluctant to employ disabled people because of extra costs that there might be to the employer or because the disabled person might not be able to work as many hours as the employer wants. As a result many disabled people who could work and would like to work cannot do so as they cannot get a job, not because of their disability or impairment but because of inherent discrimination in the job market.*</p> <p>Another problem with the Disability Discrimination Act is that, unlike for other minority groups, the DDA only provides a civil liability, not any criminal penalties. Therefore where discrimination exists, there is no state assistance for disabled people. They have to seek redress themselves via the civil courts. This in itself is a considerable barrier to disabled people seeking to exercise the rights supposedly conferred on them by the DDA.*</p> <p>In summary therefore there are considerable barriers that prevent disabled people from fully participating in society, despite the Disability Discrimination Act having been in force for a number of years, as its provisions are ineffective. It is therefore misguided for this reform of Disability Living Allowance to be carried out based on the assumption that we now have an equal society where discrimination against disabled people and barriers to their participation in society have been removed, as this is simply not the case.*</p> <p>2. Your response: If a person cannot walk, this should continue to be a qualifying criteria for the new benefit. The fact that such an individual can be mobile using a wheelchair does not mean that they no longer face and barriers to participating in society and leading independent, full and active lives. They will still face considerable barriers and, importantly, additional financial burdens relating to their mobility. I will expand on this subject in answer to other questions.*</p> <p>Also, it should not be necessary for all claimants to be assessed in person for the new Personal Independence Payment. Many disabled people have physical or mental impairments which are long term or permanent, which are not in any dispute and which can be confirmed by a number of their treating doctors and other health professionals.*</p> <p>Therefore making all claimants have an assessment in person for the new benefit would be a considerable unnecessary administrative cost. In addition many disabled people would suffer considerable uncertainty and stress, which would only compound the day to day difficulties they already face.*</p> <p>3. Your response: I would not be able to comment generally on the costs all disabled people face as this will vary widely from person to person. However, from a personal point of view, I am the father of a [REDACTED] year old boy who has spina bifida and hydrocephalus. We are a family of four, my wife and I also have a daughter aged [REDACTED].*</p>

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		<p>Our son has approximately 25 appointments of various types in a year. These include neurology, physiotherapy, orthopaedics, occupational therapy, splint fitting, continence, general paediatric, ophthalmology and wheelchair servicing and repair appointments. Some appointments are at our local hospital a few miles away, others at Alder Hey Children's Hospital, about 25 miles away. There is a dual cost to all of these appointments. Firstly there is the travel cost involved, and the cost of phone calls, which are considerable over a year.*</p> <p>Secondly there is the time involved in attending the appointments with our son, arranging appointments, informing school etc. I work full time but my wife only works part time. This is primarily so that she has time to arrange and attend all of the appointments. Working more would be difficult given the amount of time my wife would have to have off. Consequently our family income is considerably reduced. If we didn't have all my son's appointments to go to she would be able to work more and thus earn more.</p> <p>Because my son has a wheelchair, we need a bigger car than we would otherwise, in order to transport the wheelchair. When we go away we also need to take a supply of continence products, again these take up additional space in the car. *</p> <p>We have a large family car (a Mondeo) whereas if our son was not disabled we would only need a medium sized family car, which would be cheaper to acquire (either directly, or as we do now, via Motability) and cheaper to run. When our son is old enough to drive, he will need an adapted car with hand controls etc. There will be a cost to this over and above the ordinary cost of buying a car.*</p> <p>Our son needs a lightweight wheelchair as he is a fulltime wheelchair user. The standard issue NHS wheelchair he was offered was not at all adequate. We received a voucher from the NHS worth about £500 towards a better wheelchair. The wheelchair cost £2500 so we had to pay £2000 ourselves. He will need a bigger wheelchair in two to three years. We also have to pay for servicing*</p> <p>If we go on holiday this often costs more. We are limited in the accommodation we can stay in as we need wheelchair accessible accommodation and a bathroom. This rules out many cheaper options such as various types of camping holidays.*</p> <p>If we go abroad, holiday insurance is much more expensive because of our son's medical conditions. We went to France in 2009 and insurance cost us over £100, whereas insurance for a family of four without a disabled child would have been about £20.*</p> <p>There are lots of small items of expenditure that add up when considered together. We have to buy "baby" wipes and extra hand sanitizer for when we help our son go to the toilet. Our son crawls on the floor at home and at school, so he goes through trousers faster than other children, as he wears out the knees.*</p> <p>Our son needs one to one swimming teaching, so his lessons cost £10 per lesson. Our daughter by comparison can attend a regular swimming lesson class which costs £12 per month (both have one lesson a week). Our son's lessons are also further away so again there is additional travel cost.*</p> <p>Our son also wears out the sleeves of his coat pushing his wheelchair, so has to have a new coat more regularly than other children. We also have increased accommodation costs as our son is disabled. We need a house with a drive and off-street parking, so that our son can safely transfer in and out of the car from his wheelchair. We therefore have a more expensive house than we would otherwise have. We have also paid for adaptations to the house, such as having a downstairs wetroom fitted.*</p> <p>4. Your response: Having two rates for each level of component would not really bring any great advantage.*</p> <p>There are already only two rates for the mobility component of Disability Living Allowance and this works well.*</p>

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		<p>However changing the care component from three to two components would oversimplify this part of the benefit. There is too major a spectrum of impairments, care needs and disabilities for it to be fair to split benefit recipients into only two categories.</p> <p>The obvious outcome would be that severely disabled people would lose out and the new benefit would not properly meet their needs as they would be forced onto the higher of two new components, which would probably not be as much financially as the current high rate of the care component.*</p> <p>5. Your response: There are not that many impairments which qualify for automatic entitlement to the current DLA. Removing these would cause considerable extra difficulties and stress for those people would now have to make a full application, and there would be an additional administrative cost in assessing those claims.*</p> <p>6. Your response: • Washing• Dressing• Using the toilet• Preparing, cooking and eating food and drink* • Getting around• Accessing shops and other services and activities, including leisure activities* • Being able to take medication and carry out treatments such as physiotherapy etc. and to attend appointments* • Being able to work and therefore support yourself financially.*</p> <p>7. Your response: Disabled people with variable conditions should be entitled to DLA or the new benefit on the basis of their worst days. Information about their conditions should be confirmed by the medical professionals providing treatment or care for them. People with variable or fluctuating conditions should not be penalised for being open about the fact that they have some days better than others.*</p> <p>8. Your response: I very strongly feel that aids and adaptations should not be taken into account when assessing for entitlement to the new benefit unless the adaptations (as may be the case with prosthetic limbs) allow a disabled person to live exactly as a non-disabled person would* Particularly I feel that if a disabled person can mobilise using a wheelchair, this should not be taken into account when assessing entitlement to the new benefit.*</p> <p>Just because a disabled person can mobilise using wheelchair does not mean that they do not have mobility needs. As stated in reply to question 1, the Disability Discrimination Act does not go very far at all to taking away discrimination and barriers to mobility that wheelchair users face. Many shops, services, businesses, places of employment and public transport remain inaccessible.*</p> <p>Also, wheelchair users face considerable additional financial costs even where there is access available.*</p> <p>Wheelchair users push or operate their chairs with their hands, so have difficulty carrying as much as a person who can walk. Therefore wheelchair users have to drive or use public transport on more journeys than other people, so there is an additional financial cost.*</p> <p>Manual wheelchair users also may not have the same “range” as an able bodied person. Arms are not meant to do the job legs do so they get more tired than an able bodied person and will therefore again need to take more car or public transport journeys.*</p> <p>There is a financial cost of obtaining and maintaining a wheelchair (over and above the inadequate NHS provision).*</p> <p>Some journeys may not be possible by public transport, even with a fully accessible public transport system, however, as set out in reply to question 3, there is a cost to obtaining a larger and/or adapted car over and above the usual costs of motoring.*</p> <p>Therefore, it is not right nor fair to say that just because a disabled person can “get around” using a wheelchair, that they do not have a considerable mobility difficulties both in terms of physical access (despite the DDA) and additional financial cost. It therefore would be extremely unfair to take into account the use and availability of a wheelchair when</p>

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		<p>assessing entitlement to the new benefit.*</p> <p>9. Your response: The form is very long and lots of the questions require very similar or the same information as answers, i.e. the form is very repetitive and could be simplified so that the information only needs to be given once.*</p> <p>It should be clearer what level of impairment and care requirements give rise to entitlement to benefit and at which level. Currently information about entitlement to mobility component is a lot clearer than for the care component. The assessment process should be as quick as is practical.*</p> <p>10. Your response: Information from medical professionals who treat the person applying, as they have regular contact with the applicant and a full knowledge of their medical conditions, impairments and capabilities.*</p> <p>11. Your response: A face to face meeting in every case is not necessary. Many disabled people have well documented medical conditions, which there is no doubt about the existence of. Many applicants will be under the care of several medical practitioners. Their treating medical professionals should be able to provide all the necessary information without the need for a face to face meeting. Disabled people face many challenges and stresses in their everyday lives trying to do things on a daily basis that non-disabled people take for granted.*</p> <p>Requiring every person applying for the new benefit to have a face to face meeting would needlessly add to the considerable difficulty stress and worry disabled people face. Such assessments would also be demeaning for many people, who might feel that their integrity or the genuineness of their impairment or requirements might be being questioned, even when these were well documented and longstanding.*</p> <p>Due to the number of assessments that would be required, there would be a considerable additional administrative cost to the assessment process. Processing of applications would inevitably take longer, leading to hardship for more disabled people who would have to wait longer to receive benefits.*</p> <p>There would be costs pressure on assessments and this may lead to them being carried out by staff who are not sufficiently qualified or experienced to properly carry out the assessment, or to the assessments being merely a "tick box" exercise.*</p> <p>There is a danger, with so many assessments that many rejections of applications would be appealed, then overturned on appeal, again incurring extra administrative cost and stress and delay for the applicant.*</p> <p>12. Your response: There should be a minimum period of award of at least three years as with the current benefit, to allow recipients some certainty. It should be possible for there to be awards of longer than three years, up to lifetime awards where appropriate, where a disabled person has a condition which is not expected to fluctuate.*</p> <p>Our son for example, is unable to walk and has been awarded the mobility component until he is 16yrs old. Unless there is a miraculous treatment developed he will never be able to walk so there is very little point in assessing his mobility again for several years, if ever.*</p> <p>Where an individual has a condition that is expected to be relatively stable over a number of years, there should be a "fast track" renewal process simply to confirm that nothing has changed. Currently, unless the individual has a lifetime award they have to fill in all the same forms each time they renew their benefit as they did when they first applied, which seems to be a huge waste of time.*</p> <p>13. Your response: DLA recipients get an annual letter confirming the annual level of benefit increase. These and all other letters sent should include a reminder to report changes in circumstances. Also if a recipient attends for medical treatment, appointment letters should remind them to report any change in circumstances.*</p> <p>14. Your response: Applicants should be provided with information about where other assistance might be available to them from local or national</p>

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		<p>public sector sources, charities etc. The existence of other forms of assistance should not be used as an excuse to reduce or remove payment of DLA or the new benefit.*</p> <p>15. Your response: No response.*</p> <p>16. Your response: It should be up to individuals how they spend their benefit. If some disabled people require large one off items, there should be separate provision for this. Disabled people should not be forced into spending DLA/PIP on large one-off items if they do not wish to.*</p> <p>17. Your response: Families with disabled children face many challenges. Disabled children often have many medical appointments to attend, which impacts on family life and their schooling. Also siblings of disabled children are affected as they have to go along to the appointments and often feel that the disabled child receives more attention. They also worry about their disabled brother or sister if they have a lot of appointments.* Parents have to fit work around their children's appointments, which also impacts of family life and on the parents earning capacity. Therefore it is very important that the application process for applicants who are children is as simple as possible and whenever possible avoids the need for any more appointments for the child and their family. *</p> <p>We feel strongly that any support a disabled child receives at school should not be counted against them when assessing them for benefit. Assistance provided to disabled children at school is to help them access the same education as non-disabled children, not to help disabled children and their families meet the additional financial and social costs and challenges they face.*</p> <p>18. Your response: DLA is currently a very useful passport to a number of other types of assistance, such as the blue parking badge where having a DLA award means the disabled person does not have to spend time duplicating applications. This also keeps the administrative costs of these services lower than they would be if every application had to be an individually assessed full application.*</p> <p>Some commercial attractions and services offer reduced rates/prices for disabled people, and some of these require sight of a DLA award letter as proof of disability. The most important passport DLA provides for many disabled people who receive higher rate DLA mobility component is that they can obtain a Motability car, adapted vehicle or powered scooter/wheelchair.*</p> <p>Motability allows disabled people the chance to be able to afford reliable, worry free transport, or indeed to able to afford their own car at all. It is essential that those who qualify for the Motability scheme still do so under PIP. If this were to change, large numbers of disabled people's lives would be extremely severely adversely affected.*</p> <p>Also if the numbers of people eligible for Motability reduced considerably, it might no longer be financially viable for the scheme to exist at all, as it relies on its buying power, which arises from the number of disabled people who qualify for the scheme.*</p> <p>19. Your response: Please see reply to question 18.*</p> <p>20. Your response: Assessments for DLA/PIP could be shared where appropriate, with other benefits such as ESA or the proposed new universal "out of work" benefit. However, it should be remembered that DLA/PIP is a non-means tested benefit available to all disabled people, not all disabled people will be in receipt of other benefits.*</p> <p>21. Your response: The changes could considerably increase inequality between disabled people and the rest of society.*</p> <p>22. Your response: Many disabled people rely on receiving Disability Living Allowance to help them survive financially. DLA at current levels does not fully compensate disabled people for the additional costs they incur as a result of their disability.*</p> <p>Any change to DLA which reduces the value of benefits a disabled person receives will therefore badly affect many disabled people, reducing their quality of life. Many disabled people would then be forced</p>

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		<p>into poverty or further into poverty.*</p> <p>Disabled people already have lower prospects in terms of life chances in many areas, such as earning potential, the opportunity to obtain employment, travel, accessing services and leisure activities etc. Many disabled people already struggle financially and in other ways in their lives. Causing them to lose benefits, or to have greater stress in applying for benefits would be a serious problem and would compound the difficulties disabled people already face.</p>
EM571	13-Feb-11	<p>Good Morning*</p> <p>i have Multiple Sclerosis. I find having DLA helps me to remain independent and have my own car. Over the years I have found my MS getting gradually worse, and one of the "factors" that does not help one that has MS is stress and worry. I find I am no longer able to work, and in 2008 I was advised to take the Voluntary Redundancy from BT, due to my ill health. We are also undergoing concerns regarding the going over from IB to ESSA, from a personal perspective I have to say having Remitting Relapsing MS, I never know how I will feel from one day to the next, how is it possible that I, and many others. And can be assessed to see if i can continue claiming these benefits. I really could do without the that my DLA may be taken away from me!! Is there anything in place to help protect people that already have DLA, and have a chronic illness like MS or indeed cancer? Thank you for reading this</p>
EM572	13-Feb-11	<p>To Whom It May Concern, I write as a disabled person and enclose my individual response to the *</p> <p>DLA Reform Consultation. Yours sincerely*</p> <p>*</p> <p>1.Disabled people experience significant problems and barriers in all areas of their lives including access to services, support, accommodation and activities. Although there has been implementation of the DDA and the Equality Act this cannot eradicate negative attitudes and discrimination. The DDA continues to allow reasonable adjustment allowing discrimination, and legislation alone does not change attitudes. These limitations severely impact on opportunities and therefore on a person's ability to find employment, participate actively in society and to live independently both in daily tasks and financially. Due to the difficulties suffered through an impairment or disability there is an increased financial burden to be able to manage which is caused by the cost of care and mobility needs. These costs exist due to the need to pay for services and the maintenance of both equipment and aids. Not only do you require aids and equipment to enable daily activities to be carried out but there are physical barriers to public transport, accommodation and everyday living. Disabled people are restricted by society and not valued as individuals. Due to the lack of understanding disabled people are often treated as invisible or an inconvenience that has to be managed. They are too often required to obtain permission over and above the norm to give notice for travel arrangements etc and are excluded and isolated from the community. *</p> <p>2.The proxies of mobility and care should remain as there is no better way of assessing an individual's needs on what help and support may be required as these are the issues that impact on everybody not just the disabled. *</p> <p>3. The main extra cost lies in support and equipment needed to live and be independent as adaptations that are required for the home and travel costs are higher due to restrictions that a disability or impairment can cause and are continually ongoing, as well as increased heating and clothing costs due to restricted mobility. *</p> <p>4.This would simplify the benefit which could lead to over complicating the system and the disadvantages would be that people entitled would now not be eligible but still living with a disability and all the difficulties incurred by this. *</p>

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		<p>5. Automatic criteria should remain in place due to the severity of some disabilities or impairments as they can be life-long with no improvement and in some cases worsen. *</p> <p>6. All aspects of daily living and care needs are important as well as social inclusion; therefore all care and mobility activities could be seen and are essential to being a valued member in society with no restriction. *</p> <p>7. Ensure that medical professionals employed to assess are imposing realistic timelines and that they see more than a disability and have a better awareness and knowledge of how this disability impacts a person. Being able to diagnose a condition does not mean you understand or appreciate the difficulties living with this can cause. Often the most understanding are those who work or live with people facing these disabilities and more has to be understood by the medical professionals for this to be improved upon, training etc. *</p> <p>8. Strongly disagree with this question as providing someone with equipment or aids does not remove the disability or take away problems including pain they have to overcome daily to be independent. Just because there are improvements everyday with what is available does not make it accessible or affordable, in fact the more technology advances the higher the cost to the individual. *</p> <p>9. Less jargon should be used within the questions. Promotion and advertising of benefits should be more readily available and clearer. People providing advice and guidance should be given more material with ongoing training in this field. *</p> <p>10. Supporting evidence should be obtained from medical professionals in the relevant and varying fields along with people who provide help and support daily or regularly however the questions that GP, consultants are asked to answer may be better if tailored to the individual claiming and not fixed questions as at present. *</p> <p>11. The benefit is that the individual if able to can better put across difficulties faced. The disadvantages are that the situation is stressful and can leave you feeling you have to justify your disability on top of living with it. People with permanent or long term disabilities often are not open when asked about what difficulties they face as they will tend to consider positives not negatives. The word 'manage' should not be used unless time is given to explain what the difficulties there are in managing, as this does not currently happen and people with a disability often feel misquoted. The smallest symptoms of a disability can be worsened through stress and tension of the assessment. The face to face meeting can be inappropriate when you are unable to communicate or understand the essential need for the benefit, assessor should have a better understanding of the need for the assessment. And preferably wholly aware of how the specific conditions/illness can affect a person and not look at it as a general one. *</p> <p>12. Reviewing should be undertaken on realistic timelines for example type of disability and severity. At the time the award is granted it should be understood by the assessor whether this is a lifelong condition or not and if there is a realistic likelihood of improvement. More notice should be given to information provided from GP, consultant when condition is permanent. *</p> <p>13. Continuity of professionals assessing as they should be better placed to see and understand changes good or bad in person's circumstances / situation. It would also make the process less stressful. Medical and care professionals should be better made aware of the benefit system so as to be able to provide encouragement and guidance on when and how to notify the relevant agencies of these changes. *</p> <p>14. Benefits and advice should not be advertised on a need to know basis. Very often the people that should be telling you about these benefits are not telling you that you are eligible. This is due to a lack of understanding of disability in society as a whole. It should be that all</p>

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		<p>medical or social care professionals should be put through some disability awareness training and be better aware of the benefit system and people's rights. Automatic referral (with consent) to welfare rights organisations may be a way of ensuring that benefit entitlement is looked at and appropriate claims made.*</p> <p>15. At time of diagnosis professionals should be making people aware of their rights and eligibility to these benefits and should provide the information needed to access such. Again automatic referral (with consent) to welfare rights organisations may be a way of ensuring that benefit entitlement is looked at and appropriate claims made.*</p> <p>16. Current understanding of purpose of benefit is to pay for additional and reoccurring aids and support. Clearer understanding should be given to people on how or why benefit has been granted so that there is no misuse of monies or reason to make claim. DLA should not be used to meet the cost of adaptations or one off costs, the allowance should remain to meet the additional costs of everyday living.*</p> <p>17. Knowledge of how disability / impairment can change due to growth is essential. *</p> <p>18. It has been important up until now but can be improved upon by advertising that if you are awarded this benefit there is eligibility criteria for other services or benefits which should be included in the claim form. The passport arrangements are an essential addition to the basic DLA and should continue.*</p> <p>19. Vulnerable people in society would be unaware of their rights to such benefits or services and this would further isolate them from society, including access to work, adaptations, special equipment etc.*</p> <p>20. 21. 22.</p>
EM573	13-Feb-11	<p>1.Your response: Lack of public transport suitable for independent travel and low income on benefits.*</p> <p>2.Your response: Mobility component should remain for people in care/residential homes*</p> <p>3.Your response: Suitable clothing for wheelchair users. Travel costs including car expenses .Cost of escort to travel with disabled person. Cost of food for special diets.*</p> <p>4.Your response: Difficulty in applying for any benefit is underestimated. *</p> <p>5.Your response: Some degenerative conditions should have an automatic entitlement for renewal as the condition does not improve.*</p> <p>6.Your response: The ability to get out of a home and to participate in society in general should be a minimum expectation. Travel costs/mobility component must remain payable to all entitled for this to happen. Local authorities do not provide any level of transport to residents of care homes which are comparable to receiving the DLA mobility component. Care homes often charge extra for transport, in spite of supposedly being funded for this purpose.*</p> <p>7.Your response: Look at the evidence from claimants who know their condition best.*</p> <p>8.Your response: If the aids are artificial limbs etc then yes they should be included., but only if they are supplied .*</p> <p>9.Your response: Consult actual users for their experience plus the many CABx who give free help and have experience of the difficulty of the form.*</p> <p>10.Your response: Medical staff involved with the applicant plus carers.*</p> <p>11.Your response: Difficulties in that professionals can often be rushed for time to meet targets and do not give the applicant opportunity to explain their condition fully. If someone has a terminal illness with a short life expectation this may prove inappropriate for a face to face meeting.*</p> <p>12.Your response: Reviews should only be carried out when the condition is likely to improve. Degenerative/progressive illnesses should be reviewed less often.*</p> <p>13.Your response: Remind them by letter and encourage medical profession to be aware and also remind claimants if appropriate*</p>

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		<p>14.Your response: Advice as to the way the form is scored would be helpful! Plus refer people to the many agencies who can also give impartial advice, as long as they still exist after the current round of cuts to charities!*</p> <p>15.Your response: The CABx are excellent at addressing these sorts of issues so you could use their expertise , but forcing people to access advice may not be the answer. Training hospital auxiliaries/outworkers in basic benefit entitlement would help encourage take up of benefit by minorities.*</p> <p>16.Your response: Aids come from local authorities or from relevant charities who can often help fund equipment. Any other sources of funding may be welcomed.*</p> <p>17.Your response: That they grow quickly and can often have greater need for replacement of aids/adaptations*</p> <p>18.Your response: DLA is not means tested which has meant that many more people are willing to apply for it as an entitlement. It has been a very important lifeline for many in allowing them access to other benefits, transport and services which make life more bearable.*</p> <p>19.Your response: If PIP were not to be a passport benefit it would mean even more obstacles to achieving a quality of life that non disabled people would see as the norm.*</p> <p>20.Your response: DLA entitlement should be used for assessment for blue badge scheme.*</p> <p>21.Your response:*</p> <p>22.Your response: The withdrawal of Mobility Component from residents of care homes will condemn many to never getting out or being able to interact with friends and family. This must not be withdrawn.</p>
EM574	13-Feb-11	<p>1.Your response: Lack of facilities in the public and work environment to allow disabled people to travel, work and socialise alongside the able bodied.*</p> <p>2.Your response: The three tier system that allows for change if a disability deteriorates over time.*</p> <p>3.Your response: Adaptions in the home, physical and transport requirements*</p> <p>4.Your response: Would not be discreet enough if an individuals condition deteriorates.*</p> <p>5.Your response: Automatic qualification for some conditions would simplify the assessment.*</p> <p>6.Your response: Personal health and hygiene followed by mobility.*</p> <p>7.Your response: Feedback from the individuals own GP.*</p> <p>8.Your response: I do not understand this question*</p> <p>9.Your response: Allow the Disabled Voluntary Organisations help draft any documentation and information*</p> <p>10.Your response: The individuals GP.*</p> <p>11.Your response: This is already an intimidating experience for many disabled persons as the examiners appear not to have any background information of the applicant*</p> <p>12.Your response: Very difficult to answer this question as the spread of disabilities are so wide.*</p> <p>13.Your response: This would depend on the level of disability*</p> <p>14.Your response: Any information relating to Hospital or related treatments*</p> <p>15.Your response: I do not understand this question*</p> <p>16.Your response: From their disability living allowance. Aids or adaptations normally require periodic replacement.*</p> <p>17.Your response: Not known. This is a specialised area.*</p> <p>18.Your response: Very important but rarely provided by local authority services.*</p> <p>19.Your response: Not known*</p> <p>20.Your response: The merging of national and local government services. There is duplication in many areas.*</p>

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		<p>21.Your response: There should be no difference in the assessment of those of the working age group.*</p> <p>22.Your response: It is highly likely that there would be little improvement in the health of the over 65's. It is more likely that their physical condition would progressively deteriorate. Therefore the cost of reassessing could not be justified.</p>
EM575	13-Feb-11	<p>1.Your response: Problems include difficulties in the areas of: mobility; communication; sight; speech; behaviour; exceptionally frequent toileting needs; severe anxiety, depression; eating disorders, mood disorders or regular loss of consciousness, fitting etc.*</p> <p>2.Your response: Certain severe disabilities should still mean automatic entitlement. What is the point of spending public money constantly re-assessing someone who is clearly going to be severely disabled for life?*</p> <p>3.Your response: Costs in the areas of: care; special transport; special diets;,, clothing or adaptations of living areas; loss of earnings because of the need (in some cases) to have frequent odd days of work with no possibility of claiming Employment and Support Allowance (not payable for odd days).*</p> <p>4.Your response: Some will probably lose out and gain with any change.*</p> <p>5.Your response: Certain severe disabilities should still mean automatic entitlement. What is the point of spending public money constantly re-assessing someone who is clearly going to be severely disabled for life?*</p> <p>6.Your response: Activities most essential: eating, sleeping, drinking, toileting, mobility, communication, social interaction, education etc. *</p> <p>How to prioritise support: Look closely at the level of disruption to everyday life the person experiences. For example someone with a chronic bowel condition might have to face frequent, urgent toilet trips throughout the day and night. Even though their walking ability might be OK and they might not need care in the normal sense, the extra cost through lost working opportunities, need for special diets etc can be considerable. The current DLA perhaps does not take this sufficiently into account.*</p> <p>7.Your response: This is an important one. Many conditions including those relating to mental health, epilepsy and certain physical conditions affect people much more on some days than others. There must be appropriate consideration of the nature of certain conditions and also understanding of the combined effect of certain conditions (eg. A person with severe anxiety who also has physical conditions that require frequent tests might have additional anxiety about the tests and/or side effects of medication.*</p> <p>8.Your response: The emphasis again should be on the level of disruption caused to a person's life and cost implications of their condition. The question about aids and adaptations is a difficult one. Who is to decide in a benefit decision what aids or adaptations any one individual could reasonably use, particularly where a person has a range of conditions or a combination of those which are mental and physical? It would need a highly specialised decision maker and the cost of administration and appeals could be considerable. *</p> <p>9.Your response: Rather than focussing on the need for care or problems with mobility as with DLA, the new benefit should perhaps focus on the disruption caused to normal living and cost implications, including those of reduction in earnings potential (particularly where the person is likely to need a much higher number of short periods off work sick than a typical person.) *</p> <p>10.Your response: Medical report from a person's GP or (where applicable) consultant(s).*</p> <p>11.Your response: Benefits: Might help keep down fraudulent claims.*</p> <p>Difficulties: Health professional might feel under pressure from government to keep down number of successful claims, resulting in a high number of costly appeals, many which might be won by the disabled person.*</p>

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		<p>12.Your response: The more severe the conditions / combination of conditions, the less frequent the review should be. *</p> <p>13.Your response: Provide at the outset of the award a change of circumstance pack / booklet which clearly and simply sets out what, when and how to report changes. Any telephone line used for such reporting should be free and properly staffed so that people can get through first time on most occasions and not have to face a marathon session to try and get through (as can happen at present on some current benefit lines).*</p> <p>14.Your response: A clear statement of what the new benefit is and is not meant to cover. Clear information of how to apply and get help in applying where necessary.*</p> <p>15.Your response: Facility to have someone call at the house to help make the claim where necessary.*</p> <p>16.Your response: Currently, various ways of funding. Not sure about other question.*</p> <p>17.Your response: The main difference with children is that account should only be taken of conditions that provoke a level of disruption to normal living or level of expenditure over and above what a typical child of that age would normally have or require.*</p> <p>18.Your response: Very important. People awarded the new benefit should be given a list of other benefits which they might access.*</p> <p>19.Your response: Possible financial hardship and social exclusion.*</p> <p>20.Your response: ESA /IB sections could share information with the new benefit section.*</p> <p>21.Your response: No sure.*</p> <p>22.Your response: As mentioned above, the new benefit should take a wider look at the overall disruption of their disability on a person's life and finances, taking account of all aspects, including effect on earnings potential in relation to the possible need to take more frequent odd days off work which might not be supported by other benefits. Any assessment should also take into account exacerbating factors, such as multiple disabilities or combination of mental and physical issues.</p>
EM576	13-Feb-11	<p>██████ – until recently resident in Hampshire*</p> <p>We respond as individuals but have both worked in the voluntary sector supporting people with mental illness and parents who have children with special needs.*</p> <p>We have a son aged ██████ who is a community near Exeter. He is profoundly autistic.*</p> <p>We also have an older daughter who has a chronic mental illness and is unable to work.*</p> <p>Response. *</p> <p>Note we were unable to find a dedicated reply form on your web site.*</p> <p>1. The problems that may prevent people who are disabled may be prevented from living a full and active life due to problems with:*</p> <p>Mobility, perception, communication and awareness.*</p> <p>Mentally handicapped people may have limited speech to a point where they are unable to communicate their needs or feelings. They may lack self awareness to a point that they may at risk at getting into dangerous situations*</p> <p>2. Whether DLA continues or if replaced by some other benefit disabled people will need a special allowance to cover their particular living needs such as care and help in moving around and that should include leisure as well as essential travel such as medical treatment or buying clothes and shoes.*</p> <p>3. Disabled people may have odd posture or be incontinent. Either of these can lead to excessive wear and tear on clothing and may necessitate a higher rate of replacement than the norm.*</p> <p>Some people may be clumsy due to their disorder or may be prone to tantrums. They may break crockery or furniture. Some care establishments encourage personalisation of living space and any</p>

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		<p>replacement may be at the cost of the resident.*</p> <p>Regarding mobility some people may be agoraphobic or in the case of our autistic son prone to tantrums. Public transport may not be feasible due to crowding (in urban areas bus/coach use is up 30% and some rail use is up 50%. Some people may need to be accompanied by 2 people. Public transport will be uneconomic.*</p> <p>4. Essentially this is merging DLA and Mobility allowance. *</p> <p>There may well be cases where a person has special and high mobility needs but has sufficient self help that they need less support in other sectors. In other cases a person may be able to get about but may have care needs for physical or mental reasons.*</p> <p>The assessment process may be burdensome on the department and may bring applications for review, or after that, appeals. *</p> <p>A high proportion current applications are appealed. Have the reasons for this been explored? Is it due to poor first time assessment, complex rules, difficult to use forms?*</p> <p>5. Conditions and impairments may be a guide to entitlement but specific needs, particularly with conditions that have very varied effects should drive decisions. This may create a resource burden in determining specific cases and their entitlements.*</p> <p>6. Support should match needs. Activities that are needed for everyday life include:*</p> <p>Ability to get about (Mobility). This can be either due to physical problems (walk/use mobility aids or sensory – blind) or awareness and safety in the case of people with special needs (i.e. mental handicap.*</p> <p>Communication – some people may not have coherent speech due to neurological damage such as stroke or not have speech development due to mental handicap – Dressing - Toilet and personal hygiene - Preparing and eating food - Obtaining goods and services*</p> <p>These needs may vary between individuals with similar conditions, thus the need for assessment.*</p> <p>Some people may be able to manage on most fronts but may need help with goods and services as they may buy inappropriate things, lose money or be defrauded by scrupleless individuals.*</p> <p>7. This is probably the driving force for interim reviews 2 x 6 monthly then at least one annual to judge the severity of the condition and how the claimant adjusts to their situations and other forms of help that may be provide or they may simply get better.*</p> <p>This could be demanding on resources so longer term awards may be appropriate for some profound or chronic conditions*</p> <p>8. Whilst taking into account into account aids and adaptations due consideration should be given to their effectiveness in improving the claimant's quality of life.*</p> <p>Assessments should only take into account aids that are already in place as the effectiveness of promised help cannot be certain. Where it is known that the claimant is being considered for some form of aid or adaption it could be a driving force for a special review after the claimant has become familiar with such equipment. This could be on the basis of come back, perhaps 3 months, after services have been provided or remind the claimant of their duty to inform the department if their condition or their ability to live with their condition improves.*</p> <p>The provision of aids should be a partnership between medical and social teams and in some cases voluntary associations that provide guidance to people with specific conditions. Sign posting by the department may prove difficult as there are dozens of voluntary organisations. Also the willingness of social service departments, NHS trusts and local authorities to provide help varies across the country.*</p> <p>9. The current forms for DLA and its predecessors are large and difficult both to understand and to fill in.*</p> <p>Electronic forms might help but experience with income tax where it takes in excess of 3 weeks to get a password to activate the form is not</p>

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		<p>encouraging. Even when the form goes in there needs to be some flexibility. In the case of small errors or additional information it is unreasonable to return the whole form. Sending out an extract, either by post or by email would be more user friendly.*</p> <p>Electronic forms won't suit all cases. Some people don't have access to or can't use a computer. Many carers are elderly and just won't get the hang of the system.*</p> <p>Claimants may be helped to understand guidance and deals with form if guidance documents and forms were better phrased and designed. Wording should be checked for ease of understanding and "greyness." Focus groups of claimants, carers and voluntary associations may be useful.*</p> <p>10. Evidence could come from the claimant or carer but it would be useful for them to have some guidance on what the allowance is for. A starting point is what help, personal or physical do you need for your everyday life. Clarity is needed on night care. At one time it put incontinence above wondering or unsettled nights in judging cases for higher rate or all day care. In the case of very erratic persons carers often have to sleep in shifts to ensure that there charge is safe. In other cases someone may be being nursed at home and the carers have to monitor bio-medical devices to keep the patient safe or alive.*</p> <p>11. The visiting healthcare professionals will need to be better than the form BAMS personnel. Often they were good with orthopaedic or respiratory cases but frankly useless with psychiatric or mental handicap cases. They didn't know where to start with disorders that aren't physical and their assessments were often the source of appeal. Home visits etc may not be appropriate with people with behavioural disorders. This is where trust in the very specialised consultants in psychiatry or learning needs comes into play.*</p> <p>12. If the effects of the disorder might vary or time or be eased by aids there is a case for reviews to see how their condition beds down. They should not get lower awards in anticipation of promised help. However, some people may have profound conditions that are well diagnosed and unlikely to improve over time. An example could be someone with very serious learning and development problems who cannot be left unaccompanied and may have limited or no speech. Where someone has well documented evidence of a profound condition that is unlikely to change it would be wasteful in resources to have avoidable reviews. Claimants and carers have a duty to inform you of any changes.*</p> <p>13. Better explanation of how benefits work might help. Claimants need to know that the disability elements (to be PIP) and additional help for basic needs for example income support are quite different. PIP is not means tested so should only vary if their condition changes. If a person is still unable to work their support for basic needs will remain.*</p> <p>14. They should be given a better explanation of what the benefit is for, i.e. meeting the cost of dealing with the condition and the needs that arise and that it is not a source of general income or compensation for the inconvenience of the condition. Even where the condition creates problems that might be frustrating its purpose is to meet the costs of dealing with the problem not compensation for living with it.*</p> <p>Some benefits may be for a short term for example unemployment where it expected that there will be a return to work or illness with short (suggest less than 8 weeks) where there is a sound prognosis for full recovery and that there are no special care needs in the interim.*</p> <p>15. It is sometimes said that there is as much under claiming of benefits as there is fraud. There is a lack of knowledge about the availability of DLA and where it applies. Many people still associate disability with mobility and don't consider conditions that make life difficult in other ways. It would help if medical practitioners, or other healthcare specialists, were to provide information directly or through their support teams when conditions are diagnosed. Also health visitors/district nurses</p>

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		<p>could have a role to play where people are being cared for at home.*</p> <p>16. Disable people use a whole range of sources of funding. If they are declared special needs tenant in social housing their housing association may pay for adaptations.*</p> <p>Some help is provided by local authorities and in some case voluntary bodies or local appeals may meet the cost.*</p> <p>Where the condition is associated with an accident part of the settlement may include the provision of aids; indeed they may be a condition of the settlement in order to mitigate the cost of personal care.*</p> <p>I think it would be a mistake to use PIP for some of the more expensive aids as disable people may not be able to get loans and public sources such as the Social Fund are cumbersome to administer. Loans might be subject to interest would this be chargeable against PIP. What if the aids don't work?*</p> <p>17. In nearly all cases children will be looked after by their families. However, these parents and families will have to provide the same help as that would be obtained by an adult disabled person.*</p> <p>In the assessment process much of the information you use will be provide by or through the family.*</p> <p>In paragraph 2-39 you mention needs being provided by schools. Children at day schools come home every day, they spend more time at home than school so there is this a need to cover aids and special expenditure. Children in residential school go home for weekends and holidays. These institutions are often far away from home. Most local authorities don't pay for travel costs after age 12 or if the child is placed "out of county." Mobility allowance or mobility components in benefits enable children to remain in contact with their families.*</p> <p>18. "Passporting" simplifies claim management for other authorities who provide help or service to disable people. Spare copies of award letters or information slips with the claimants' name and award details would be useful. Confirmation of eligibility for mobility payments is now needed to obtain a Blue Badge.*</p> <p>Subject to controls set out in Data protection legislation and departmental codes that goes with it other public bodies might have access to limited fields of data. This could ease paperwork for claimants and might limit fraud. Also a very busy file could be a warning sign of excessive and unreasonable claims and be part of an alarm mechanism. *</p> <p>An example of share data is that, with the agreement of the client, DVLA obtains photographs and birth records through the Passport Agency.*</p> <p>19. If "passporting" were to ease it would place a burden on claimants in proving evidence and on awarding bodies seeking evidence. In reality it would be such a useful tool that some organisation would still continue to use it as a means to clear first base. Also as DLA is used so extensively, human rights lawyers might say that it is such a useful tool that it cannot be ignored or exclude from the decision making process.*</p> <p>20. Needs and care assessments used for PIP are likely to contain information that will be useful for housing allocation, provision of adaptations, mobility equipment including special vehicle and general support payments. With appropriate data control procedures pooling could improve efficiency and may speed up processing.*</p> <p>21. Mentally handicapped people in residential care might end up with no income what so ever. How will they pay for basics such as clothing, toiletries and things to personalise their personal living space*</p> <p>22. Withdrawing all payments, including mobility allowances, to people in residential care takes no account of the fact that local authority social services departments claw back most of the client's benefits leaving them only with a few pounds, often less than £20 per week for clothing and toiletries. *</p> <p>Likewise with mobility payments. Most care establishments only cover the cost of travel for shopping and the odd day out a leisure centres or for day trips. Families such as ours use the mobility component to keep in</p>

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		<p>contact with our son. A short stay with us involves two round trips with a total mileage of 600 miles. Journeys that long carry the extra cost of meals en route. If the home was to bring our son they would ask for the travel and subsistence cost of 2 members of staff. They will only cover staff costs for one visit per year; that is all that is covered in their contract with the LA.</p>
EM577	13-Feb-11	<p>Dear DLA Reform Team, I would like to raise a point with regard to your proposal to change DLA to Personal Independence Payment.*</p> <p>*</p> <p>My husband is a paraplegic, that means his spinal cord is completely severed and he has no feeling at all below the waist. He uses a wheelchair to get around and gets DLA to help pay for our car and also extra expenses that life in a wheelchair brings. Claiming DLA, in fact claiming any benefit, doesn't make a person wealthy by any stretch of the imagination...we live on the borderline of poverty and worry about money for bills every single day!*</p> <p>*</p> <p>This newly proposed Personal Independence Payment means even he may be refused it as you class his wheelchair as a tool that makes his life normal...what absolute rubbish. His life will never be normal again and although it gives him some degree of independence he needs a great deal of assistance from myself, transferring and sometimes pushing his chair and with his personal hygiene. Life is never normal in a chair, no matter how great a 'tool'*</p> <p>If he lost DLA or this new PIP wasn't awarded to him, we would be without a car... he would be stuck at home all day everyday as there is no public transport here, never mind any that he could actually get on to. *</p> <p>We would also lose the abysmal amount that carer's allowance benefit awards us...it's not much on a weekly basis but it keeps us afloat and we would likely lose our home because we could not afford to pay the basics.*</p> <p>*</p> <p>I do understand there are those who 'work the system' and these need to be rooted out but you are going WAY BEYOND that and you are attacking the vulnerable people in our country. *</p> <p>This Government should be ashamed of what they are subjecting disabled people to. The stress and worry that those with long term chronic illnesses and disabilities are all going through is tremendous anyway never mind having to think about what will happen if benefits are lost. You are penalizing those people who need help the most, But you are going to make damned sure a lot of sick and infirm people won't get what they need to survive, just to save money...you certainly are going to be in trouble when people start dying through ill health and committing suicide because they have nowhere to turn. Having no car would take away my husband's independence and it would make his already very difficult and challenging life utterly miserable.*</p> <p>If you think his wheelchair is just another 'aid' then try sitting in one for a day...or a month...or a year...or the 26 years he has been in it and will never get out of it because science is no-where near finding a cure for Spinal Cord Injuries.*</p> <p>Please listen to the sense in these two quotes: "...the moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; those who are in the shadows of life; the sick, the needy and the handicapped. " ~ Last Speech of Hubert H. Humphrey & "A nation's greatness is measured by how it treats its weakest members." ~ Mahatma Ghandi*</p> <p>*</p> <p>Why did the UK bother signing the United Nation's CONVENTION on the RIGHTS of PERSONS with DISABILITIES when you aren't sticking to it?!?!?!?</p>

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EM578	13-Feb-11	<p>3. What are the main extra costs that disabled people face? As disability is such a varied condition, people's extra costs will be for a variety of things. I have found that it is simply more expensive living with MS – I do not have the energy or ability to live on a tight budget - shopping around for the best deal, performing domestic repairs myself, running a cheap but unreliable car or going without a car. There are times when a sudden exacerbation leaves me temporarily unable to get home and I might have to buy a meal, or more rarely have to pay for overnight accommodation before I am able to move on. Such contingencies are not necessarily covered in benefit forms but it is nevertheless important to have funds to cover them. Mobility needs can be very expensive, and not necessarily covered by the mobility component of DLA. I need a reliable car that I can get in and out of, and so my entire mobility allowance goes on that, but that does not address all my mobility needs.*</p> <p>Aids and appliances provided by the NHS/local councils often have long waiting lists – I have been informed, for example, that it can take over 2 years for a stairlift to be fitted. If you need one sooner, you have to pay for it yourself. There are also treatments not available on the NHS that can bring substantial improvements to quality of life eg reduction of pain. Another example is a course of Alexander Technique I had which improved my posture with significant effects on balance and gait, as noted by my neurophysiotherapist.*</p> <p>4. The new benefit will have two rates for each component... "Disability" is a very broad and complex state, so I am dubious it can be easily and fairly divided into 2 rates per component.*</p> <p>6. Which activities are most essential for everyday life? Eating healthily, toilet needs, mobility, keeping oneself and ones environment clean and healthy, thinking clearly, keeping pain to a minimum, communication*</p> <p>7. How can we best ensure ...? 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 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>8. Should the assessment ...? 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. 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>10. What supporting evidence will help provide a clear assessment of ability and who is best placed to provide this?*</p> <p>Consultants, GPs, and particularly physiotherapists. *</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>Several years ago I was advised to apply for a higher rate of DLA care component. All the evidence from health professionals who had contact with me was ignored in favour of the report by the independent GP, which he filled in with my answers for how I was AT MY BEST, although I had given him a more complete picture for each question. As it was a good day I could perform the simple, single movements he asked me to, and although I told him that repeating them would show more difficulties, and that on some days/times of day I would have more trouble, again, this information did not make it onto the form. By the end of the visit I was exhausted, and signed the form, assuming that as I was not claiming</p>

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		<p>falsely it would be alright, but my benefit was stopped. (It was reinstated after a year of appeals and a tribunal – surely this is NOT a cost-effective process? It certainly isn't a fair one.)*</p> <p>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>12. How should the reviews be carried out? 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. 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>13. The system or 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>By making sure the whole system is absolutely fair.*</p> <p>16. How do disabled people currently fund their aids and adaptations? Should there be an option to use Personal Independence Payment to meet a one-off cost? *</p> <p>My aids and adaptations have been funded by a combination of local government, NHS and DLA. Having a one-off cost met would be marvellous if it could be swifter than local government, but 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>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>It has been fairly useful for me, particularly for a blue badge and a railcard.*</p> <p>19. What would be the implications for disabled people and service providers if it was not possible for Personal Independence Payment to be used as a passport to other benefits and services?*</p> <p>Unnecessary amounts of paperwork/red tape, delays, limitations and stress.*</p> <p>22. Is there anything else you would like to tell us about the proposals in this public consultation?*</p> <p>1. To take mobility allowance from all people in care homes would in many cases be inhumane as it would render many prisoners unnecessarily.*</p> <p>2. "A greater emphasis on objectivity and increased use of evidence" -I'm all for objectivity and evidence, but how can that be achieved for "invisible symptoms" such as fatigue and pain? Are they to be discounted? Also, how is objective evidence to be gathered for fluctuating conditions?*</p> <p>3. "...the claim form for DLA ... can require them to talk about their disability in a negative way, focusing on what they cannot do rather than what they can do." -As part of a benefit assessment, I had a visit from an Independent GP, who focussed his questions on what I was able to do at my best. Although I answered in each case with my best and my worst states, he only wrote down what I could achieve at my best, without even including information on how doing such things impacted negatively on my condition. This gave a very distorted picture of my condition,*</p> <p>If the new claim form is to focus on what an individual can do, it needs to make sure that all difficulties are equally thoroughly represented.*</p> <p>But above all, the criteria for disability benefit review should not be about saving money.</p>

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EM579	13-Feb-11	<p>Question 1. Occasional or frequent or continuous or virtually continuous inability or partial inability to perform some task or tasks by virtue of some diagnosed or undiagnosed disability that the person would expect to accomplish if they were not disabled. The task is anything from breathing to marathon running, it depends on the person. Some I have personal experience of are - Communication for those who stutter or are frightened or partly deaf. Management of medication for those less stable diabetics who need someone to keep an eye on them. The need to have a companion virtually continuously present for when an occasional emergency arises. The need to be checked frequently throughout the night *</p> <p>and be woken by a companion every night at 3.30am to perform medical procedures where the disabled person can be too deaf to hear an alarm and unpredictably often be too unwell to respond to a vibrator themselves. Hearing loops in public buildings that have not been turned on. Parking bays for the disabled being occupied by the able. Potential employers (including local authority) who advertise guaranteed interviews to the registered disabled but fail to offer any. Potential employers who reject applicant as being over qualified. Also: Lack of money.*</p> <p>* Question 2. Payment is not linked to cost of particular aids, but is awarded on account of having a disability, an element of this should be retained. DLA is not means tested so payments don't reduce if there are earnings, this should be retained for the disability component of PIP. No re-assessment unless circumstances are declared as having changed. *</p> <p>Watching over the disabled by a companion, and other "help from Others" needs retaining. The person "can do <something> with help" needs retaining. Some health conditions eg. deaf-blind to maintain automatic approval. Subjective assessment remains inevitable unless comprehensive information is collected. The information provided for DLA assessment is *</p> <p>not used for any other purpose and should remain so.*</p> <p>* Question 3. It's not about costs, although it's measured in costs. Somewhat unstable diabetes - means no driving licence means no driving employment means no employment - the disability causes almost complete loss of income, this can be seen as a cost when compared with what others may earn, and should be replaced by benefits by virtue of the disability not by showing costed receipts. There are of course costs of household adaptations, various aids, taxis, paid companion, etc, etc but the particular magnitude of these costs need not reflect or relate to the degree of disability.*</p> <p>Question 4. OK, but do keep this under review with input from disabled representative bodies. There may be problems in selecting and assessing the key activities and in determining the qualifying levels for each.*</p> <p>Question 5. It is arguable that short term disabilities should qualify eg. taxi hire to get to work while a broken leg heals, please consult disability organisations about this. The "qualifying period" must be back-dateable and not act only as a waiting period from the date of application. Some variable conditions can impose the same disabling consequences as more *</p> <p>persistent conditions, for example, a paid companion has to accompany and be on hand to assist with unpredictable frequent emergencies caused by the condition, please consult disability organisations about this. Automatic passporting of benefit according to certain conditions needs retaining, there's no point formally assessing a deaf-blind person as to *</p> <p>mobility problems, you already know the answer from the diagnosis.*</p> <p>Question 6. Focusing support on "those who need it most" will leave behind the others who still need it but not so much, or not so often, and</p>

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		<p>they should not be left out - setting the cutoff between the two is not an issue to be settled by politicians, please consult with disability organisations about this. An "individual's specific needs" is something that is subjective by the information provider, often the individual, and is subjective by the assessor who would each have their own opinion about How many times in the night, or How far away the local shop needs to be, etc. Specific questions, counting up points, applying rules, will only take you so far, there are relevant topics that will be missed by a prescriptive objective system. It is subjective at some point and will fail in its aim if this is ignored. What's important to me may not be important to you, so where is the objective truth to be found? Variable conditions need assessing at their "worst case" (not "typical") state and be adjusted for frequency - Like this example: Something that is severe when it happens (high rating) but not happens often (low adjustment) never the less gets a high assessment because a carer has to be present most of the time (high implied cost). The list of activities is badly chosen, and I say that with confidence regardless of how the list is chosen because it can't be this prescriptive if it is going to work. Please consult disability organisations about this, and keep under review.*</p> <p>*</p> <p>Question 7. What's important to me may not be important to you, so where is the objective truth to be found? Variable conditions need assessing at their "worst case" (not "typical") state and be adjusted for frequency - Like this example: Something that is severe when it happens (high rating) but not happens often (low adjustment) never the less gets a high assessment because a carer has to be present most of the time (high implied cost). Some variable conditions can impose the same disabling consequences as more persistent conditions, for example, a paid companion has to accompany and be on hand to assist with unpredictable frequent emergencies caused by the condition, please consult disability organisations about this.*</p> <p>Question 8. Don't mark down an applicant because they use some aids or adaptations and can perform fairly successfully as a result, but recognise instead that these are used because they are needed and the success shows how necessary they are, so mark them up as demonstrably needing aids and adaptations having shown this. It is irrelevant to the assessment of entitlement whether the aid or adaptation is provided privately (by the individual etc) or by a state agency (NHS etc), this only becomes relevant when considering who is to make a payment in future, the need for the payment is not affected. It is doubtful whether the assessment process is suitable for prescribing aids and adaptations that the person might be eligible for and can easily obtain, that is the domain of the GP etc. It would be possible to offer advice and suggestions without compulsion on where the individual can get information about suitable aids and adaptations. The award money would probably be used to obtain aids and adaptations and is in some degree the reason for applying, nevertheless there must be no compulsion to "get this aid or lose your benefit". Don't assess what a person can do if they were to have some item that is currently absent, instead assess what they can do now without aids. The addition of aids and adaptations does not change the need, it only changes what can be achieved while living with the need. On this basis people who wear glasses or use hearing aids for example, would be eligible and this would be on a sliding scale (of assessment points) so that mild disability attracts few points but more severe disability that cannot be alleviated properly with aids gets a lot more points, regardless of whether the aid is present or not. Putting more emphasis on aids and adaptations means less emphasis on the disability as such, this is not fair.*</p> <p>Question 9: Please take advice from disability groups. The things that disabled people cannot do are just as important as what they can do.*</p> <p>Question 10. Please take advice from disability groups. The information</p>

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		<p>(evidence) would be anything that helps provide an in-depth analysis of the individual's circumstances and needs. The test of key activities can omit much that is relevant like the need to be "watched over" by a carer, so make sure that care needs are assessed as well as activities. There is a danger that the information will be accepted only by ticking boxes or saying what the individual can do. The info should be presented in a form describing the generality of the circumstances and what the individual cannot do, and be asked "is there anything else to say, which might support this claim, about things the individual has difficulty with?" Rather than "can the individual do <something> somehow?". Those best placed to provide information are: The individual, their carer, their companions and family, their GP and specialist consultants, their friends and contacts, and any competent contributor. The department-approved professional may be some help in confirming the other information, but must not be taken as having overriding significance, especially as their meeting is a snapshot and their agenda is questionable.*</p> <p>Question 11. Please take advice from disability groups. The department-approved professional may be some help in confirming the other information, but must not be taken as having overriding significance, especially as their meeting is a snapshot and their agenda is questionable. The meeting is subjective, it can only be objective if it includes everything, which is impossible. A single snapshot meeting is no basis for an in-depth analysis which would require numerous meetings and copious evidence from many sources. There is a danger that the "professional" would be incentivised on outcomes by profit seeking bodies and ticks boxes & departs too quickly. Focusing on a range of key activities may be helpful but must not be so limiting as to ignore other activities that happen to be relevant to the individual but are not on the key list and deserve equal weight. The generality of the disablement may not be clear unless an unfocused view is taken, focusing on particular activities loses sight of the disability. "Can't see the wood for the trees" and "The whole is greater than the sum of its parts". The meeting must be open to scrutiny and challenge so must at least allow recording by simple home audio and video equipment. There does not need to be a meeting in certain cases, there is no need to check how quickly a quadriplegic diagnosed person can walk. The default meeting location should be the individual's home, and this to be varied only if there are only minor mobility problems to - meeting in the nearest town or community centre or GP surgery etc. at DWP expense.*</p> <p>Question 12. Please take advice from disability groups. It is mainly the effect of changed items that needs reviewing. The diagnosis and prognosis can determine the frequency of reviews. A declaration of changed circumstances triggers a review. It is unlikely that a full repetition of the original in-depth assessment is needed. It is especially important that any shorter contact, like a telephone call, be announced specifically as gathering review evidence, and allow the individual extra opportunity to contribute subsequent amendments to what is said. DWP should not put the individual to the inconvenience of repeating their own information gathering exercise to contact friends and experts etc for each review when the information may be largely unchanged. Don't make a review the same as repeating the original application.*</p> <p>Question 14. A leaflet and website accessible to all, is needed showing all possible benefits and sources of help. A copy of this to be given to each claimant whether they are successful or not. The information could include decision/flowcharts to assist their identifying which * benefits/help might apply to them. Additional leaflets etc to be provided that are more relevant to the specific benefits and the specific diagnoses that apply in each case. In some cases the DWP may put the individual and the helping agencies in touch with each other. This includes charities. Emphasise that there is no compulsion.*</p>

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		<p>Question 15. No No No. Offer advice, do not compel. DWP might "nag" the individual about - "Have you contacted X yet?" but do not compel. DWP could put the potential helper/agency in touch with the individual, but do not compel.*</p> <p>Question 16. Aids, taxis, whatever, are paid from the household budget which is topped up by DLA etc. Notionally one says "DLA has paid for that <thing>". One hopes to be not too much out of pocket by the end of the month. It would be nice to be able to ask PIP to pay for one-off costs for items over say £400, like a wheelchair, in which case the standard * PIP rate could be lower while access to one-offs is guaranteed. There should be no complex vetting of the one-off request, a pro-forma-invoice and doctor's note should suffice, and be accepted as often as needed. If you think this is likely to be abused (and I do) then you must increase the standard PIP rate to a level that anticipates the one-off needs as determined by the in-depth analysis, with the individual having the opportunity to challenge the decision. As well as refunding existing purchases, the payment would often need to be made before the item can be purchased of course, hence the need for a pro-forma invoice, possibly supported by a later receipt.*</p> <p>Question 18. DLA passporting to Carer's Allowance, Pension Credit uplift, etc has been a significant help. The current arrangement is automatic and fairly straightforward.*</p> <p>Question 19. If PIP were not passporting, it would become necessary to apply for each benefit in a more detailed way, causing administrative expense and much inconvenience. The other benefits would still take account of the PIP award or disability status, so it might as well be automatic. If other benefits ignore disability or apply their own assessment criteria * that differ from the definitive objective in-depth assessment of PIP then there will be no confidence in the Government's policy.*</p> <p>Question 20. Please consult with disability groups, and "Liberty" about this. Information given for one purpose should not be used for a different purpose because it was assembled and presented with the declared purpose in mind, using it for another purpose, out of mind, must produce poorly crafted and inappropriate information which is incomplete and somewhat irrelevant for the second purpose which will therefore be inappropriately assessed. If it is to contribute to the second purpose it should be flagged as provided initially for PIP, and when being provided by the individual and others must be requested with a prominent note against every item as to what the other purpose might be. A non-specific blanket statement that some info may be shared with some other DWP departments or some other Government departments is unacceptable, either as a condition of PIP or as an opt-in or an opt-out.*</p> <p>22. Watching over the disabled by a companion, and other "help from Others" needs retaining. The person "can do <something> with help" needs retaining. Targeting benefit to the most disabled must not significantly withdraw benefit from the less disabled, who, by definition, are still in need. Individuals must not be compelled or penalised for not working. *</p> <p>The disability component of PIP should not diminish with earnings if it is truly non means-tested. The caring component of Universal Credit should be passported from an appropriate disability component. Individuals over 65 should receive disability benefits because they are still disabled, and also may still be working, and not be limited to carer's allowances. Don't ignore implied costs (carer may be paid or unpaid).</p>
EM580	13-Feb-11	<p>The introduction raised several questions for me that the rest of the proposal did not properly answer:*</p> <p>DLA presented barriers to work; how will PIP avoid this, esp. as there are so many links to work throughout the paper? Surely better info. at entry point would have remedied this.*</p> <p>The fact that present levels are unsustainable is the crux of the reform,</p>

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		<p>and genuine claimants see this; it's not easy qualifying for DLA as it is, and most also know that it is the benefit least abused. Also the phrase 'prioritize the people who face the greatest day-to-day challenges' is open to many interpretations. So they anticipate humiliation by assessors who will make ill informed judgements on their condition and refuse benefits which currently go some <i>little</i> way to provide help and independence.*</p> <p>What are 'key activities necessary to participate in everyday life'? This is also open to interpretation, so the stress on 'Objective assessment' seems meaning -less. For instance, some conditions mean one day someone can wash a certain proportion of their body, and the next they can't. How is this going to be assessed?*</p> <p>PIP will only be payable for long-term conditions. This seems no different from DLA. Similarly the 6 month before and after requirement.*</p> <p>Re aids and adaptations: this needs clarification; eg I have restricted mobility due to illness and can't selfpropel a wheel-chair. I can however get about my small cottage, so am not eligible for an NHS powered wheelchair. So I use my low-rate care/high-rate mobility allowance to fund a mobility scooter and Motability car so I can 'get about'. I can't afford these without DLA, and neither can I afford to go everywhere by taxi. Am I now to be considered no longer in need of mobility benefit? Someone with a much larger income could afford these 'aids' and is one reason I would favour means testing.*</p> <p>Also re one-off payments, these aids need maintaining, servicing, occasional repair, and replacing at intervals, so re-applying for PIPs at those intervals will be stressful and labour intensive for all concerned.*</p> <p>Re supporting evidence---Social-workers are in short supply in most areas of the country. In the past I had a very helpful assessment by a local authority OT, but more recently my mother was assessed by a social worker only. LAs in my experience are, like central government, mainly intent on saving as much money as possible, giving varying opinions regarding people's ability depending on who you get, when in the financial year you apply, how much is left in the coffers, how determined/vocal you or your relatives are. I speak as a former local government employee, a friend of several social workers and the daughter of a frail 98 year old mother. Therefore, as one of the sources of objective evidence, they are not reliably objective.*</p> <p>In Chapt.2,point 29 the quote "Disabled people are experts in their own lives and information they provide will continue to be vital", seems a rather hollow assurance given the amount of weight you give to the "objective assessment" elements, by comparison with the <i>subjective</i> information we are currently able to supply on DLA forms. This is far more detailed than my G.P. can test, remember, or record. Access to OTs is variable as I've said, as is access to specialists who deal with a patient in <i>entirety</i>, rather than symptom-by symptom in multi-faceted illnesses like M.E./Fibromyalgia/M.S.*</p> <p>Re. 'emphasiizing what one can do rather can't do'. The people I know in receipt of DLA survive already by concentrating on what they <i>can</i> do, and use their benefit to allow them to pursue work, contribute to charity,to family life, and community life in general. I cannot see how down-playing the genuine difficulties they face should be lauded as a more positive attitude to life, when it will likely result in the refusal of the monetary help which facilitates their contribution to this country's life.*</p> <p>I have already given answers to the specific questions you have supplied in a response to the M.E.support group's presentation of these. In conclusion ,I repeat what I suggested there: that patient support groups need to be asked for a detailed description of the type and level of problems that people with that specific illness will experience. This should be the foundation of what an assessor uses to judge individual cases. It would give an objective and consistent description of what is likely to</p>

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		<p>occur, made by experts in that condition. No assessor chosen by the Dept. can have reliable knowledge of this kind of every illness and condition they will meet. *</p> <p>Regards.</p>
EM581	13-Feb-11	<p>To whome it may concern this is very important tome and lots of other disabled people, I would be happy to meet to represent myself as a disabled person with lots of differing impairments including physical and mental health I look forward to hearing from you*</p> <p>I can think of hundreds of ways to save money to enable you to cut costs but at the same time supporting disabled people like myself to live more fuller happier lives it just takes common sense not accusations that make us all feel like scrounger when the majority of us are not in fact i know a few disabled people that should clamin and dont as they feel to ashamed. these are the people we should be reaching out to, why is the stigma in this free country still allow people to feel that way it is a disgrace and any governemt should be ashamed and trying to right that not make it worse.*</p> <p>I have attached my response as an individual and i hope it can help make a difference, Our local council are also making massive changes that will affect front line services, mental health, learning difficulties and support services where will it end.*</p> <p>Thank you for taking the time to read this response i have lots of ideas and lots of common sense, and i see the system been abused but we can not and should not tar everyone with the same brush, i would love to meet with someone to discuss my thoughts and ideas if that is possible I look forward to hearing from someone soon *</p> <p>Regard*</p> <p>*</p> <p>Q1 These barriers have been more than adequately presented in a series of disability sector, mental health, sector learning difficulties sector, academic and public sector reports. Government should not be asking about what we already know. It should be looking forward to seek future barriers to participation. I feel that if the Government is not already aware of these answers it should be conducting a full and separate consultation on these problems and barriers, for all impairment groups especially underrepresented group such as mental health*</p> <p>Q2 I feel that the Government should recognise that in this instance the critically important "expert" is the disabled person him or herself and should retain the focus on self assessment of limitations and needs. The three month qualification period should be retained, and the model should be based on the "social" rather than the "medical or financial" model of disability. I am also concerned that the focus of this reform is to cut costs rather than ensuring that the needs of disabled people are met.*</p> <p>Q3 As with my response to questions 1 I believe that enough research has been undertaken on this issue. Obviously key to financial deprivation is the lack of economic activity among disabled people. Alot of extra costs incurred for disabled people to just enjoy or do the simple things in life that most people take for granted for example I use oxygen, whilst this is supplied to me in my home, alot of hotels, caravans, airlines will not allow this on site, if you wish to holiday abroad as lots of non disabled people do we have to pay for being disabled and it does not come cheaply. Try to go to some countries if you are diagnosed with a mental health difficulty and the cost increases to way beyond what one can afford even with the measly amount of DLA that people receive, an example of this is 100.00 per day to rent oxygen if that hotel you are staying in will accept it. Paying for oxygen on some flights, power chairs not been accepted on all flights and lots of areas in this country not accessible let alone in other countries, Also the basics such as travel insurance is tantamount to robbery when you declare what your disabilities are, the cost of this is phenomenal if they will insure you in the first place, specialist holidays cost a fortune and respite has to be paid for.*</p>

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		<p>Q4 I am very concerned that there is no detail given in the consultation regarding the criteria for the two levels of care and mobility. I would like to request the Department to provide full details of these criteria to consult on. I cannot respond to this question unless this information is supplied.*</p> <p>I am personally also very worried about the proposal to remove one rate of the care component and would call on the government to detail which rate it intends to remove. It is well documented that disabled people have a much higher cost of living because of their extra care and mobility needs. I again feel that the removal of one of the care components will financially disadvantage many disabled people and both push them further into poverty as well as further marginalize them. I would ask the Government to rethink this and retain the current three levels of care component. *</p> <p>Q5 I am strongly opposed to the removal of automatic entitlement to the benefit for certain groups. The groups that are currently listed in the automatic entitlement have to supply medical evidence that they fulfill these criteria. I believe that the reasoning behind this proposal is to save money without any consideration at all for disabled people *</p> <p>I do not agree with the qualifying conditions being increased to six months. This waiting period would have caused a significant financial disadvantage to new claimants. I also feel that this increase in qualifying time will disadvantage claimants with short-term or fluctuating conditions as this may mean that they could not apply. I again am also concerned that the Department is using draft guidance from the Equality Act for guidance on PIP. Equality legislation has an entirely different function from welfare payment As stated before I feel that the Department has presented DLA as a work related benefit, which is incorrect and does not take into account the much higher costs of living with a disability. *</p> <p>Q6 Before answering this question on a personal level I would like to point out that many disabled people lead full and active lives and I do not believe the Government would use similar statements relating to other groups.*</p> <p>I am very much opposed to changing the residence and presence tests. This will mean some disabled people who could have applied for DLA will be unable to apply for PIP. I am very concerned that this group of people will have to meet the extra costs arising from their disability without any assistance from PIP.*</p> <p>We also disagree with the proposal to remove both components after 28 days in hospital (84 days for children). This will disadvantage both the disabled person and their carer. Being in hospital can frequently mean additional costs such as travel, parking, loss of earnings etc. Other costs associated with disability will also continue to be paid such as car, aids and equipment, adaptations to house etc. I would also like to ask the Government to clarify what arrangements it has made with the Motability Scheme if any in relation to these changes.*</p> <p>I would also ask the Government to provide more information on the proposed assessment to enable me to make an informed comment.*</p> <p>Disabled people have extra costs associated with the effects of disability and these can include heating, transport, fuel, housing, shopping, clothing, aids and equipment and paying for care. There are many reports available to back up and illustrate the extra costs disabled people incur and I would be more than happy to discuss these with the Department. I would also refer back to question 3 in relation to this issue.*</p> <p>Q7 I would ask the Government to provide information on the proposed assessment to enable me to make an informed comment. In my own experience people who have fluctuating conditions can experience difficulties in being awarded DLA. I would ask the Government to give clearer guidance for fluctuating conditions. I would call for the Government to retain the three-month qualifying periods (Question 4).</p>

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		<p>The increase in qualifying period will mean that people in this group will have increased difficulty meeting the qualifying period. People with fluctuating conditions face the same barriers that all disabled face in relation to higher costs of living. I believe that the Government should consult closely with the organisations representing people who may have fluctuating conditions before finalising this issue. Different disability groups should be consulted, not the national groups, local groups have a much better understanding I feel for the needs, wishes and wants of disabled people across all spectrums of impairment for mobility through to mental health etc.*</p> <p>Q8 I again feel that the Government is using a "one size fits all approach" here. Some people can use aids and equipment to great effect whilst others struggle to use them. I do not believe that an assessment taking into account aids and equipment will accurately reflect the extra care and mobility needs and costs experienced on an individual basis and would advocate strongly against this. I would also point out that using aids and equipment does not reduce the extra costs of living with a disability, and more often than not it is just local councils fulfilling their criteria and ticking the right boxes, I agree that some aids help disabled people to be a little more independent in some cases although far from all, a lot of equipment cannot be used without carers, friends etc, and some is just plain useless, they will provide you with a wheelchair which is what has happened in my case, they supply manual chairs as electric chairs are more expensive, this is fine for in my own home although very painful to use, I can not go out of the house as I am disabled and am not strong enough to use this outdoors and could not fit it into a car, so extra expense for me again in either taxis, or carers.*</p> <p>Q9 I would like to recommend that all staff involved in this initiative receive comprehensive disability equality and awareness training, mental health awareness training and this should come from the client groups that the changes will affect. One of the groups that I use gives assistance on a daily basis to claimants wishing to complete a DLA form or any other forms. Many of these claimants state that they would not be able to complete the form without our assistance due to its length and the fact they do not know if they fit the conditions. Also for disabled people to admit that they can not do something is degrading and embarrassing and some people with mental health find this even worse. *</p> <p>I would encourage the Department to work with disability organisations and individuals who are passionate about these changes as I am in the design of any new claim form to ensure it is user friendly and accessible to all disabled people not just visible impairments that you can see. I would also like to encourage the use of a variety of media including radio, television, newspapers, disability organization, local Minds networks and social networking sites. Information should also be available in a variety of formats including, large print, audio, cd and easy read, as well as in different languages, disabled people come from all walks of life and this should always be reflected.*</p> <p>Q10 I strongly feel that the wording used in the consultation suggests that the decision has already been taken to use evidence from an independent healthcare professional. *</p> <p>I am very much strongly opposed to using independent healthcare professionals to provide advice to the Department on an 'individual's condition'. Support evidence should only be sought from healthcare professionals who are familiar with the individual, for example their GP or Consultant. They are familiar with the claimant's case and will be much more aware of their difficulties. I am also very concerned that using an "independent" to gather evidence could severely disadvantage some claimants especially those with mental health and learning difficulties who will have more difficulty stating their needs due to the effects of their condition and their own denial or non recognition in some cases*</p> <p>Q11 I have always and consistently argued that evidence from the</p>

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		<p>individuals GP and Consultant is a truer and more helpful assessment of need. I also feel that it would be very difficult for a healthcare professional, in a one off meeting to elicit a comprehensive response. This would be markedly difficult and inappropriate from someone who may have difficulty with social contacts such as those with autism, intellectual or mental health difficulties, let alone the shame that some of us feel as disabled people feel of having to explain our needs to people we do not know. I personally feel that this has the potential to cause increased anxiety and distress to the disabled people, who are under enough pressure with the way we are portrayed as scroungers by both ministers MPS media and other professionals that tar everyone with the same brush *</p> <p>I am personally very concerned that such change will be working towards reducing costs by cutting entitlement, and not taking into account need*</p> <p>Q12 Current DLA awards are already subject to review through the Periodic Review where cases are randomly selected. Claimants are also legally bound to inform the Department of any change in their circumstances that could affect their entitlement to DLA. It is our understanding that other disability benefit Departments, such as ESA and Incapacity Benefit, routinely inform DLA if an individual no longer has entitlement to benefit (it does not appear to happen if an individual is successful).*</p> <p>I am also very strongly opposed to the Government introducing reviews for all PIP awards. Many disabled people have needs that are not going to change and this will cause unnecessary stress and also be an ineffective use of resources. Indeed in many cases where claimants have progressive conditions their needs will increase. The process of submitting these people to review will cause them undue stress and is also a waste of money which could be targeted more effectively. I am also extremely concerned that this question coupled with Question 6 implies that the Government is indeed going to abolish automatic entitlement to this benefit and would ask the Government to state publicly if it intends to do this.*</p> <p>I would urge the Department to take note of information supplied by claimants and their medical/care workers as they will have key knowledge about how a claimant manages rather than a departmental official or medical person, who as no idea of this individuals life or circumstances let alone need.*</p> <p>I have grave concerns that introducing reviews for all awards is a way of saving money by removing or lowering awards. This should not be the case and I will be monitoring the policy on this very closely.*</p> <p>Q13 This expectation of increased understanding is at odds with Government's intention to target the benefit to those with the most significant disabilities. There will be a need for effective advocacy services to support some recipients to identify and report change in their circumstances. In addition, a variety of media including broadcast, print and social media should be used as well as the networks of disability organisations, mental health groups i.e mind local organisations and individuals Information should also be available in a variety of formats including, large print, audio, cd and easy read and different languages*</p> <p>Q14 The people best suited to improve management and give advice on claimant's conditions are themselves or their own medical/care/support workers who are familiar with their situations already. Therefore I am personally totally opposed to the introduction of "support" as a requirement of this benefit. I also feel it shows a lack of disability awareness on the part of the Department by implying that claimants have not already taken responsibility for the management of their impairments be that physical, or mental difficulties*</p> <p>Q15 As stated above I am totally opposed for any requirement of condition management to be placed on claimants. This is the</p>

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		<p>medical/financial model of disability which is outdated and does not accurately reflect the extra costs of living that disabled people have and show a lack of understanding on the part of the Government. Our government was elected to help the community and the people that live in it, our local councils are already making massive reductions in the support they will be providing but times on need instead of need for need, again the financial model raising its ugly head, it does not matter that the government say front line services should not have to lose out, for what ever reasons this is happening, and with these dla reforms people will be struggling to live, or in some cases their conditions worsening and becoming more stigmatised, we will be going back to early century care which we fought against then and will continue to fight against now. I would not dream of questioning anyone else about you unless it was someone that knew you well i cannot see why this should be any different unless as you have denied this is amount cost and not care and support.*</p> <p>Q16 Disabled people have a range of options as have non-disabled people to pay for major purchases. We would ask the relevance of this question. The PIP if it really is to support independence should not involve government making any decision on how this allowance is used by the recipient. I use more heating than none disabled people as I am in more pain, in the house more as house bound, as stated above the extra costs like holidays that most people enjoy can in some cases be phenomenal and unfair. *</p> <p>Q17 I am very much totally opposed to any requirements for management of conditions to be extended to children. Parents of disabled children need support from government for services – not added stress. I am also very concerned that the Government is considering looking at how needs are met for children. I would ask the Government to publicly state if they intend to remove DLA for children under 16 years of age and replace it with PIP. *</p> <p>I would also point out that the caring role and extra costs do not stop because a child is at school. Indeed many parents of disabled children have had a substantial drop in income as they have had to give up work. I am also very opposed to introducing different levels of eligibility requirements for different ages. This would lead to a much more complex system. In our opinion it would also be very difficult to devise due to the many differing needs of children. The extra cost of managing and policing this would increase costs not decrease them and more disabled people, disabled children would lose out, due to the higher costs of running a scheme like this *</p> <p>Q18 I feel that Disability Living Allowance has worked quite well in some cases as a passport benefit. Better communication between the DWP Departments would ensure a more effective service. As far as I am aware the current system means that when an individual is awarded Disability Living Allowance there is no mechanism to inform Income Support, Incapacity Benefit etc. Through people that i know and Benefit Take Up Campaigns i have read about have dealt with many cases where individuals have not been aware of additional entitlements including additional premiums, Carers Allowance, Tax Credits and Income Support or employment or support allowance or access to work.*</p> <p>Q19 I am very concerned that the Government is considering abolishing extra financial support under the Universal Credit. I would again draw attention to the many reports which clearly show the much higher costs of living for disabled people. I am personally very concerned that these benefit changes will plunge many disabled people into extreme poverty. And I would like to ask the Government to be clear about its intentions.*</p> <p>Q20 I would like to remind the Government that there are entirely different qualifying conditions for other benefits. I am very concerned that the Government is again looking at a person's functionality here and their ability to work. Disability Living Allowance is not about this but is about the extra costs of living with a disability. I would also be very concerned</p>

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		<p>that this automatic sharing of information would deter many potential claimants. Many disabled people do not want to access social services or other support agencies for a variety of reasons such as personal pride and fear of stigma and embarrassment Most of these agencies are also under huge pressure and unless the Government plans to pump more funding into this area they could not cope with more referrals anyway. I would ask the Government for clearer detail on how it proposes to do this. Maybe a suggestion would be for groups specialising in areas for different impairments following the social model not medical or financial model to be more involved as they have a much clearer understanding and give out all facts and information. *</p> <p>Q21 I really believe that this document does not clearly identify and quantify those disabled people who will be disadvantaged by the proposed changes to Disability Living Allowance. The equality impact on those people cannot be dismissed in the statement "this has been justified by the policy aim....." *</p> <p>I truly believe that the Department for Work and Pensions is only working informally with disabled people and disability organisations in Great Britain and that the particular circumstances of differing impairments on a more local level i.e people working on the front line with disabled people of have not been taken into account. This tends to negate the effectiveness of equality work to date on this policy.*</p> <p>I believe the section on potential equality impacts takes a very simplistic approach to the issue of religion/belief. I presume there will be a Equality Impact Assessment undertaken on this draft policy.*</p> <p>Q22 I would sincerely like to inform the Department of the increasing fear and concern of disabled people relating to this proposed policy change. A lot of disabled people that I know and have spoke to are very concerned, that these changes are the result of a need to save costs rather than to be of any real belief in the promotion of greater independence of disabled people across all impairment groups I also believe these proposals take no cognisance of the effect these changes will have on the families and unpaid carers of disabled people.*</p> <p>CONCLUSION I have very much welcomed the opportunity to make a submission on this vitally important issue and urges the Government to listen to the voices of people with disabilities and their representative organisations. Don't forget to consult with local mental health groups and other groups that work on a day to day basis with different disabled people with different impairments, please do not target us all as scroungers who are on benefits with a little back ache that gets better when we wish to do something I see from news articles that this happens and to be honest I have seen it happen and it is as frustrating to me as it is to you, I find it insulting, but these reviews and what the media is portraying to help you support the views you have expressed is just unjust and untrue and does not give a picture at all, the only picture this gives is that some people in this world are greedy and cheats, by making these changes you are tarring everyone with the same brush and that is just not fair, it would be like my opinion been the coalition are the same as labor were before them, you claim that is not the case so you must and should understand where we as disabled people are coming from, we should be having more support like winter fuel payments not less support as you want us to have.</p>
EM582	13-Feb-11	<p>Question 1 Poor social skills and confidence leads to a lack of social support and acceptance*</p> <p>Poor concentration – lose track, forget important things, get into trouble with late bill payments and other admin, can't remember pin numbers – the latter will become critical when cheques disappear and is already extremely difficult. For secure money transfers you have to rely on someone else to hold your pin, which makes you constantly vulnerable to theft, and it is much less convenient because you always have to have someone with you to get money out, or have to wait for their</p>

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		<p>convenience to do it for you. Low stamina, can't keep up with others, tire easily, affects access to education and work particularly. Means you can't go to places where there is nowhere to rest, may have to go out of performances as can't keep up, makes long conversations difficult. Emotional withdrawal, affects social acceptance, makes it very hard to go out, which tends to make you more withdrawn, etc Poor stress tolerance, makes you vulnerable, less resilient and tough, more emotional, therefore more difficulty in relationships*</p> <p>Behavioural difficulties, make you less acceptable, and less likely to have positive relationships*</p> <p>Learning difficulties (dyspraxia, autistic spectrum disorders, ADHA, etc), makes you less adaptable, and less able to be a part of a team or social group. Impairs communication and relationships, makes you slow, chaotic, unable to manage basic daily chores over the long term, even if you can do a chore on a one off, maintaining routines can be extremely difficult. Difficulties following instructions, and doing things in the right order. Difficulties with preparation and planning. People often see these disabilities as 'poor attitude', 'poor team player', think you are 'not really trying'. People can be very intelligent and still have these difficulties. It is hard for people to accept that an intelligent person cannot do these things. It makes you very hard to live with, prone to accidents and self neglect, loss of important documents, failure to manage finances and essential admin. Failure to make appointments, even if can get to an appointment when made, sometimes forget, or get side-tracked. Performance very variable so difficult to assess on a one off. Slow learner, difficult to adapt to new technology. Internet services less accessible, automated telephone systems almost impossible, makes it difficult to deal with the benefits service, so may not be collecting eligible benefits. Constant problems lead to mental health problems and lack of confidence. Also physical difficulties with clumsiness and coordination. Hard to access sports. Difficult to do two things at the same time. Can cause difficulties with driving, cycling, and journey organisation. Navigation a constant problems. frequently get lost, and therefore commonly late. If poor fine motor skills, difficulties operating technology, phones, remote controls.*</p> <p>Largely unknown disability, often undiagnosed and unrecognised. People do not know about it or understand it. People can be very judgemental. Few GPs know about dyspraxia in adults, neither do psychiatrists, or other mental health professionals. People with disabilities of all kinds, including undiagnosed learning difficulties, are very prone to bullying and harassment. Lack of motivation and enjoyment, makes it hard to be a part of society. High anxiety and panic attacks, can paralyse and discourage people from going out, going into crowded places, or enclosed places, etc. Fear of public humiliation because of disabilities and lack of public understanding.*</p> <p>Stigma and discrimination, especially with mental health and learning difficulties*</p> <ul style="list-style-type: none"> • Not enough part time jobs• Often overqualified as easier to sign up for a course than to get a job* • No opportunities or schemes to build up stamina over a long period, in voluntary work placements, in real work situations• Particularly difficult to find work in the public sector – you should be setting an example for private sector employers, but most schemes are only for people with mild problems who will be capable of full time work within 6 months. Some people will only ever manage 4 – 9 hours per week• No national insurance benefits for very part time work, even if on good pay• If have public appointment, have to earn less or lose national insurance, as when the day rate is high NI isn't paid. (eg for 2 days per month)• People may be trapped in benefit system by the need to have National Insurance paid, because need to work over 16 hours/week to have it paid• No opportunity to develop job skills, as unable to get stamina to keep a job,

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		<p>or experience to get one in the first place• Essential car user status of jobs even when employer claims to be a 2 ticks employer – I was not interviewed because I ticked the box saying I did not have a car now (but I would get one if I got the job). This was not listed in the application as essential for the job. This means that if you cannot afford a car until you are in work, you cannot get a job. If you are on medication or have any other disabilities that prevent you driving, but can be driven by someone else, you cannot get the job. • Companies house do not have to make adjustments under DDA, which prevents disabled people from setting up a company, without having to depend on others to help them• Examination boards, eg Signature, do not have to make adjustments for disability, and refuse to make adjustments to their homework service either• Challenging bad practice under the DDA, can make it harder to get employment in future, as employers ask about whether you have any history of employment tribunals and will refuse employment if you have• Challenging bad practice through the DDA is stressful and requires skills, stamina and resources that many disabled people do not have. This legislation is therefore ineffective. We need a service to chase up discrimination on behalf of the disabled, and it must also be illegal to discriminate against applicants who have brought action through the DDA• I was refused a job by a public sector organisation when they found out about my disability, after I had a written job offer. The public sector needs to get its house in order on disability discrimination• The NHS is risk averse. Nurses and Psychiatrists positively discourage people from going back to work. They do not listen to the Occupational therapists, who know better, that work aids recovery. • There are not enough occupational therapists. They should be available to everybody through primary health care, via the GP, and/or through the jobcentre. They are not adequately valued. They are not heard. They are THE most important profession if you are going to help disabled people to live more meaningful and independent lives, with participation in society. If you are to address this issue throughout the UK, it would be best to provide OT through the job centre, (for all degrees of disability), as then you get around the inequalities caused by devolution, and around the medical model professional's lack of appreciation of their role. OT would be better provided outside the health service. • Jobcentre services discriminate against people with more difficult disabilities. I was told that the health condition management programme was only for people with mild to moderate problems. They wouldn't let me on it. This is against the DDA, services must be accessible to all• I wanted a voluntary work placement with an MP, doing constituency work. But I was told my benefits would be under threat if I did 'political work'. Why??????• Mental health services are not accessible to people with dyspraxia. The service providers don't know anything about it and because they don't screen for it people don't get the help they need. • Job centres should screen for learning difficulties, dyspraxia, autistic spectrum disorders, ADHD, etc, especially where it has been difficult for an individual to keep a job.*</p> <p>• Dyspraxia causes problems that can look like bad attitude, inflexibility and poor team working. There needs to be an awareness campaign. 1 in 7 people have dyspraxia. (Probably far more as many not diagnosed at all, and many only in adulthood). Dyspraxia is often missed in people who achieve well academically, even though it is common in intelligent people• The jobs disabled people are best qualified for are going to people who have already had more work and life opportunities. EG lay places on health care regulatory bodies, service user and carer engagement workers, public and patient involvement workers, trainers for mental health first aid• In Wales training to become a mental health first aid trainer costs £1000 if you are not employed. £750 if you are a public sector worker, or work for a charity with over a million turnover, and £500 if you work for a smaller voluntary sector organisation. This is</p>

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		<p>the kind of job people with mental health problems, would be best at. And yet they are immediately disadvantaged. How many on benefits could afford this? And the job centre won't pay for this either. • Disabled people are exploited in schemes like the expert patient programme. It seems to be OK to ask us to do things for free, instead of giving us the dignity of paid work. The expert patient programme, also fails to treat 'patients' as experts. It has to be read out of a book, which was probably not written by a patient, and which is not flexible enough to deal with the specific issues in a group. This kind of work needs to be more sophisticated, and there needs to be positive discrimination to ensure that disabled people get paid work in disability equality jobs, as well as the jobs listed above*</p> <p>• Too many jobs, especially in the public sector are only advertised over the internet. Many disabled people cannot access this information. Too many services also require internet use and internet and other services increasingly use pin numbers, which excludes many, many people with concentration and memory problems • Most disabled people, however talented they may be, end up, if employed at all, in low paid, low status jobs. • Most interesting jobs require considerable administration. People with dyspraxia struggle with this. • Most jobs are not set up for people who are slow*</p> <p>• Poverty exacerbates isolation for people with mental health problems • People with mental health problems may be physically able to do things, but mentally unable due to self neglect, anxiety, delusions, stress intolerance, side effects of medication, • Language issues – all children should be taught BSL and Braille in school. People need to be more aware of communication difficulties for ASD and dyspraxia.*</p> <p>*</p> <p>Question 2 I don't think it is beyond the wit of bureaucrats to cope with the current 3 levels of care and two levels of mobility. It is important that there is not too big a jump in the money from higher rate to lower rates, as people may improve medically before they have adapted to being more able. Recovery and rehabilitation is a very difficult process for the whole community around someone with a disability. For instance it may be hard to get people to stop helping you, to let you do more, for carers to deal with feelings that they are no longer needed, to get back into society after a long break. To get out of the attitude of being a patient.*</p> <p>*</p> <p>As you say, recovery can be slow, and up and down. It can be very difficult to draw a line and say, 'now I am better'. You only know you are better after you find you are able to do more.*</p> <p>*</p> <p>Question 3 Substitute activities when unemployed This is critical with mental health problems and learning difficulties. Boredom increases mental disturbance, deskills people, undermines social skills, makes learning and adapting harder, reduces opportunity to develop informal social support, increases isolation*</p> <p>*</p> <p>Taxis/public transport (trains) Help with household tasks and management Special food requirements*</p> <p>Prescriptions (++++++) – fortunately as yet, not in Wales Prepared meals/café meals Additional services eg psychotherapy*</p> <p>Additional accommodation costs – eg when mental health problem management may require being away from home, with various levels of care, eg B&B, for short to medium term Legal fees to deal with discrimination Cost of accessing medical records *</p> <p>*</p> <p>Question 4 • Will having two rates ..? NO • What if any ..? The cost of disability is on a sliding scale. There is no sudden jump in need or cost. A two level system is likely to mean that people will go from high to low, before their costs are reduced to that level. The more stages on the</p>

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		<p>slope, the fairer the benefit will be.*</p> <p>*</p> <p>Question 5 The two issues are not incompatible. Yes some should have an automatic entitlement because certain conditions necessarily have high level and on-going needs. Eg Untreatable deafness and blindness. Partially sighted. Permanent physical disabilities like cerebral palsy. The idea of each person's needs being individually assessed sounds to me like an employment strategy for assessors. It will cost more to administer than having automatic entitlements, and will inevitably require a horrendous form/application process, with inevitable inequalities and confusion.*</p> <p>It will be difficult to see how some circumstances, apart from wealth, good quality appropriate adapted accommodation, or institutional living, affect their situation/costs. Eg. You might assume that another adult in the household, eg a partner, off-spring or other relation, will care for the claimant. But this is not necessarily the case. My husband is adamant that he is not my carer. He does not take time off work to ensure my safety. He does not cook for me (apart from Sunday lunch every other week), he does not do any of my chores, eg washing, shopping. He is a self-sufficient and secluded individual, so he doesn't even provide much company. He actually makes things a lot harder much of the time, by constantly complaining about my difficulties and how hard he has to work, because I do nothing. If I lived alone, I would be much less stressed and probably better able to cope. My chaos would not be upsetting anybody. A lot of people have a complex mix of problems. Do you consider coping skills, and motivation to be independent as part of someone's circumstances or needs?*</p> <p>Question 6 Here is a question full of value judgements, which are, by definition, subjective. 'Not everything of value can be measured, and not everything that can be measured is of value.' The basics – breathing, drinking, eating well, sleeping enough and regularly, urination and defecation, cleanliness and hygiene, exercise, dressing, having a home, domestic maintenance- bills, shopping, repairs, chores, social contact, valued occupation, entertainment, healthcare, dignity, communication, positive relationships, companionship, meaning and purpose in life, employment, having a family*</p> <p>It is only when you cannot do something that you realise what impact it will have on your life. But for instance, one person with an amputated arm will become completely unable to function, and another may still be able to hold down a job in the construction industry (real life example known). It is impossible to make 'objective' judgements about the effect of disability on different people. Someone with a lethargic personality, may cope well with inactivity, when someone else with a lively mind, will go completely mental. Someone reclusive will be happy with isolation, when someone who is very gregarious will be extremely badly affected. One person with paraplegia, like the young rugby player who went to Switzerland for euthanasia, will give up, another like the man who played superman, will keep acting.*</p> <p>I can cope with journeys that I do regularly, when I know the way, the bus the train, etc. I get very anxious about unfamiliar journeys, even if they are local. I can still manage as long as nothing goes wrong. But if anything doesn't go to plan, I freak out and cannot cope. How do you objectify that? How do you test it? In fact just being tested will increase anxiety levels. A train turning up late, or a missed stop because I fell asleep, will lead to unstoppable tears and total shut down.*</p> <p>*</p> <p>The same because of dyspraxia, familiar situations are fine, but new ones are very very difficult. I could not pass my driving test now, because I have such a poor sense of direction, and could not find my way without continually stopping to look at the map. However, in real life I cope by not making journeys unless I know exactly where I am going,</p>

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		<p>what lane I need to be in, etc etc.*</p> <p>How essential is essential? Are we talking about essential to physiology alone, or do we get a modicum of physical and mental well-being? How much? Is it right that disabled people should have to expect a poorer quality of life than those who have more opportunities and abilities?*</p> <p>It is much harder to quantify mental health needs. Can you imagine the hell of being pestered by hallucinations that are worst when you are inactive in your home? In this situation you need company, emotional support and activity, that you would not need with a more physical problem. Can you imagine what it is like always being misunderstood and misinterpreted, and treated like a leper, never getting what you need because people don't like the way you ask for it? What you need then is an advocate, and a relationship coach. Again, that would not be essential to someone with a physical problem. I think on reflection that this is the wrong question. The right question, is what needs do people have?*</p> <p>They need to be assessed for Social needs Communication needs Advocacy needs Emotional needs*</p> <p>Behavioural support needs Relationship coaching needs Valued occupation needs Family responsibility needs (they may be carers or parents themselves) Nutrition needs Vulnerability and safety needs* Housing needs Disability aids and equipment needs Personal care needs Household management needs Organisation support needs Routine management needs Sleep management needs*</p> <p>Medication needs Mobility/transport needs (This is not an exhaustive list, just what came off the top of my head)*</p> <p>*</p> <p>According to the social model of disability, people are disabled by society. Therefore the question is, what is society doing that is disabling and excluding this person? What does it need to do to enable and include them?*</p> <p>Question 7 Need to look at what circumstances/support/services maximise the health and function/independence of people with fluctuating conditions. ie maintenance needs. They may present well today, but to be well today they need to go to the gym 3 times a week, buy all their meals at a café, go to an art class twice a week, be supported by a social services support worker 8 hours a week, regularly use an advocate, see a relationship counsellor every week, and a psychotherapist. Take medication, manage their sleep patterns, monitor their mood, and regularly attend self-help/support groups.*</p> <p>Someone may be in remission because of such active maintenance, which has costs attached. If you down-grade their allowance, they may relapse not only costing more benefit, but also more for health care.*</p> <p>Need to consider what happens to people under stress, as this often exacerbates a dormant condition. What additional needs do people have when they get a flare up. eg More emotional support. More help with transport. Supported housing. More assertive personal care. More support to access services/hospital appointments. More rehabilitation support. Less demanding and more supervised activities.</p> <p>Precautions/additional supervision to manage increased risk.*</p> <p>Sometimes disability is affected by the weather. People may be worse in the winter (or summer). *</p> <p>There needs to be an easier way to go up and down the payment levels, rather than going through a whole assessment, it would be better if you just told the 'decision-maker/assessor' what has changed. For me, I used to be in severe danger of malnutrition, with significant weight loss. I rarely saw nurses, had no OT, had no access to community activities, had no NHS psychotherapy (but paid for less frequent private therapy to compensate). I was at much greater risk of self harm. I am now overweight, and whilst my diet is not healthy, I'm not going to fade away. I used to be admitted to a psychiatric ward every year, suffering</p>

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		<p>hallucinations and suicidal compulsions. I took several overdoses, which landed me in hospital. Now I am better able to manage my hallucinations and stress levels. I haven't been in hospital for 2.5 years. However, I am better supported, I have more access to activities in the community, I have occupational therapy support when I need it, I see nurses regularly, I have a direct payments worker. I have been diagnosed with dyspraxia, so now know that it helps to go to the gym regularly (which my support worker enables), and I have special supports in my shoes. I have psychotherapy every week instead of once a month, and I am on a higher level of CPA. I now understand better why people take exception to me and seek more help to manage those difficulties. My social worker says I am in 'remission'. Do these changes mean my care level should be reduced?? My life is better, but are my needs less? Not my decision. But I have serious problems with filling in that form, and when I declared my health had improved I was totally devastated that I would have to reapply, as making appointments and getting paperwork done are real nightmares for me.*</p> <p>My social worker didn't want me to say I was better because of the risk of relapse. If going back up to a previous level was easier, this would not be so much of a problem.*</p> <p>Question 8 Hmmmmmmmmmm. My gut feeling is that the necessity of aids is a good indicator of physical and sensory difficulties, but not of mental health, learning difficulties or even language difficulties. Will you take account of the need for a sign language interpreter, for instance? Or the need for a support worker? Or indeed the need for medication? You have to remember that the main disabling factor is society, and that remains the same whether or not you have the use of various aids. Its great to be able to scoot around on a wheelchair, but you still can't get onto many underground stations!*</p> <p>I'm not sure there is any evidence that aids reduce the cost of disability. You need more evidence for this. I know my stepfather needs a very expensive chair. Would you cover that? It is essential that the costs of any 'aids' are factored in. eg fuel for a scooter or electric wheelchair, maintenance costs, purchase or replacement costs. Often aids improve quality of life, but don't change the level of need. *</p> <p>What aids and adaptations should be included? Wealth. Second home in south of France. Swimming pool, especially if large indoor and heated. Servants, private health care, chauffeur. Luxury in general.*</p> <p>Should the assessment of a disabled person's ability 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>I don't think people should be penalised on the basis of aids they do not have, as their lack may be due to oversight or supply problems. It would be good however, if you identified a need, that you made a referral to local services to provide for it. *</p> <p>There may be other reasons why an aid is not suitable. Discomfort, fear, beliefs, maintenance issues. People should not be forced to take a 'treatment'. That would be dictatorship. *</p> <p>Question 9 Some one else did it for me, and I got several supporting letters from professionals to back it up. It helped to have someone with a specific speciality in my kind of disability. It would probably be better to have different forms for different categories of disability, to better reflect different needs. Eg one for sensory impairment, one for mental health, one for learning disabilities, one for learning difficulties, one for physical impairments. You could even do it like the tax forms, so people choose the bits that apply to them. I would need to do one for mental health, one for learning difficulties and one for physical health.*</p> <p>Changes need to be reported separately, not with a re-application. A narrative description of the change should be enough, through a professional, like a GP or consultant, or other health or social care</p>

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		<p>professional. *</p> <p>How can we improve ...? You need to provide advice to professionals. It was a voluntary sector worker who suggested I got advice on benefits. Before that I had no idea I might be eligible. I had to be encouraged to apply for incapacity benefit as well. With my kind of problems, you don't put yourself in these categories.*</p> <p>Perhaps all health and social care assessments should have to identify whether someone may be eligible for such support. Maybe everyone on incapacity benefit should be screened? People with less obvious disabilities are not going to know. Many women don't apply for benefits. This can only be addressed for them through professionals.*</p> <p>It is very important to get across that this is not only for the unemployed. The advisor who filled in my form was horrified that I wanted to work. She is an expert and yet she still thinks it is not for the working wounded. Maybe you need to target information at employers, who may be employing disabled people. Getting the benefit may help them to stay in work.*</p> <p>Question 10 Occupational therapists are the best placed to assess occupational needs related to disability, and social workers to assess inclusion needs. BUT these professionals specialise and cannot provide a generic service. You need to have specialists in each of; sensory impairment; physical disability; mental health; and learning disabilities. Everyone should be screened for learning difficulties as a matter of course, because these difficulties are very common, massively affect independence and social inclusion, and most people, including professionals, don't know enough about them and the needs they cause, and they tend to fall through the gaps in services usually leading to significant unmet need.*</p> <p>To assess needs properly, you need to be able to make an unannounced visit to the person's home, so that you can get a good view of how they live. Perhaps this needs to be done by a professional working with the person concerned. *</p> <p>Reports from the person's social worker, OT, GP, psychotherapist, Consultant are all valid. (But never ask a nurse – they think they know everything, but don't, actually). You need assessments/reports from people who know the person well over a long period of time, to get a full picture of the overall impact on their life. One off assessment will otherwise miss some serious problems.*</p> <p>Question 11 From what I have heard about existing assessments by doctors employed by DWP to do this work, there is a tendency to dismiss real difficulties and focus only on specific tests which may not reveal an individual's problems or needs. The attitude has been described to me as disdainful, as if the assumption is that everyone is cheating, and they are trying to catch them out. There is real fear in the disabled community that people in real need will suffer when this new system is introduced. The tests I have heard about all relate to physical health, so I am also worried about whether this will be fit for purpose. *</p> <p>I think there is a serious problem with any professional doing only this. They will obviously, quickly acquire a jaundiced attitude, because they do not know the person sitting in front of them, and have not witnessed their difficulties over time. They are no longer involved in finding solutions, which will be demotivating, and will render them out of touch with current practice.*</p> <p>I think it is important for assessors to visit applicants, when necessary, and not expect them to be able to get to, or cope with an assessment in a strange place. But it is no good going to assess a deaf person without a BSL interpreter. You might as well give them an audiophone interview!! Alternatively, perhaps you should teach all assessors BSL! It is important that applicants have access to support and/or advocacy. *</p> <p>However, if an OT and social worker do assessments, and make recommendations and referrals, which help people in addition to any</p>

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		<p>eligibility evidence collecting, the process will always have a benefit to the applicant, whether they receive benefit or not, the assessors will be more motivated, and so everyone benefits.*</p> <p>Are there any circumstances in which it may be inappropriate to require a face to face meeting with a health care professional – either in an individuals own home or another location? The last time I was approached for an assessment, I was on the acute psychiatric ward. I guess that was pretty good evidence of the problem! They said they didn't need to see me. *</p> <p>Some people with mental health problems won't answer the door to familiar professionals, let alone DLA assessors!! *</p> <p>There are issues with people with delusions. They may well 'act up' to appear good to outsiders. This is why they often slip through the net when they should really be getting more assertive treatment. It is important to consider the views of carers. *</p> <p>People with severe behavioural problems, such as severe autism, will not only be likely not to cope with the presence of a stranger, they may also put the assessor at risk. Therefore any visit needs to have a risk assessment where an applicant may be violent, or distressed.*</p> <p>Question 12 If a person has a congenital disability that cannot be cured, they should not have to ever be reviewed. Eg deaf, blind, cerebral palsy. Unless their needs increase – which they won't if they are already on the top level of benefit. *</p> <p>The longer someone has had a disability, the less often they should be reviewed, as they are unlikely to miraculously and suddenly recover after years of difficulties. At the beginning of the benefit, with conditions that may recover eg stroke, more frequent reviews might be justified, up to the point at which no more progress is likely to be made.*</p> <p>Probably mental health patients are the most vulnerable group, who will be most disturbed by excessive assessment, even though they may also recover. It is very difficult to be secure in any recovery, since it is so common for relapse to occur. This is probably the most difficult group to judge. Maybe you should be guided in the first instance by the professionals involved in the applicant's care. Although it is also essential to take account of the carer's views as often the professionals don't see the problems especially if they don't take evidence from carers.*</p> <p>In other words, approach the care coordinator first, to assess whether a change has taken place that would justify a review.*</p> <p>Should there be different types of review depending on the needs of the individual and their impairment/ condition?*</p> <p>Yes. Only use OT's or social workers who specialise in the care of the type of disability of the applicant. And have questions/tests relevant to that difficulty only. Where need is obvious, as in being on the acute ward, you don't need an in depth review.*</p> <p>Question 13 With some problems, like mental health its very difficult to know if you are better. It is only when you face a challenge and see whether you do, or do not cope. A peaceful period may appear to be a recovery, when it is not. It also has a horrible habit of coming back just when you felt you were finally in control.*</p> <p>I think you are unlikely to make it easier to understand whether or not someone is likely to be eligible. Disability is extremely complex. If you think it can be simplified, you don't get it. Most people have nothing to compare themselves with, and will probably underestimate their needs. I know both my parents did, and my step-father is also very reluctant to see himself as disabled. (He has Huntingtons Disease). Most people will put up with a lot and still not want to see themselves as disabled.*</p> <p>I had to be directed towards applying for benefits. I would never have sought them otherwise. Its much easier with physical problems. *</p> <p>I recently reported an improvement (against the advice</p>

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EM583	13-Feb-11	<p>Sir/Madam My name is [REDACTED] and I am a Carer for my son [REDACTED] who has Autism, Learning Difficulties, Tourettes Syndrome, Epilepsy and other associated factors. I am very concerned about losing Carers Allowance as my son might lose his benefit if the Government plans go ahead. *</p> <p>I do believe that the process for applying for DLA should be streamlined and made easier and clearer but the DLA itself should be left alone. Autism is a very misunderstood and complicated field and can change from day to day so any assessment would be incredibly imbalanced and unfair. Disabled people have a rough deal in life as it is and are unable to improve thier life beyond thier financial boundaries and need every penny to enable them to access services which they so desperately need.*</p> <p>The Government should not be making cuts of 1bn to Disability payments because of the devastating consequences it could have for disabled people and Cares like myself and the result hardly bears thinking about. Carers Allowance should remain outside of the Universal Credit as Carers save the UK 87bn a year with the care that they provide and deserve the utmost respect and due recompense for the extremely difficult job that they do. It would be very unfair to take away Carers Allowance from some Carers by means testing as this would leave some Carers without any recognition of thier contribution. It would also have a tremendous impact on the quality of life for the likes of myself as I would no longer be able to afford anything and would seriously worry about my ability to carry on my caring role.*</p> <p>I urge the Government to give serious and immediate consideration to thier plans to reform DLA and Carers Allowance and be aware of the catastrophic consequences to millions of vulnerable people on DLA and the Carers whom they rely on an who do such a noble and courageous job, We deserve respect and recognition Sincerely</p>
EM584	13-Feb-11	<p>1. Your response: Society itself and the media... The sensationalism of the press when someone with a mental health issue kills someone. Take schizophrenia as an example.... 2% of all killings are committed by someone with schizophrenia, yet the outcry is disproportionate. How about the other 98% of killings? They must be carried out by so called "normal" people. Stigma kills..... more people with mental health problems kill themselves than they kill. *</p> <p>I have tried hard to fit in society, becoming and leading a independent active life. This has led me to try and kill myself many times, my daughter managed it. Why do we have to conform and fit into your society? We see the world in a completely way. Day centres help to stablise my life, along with therapy and helping people. To me this is a full and active life. To push me into a job or some other dreamt up scheme is shear torture to me. Then if I cannot keep myself and others safe, I will get locked up costing the tax payer hundreds of thousands of pounds.*</p> <p>DLA is helping me to have someone with me, when needed, allowing me to do other things and to keep safe. When I am unsafe I know I can book into a hotel or get a taxi or to call someone to get to me and help me to keep safe.*</p> <p>2. Your response: It works... yes I guess there are some people who maybe abusing the system, but I believe they are rare and far between, so why punish the rest of us who are struggling within society. Do you want to push us over the top?*</p> <p>3. Your response: There are no "MAIN" extra costs, it just costs far more to keep safe, it doesn't matter if it is when you are in manic and go on a unchecked spending spree.*</p> <p>Or if you need a taxi to get to a safe haven, or to pay for a friend to stay of to get you. Maybe you have wandered off and need a train ticket to get home. I cannot my own meals, I don't even have a cooker because when I did I kept on having fires because I would forget I put something on the cooker. So my food costs more. When in a regressed position, then I need nappies and clean bedding. But how can you understand just what</p>

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		<p>we go through. Our energies go into keeping safe.... not just for our own lives but for the lives of others. We are not bad people, but often very scared and full of fear. Like a little baby in a world of big people..... it is very scary. When full of fear, then everyone becomes a threat, when threatened, you are likely to lash out.*</p> <p>4. Your response: The system as it is seems to work fairly well with three rates for care and two for mobility. Why change? It is just giving more jobs to more bureaucrats. Keep on changing things all of the time is confusing and wasting much needed resources. *</p> <p>5. Your response: Why the question? Of course certain health conditions or impairments should be automatic. Make the local GP responsible for who should be on the benefit or not. The last time I had to go for the all work test landed me in hospital. I took an overdose and went to jump from a main road bridge. Whilst I am calm and steady, then I think fairly rationally, but with just some stress can take me over the top. At the time I was in a care home, I had a psychiatrist, five therapists, a social worker, my GP all saying I need to be in a place of safety and the Jobcentre not believing all these people and said I needed to go for an all works test interview. My mind said all my care team must be a bunch of liars, because the Jobcentre thought I could be able to do a job. It took a lot to start to trust my team and just an afternoon for the Jobcentre to wreck that trust.. I just wanted to get rid of everybody.*</p> <p>6. Your response: To be able to live in a non threatening society. To be able to be who you are and wear what you feel comfortable in. Not have to be what you are not To have enough money to live on, not to have to think can I have the heating on when cold. There were times in the cold spell where my main room was often around six degrees centigrade, the rest of my place was even colder. To have enough money to have a treat now and again or something I dream of is one day maybe a holiday, I know that is just a dream.*</p> <p>7. Your response: My condition can change by the second I can be very rational and then someone say something that don't make sense so I go into confusion and then become unsafe. So what would help me? To leave the system as it is..... it is working so don't fix it.... You could make the present system a bit easier for people to understand it and make it a lot easier, so has to stop the anxieties of appeals etc.*</p> <p>8. Your response: If you are disabled or cannot function within society, then that is punishment enough, why do you want to make it harder for them? If an aid or medication helps a little.... that's what it does is helps a little, why shouldn't they be able to also enjoy their lives? If you can get around you are not penalised, so why if you don't function properly?*</p> <p>9. Your response: Give the form to the different disability / LD / MH service user groups to come up with an easy to fill in form.*</p> <p>When I see a question like the second one..... this worries me.... what is says to me is.... we are going to make your life even tougher than it is now, we are determined to cut benefits and we do not give f*</p> <p>*</p> <p>*</p> <p>about who kill themselves. We really don't give a toss because we are alright jack, we can function and we got a job making lots of money at the expense of ill or disabled people. We will roll out this new benefit even though we do not know the impact it will have on people.*</p> <p>10. Your response: A report from the person's care team including the GP*</p> <p>11. Your response: Once again you really do not know or have any understanding of anything but your own warped perception of life.*</p> <p>Unless the healthcare professional is one who knows the person, then they will always pick up what is required. It took me many years before any health of social professional could start to understand what is going on for me. I once had a new social worker and he thought I was alright and could go looking for a job. It was only when a care plan meeting was</p>

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		<p>called and he told my psychiatrist what he thought was good for me. The psychiatrist went nuts and removed the social worker off my case. He knew that I would agree with anyone, yet I was also under the forensic team. I was at a very high risk to self and/or others. I couldn't tell the social worker what was going on for me because I didn't trust him. So a face to face meeting with someone I do not trust could put others at risk. Workers are not allowed to come to my home, so someone I do not know could come to my home. I hope they do not trigger me.*</p> <p>12. Your response: The evidence must come from the care team. There needs to be different types of review depending on the needs of the individual and their impairment/condition*</p> <p>13. Your response: By giving them a yearly reminder to inform the department.*</p> <p>14. Your response: What they are entitled to claim. That is the one failure of DLA, it is very hard to understand the criteria and to be able to claim. So a easy step by step flow chart.*</p> <p>15. Your response: Do not understand the question you are asking.*</p> <p>16. Your response: ???????*</p> <p>17. Your response: ???????*</p> <p>18. Your response: Once I got to know about DLA it made my life so much easier and has kept me out of hospital. It has helped me to fund activities that I couldn't afford before.*</p> <p>19. Your response: Didn't know of any other help available. Though I still struggle to keep within my budget, without DLA then life wouldn't be worth living and I will be joining my daughter.*</p> <p>20. Your response: Why do disabled people have to jump through all of these hoops? How would you like it if you were constantly under a microscope? Why can't people who need disability benefits also have some human rights?*</p> <p>21. Your response: I am getting more and more despondent, the more I read, I am feeling more and more at risk. *</p> <p>22. Your response: Is this a public consultation? Or is this a "This is what we are going to do, now we shall pretend to have a public consultation. People are getting restless with the way you people are treating us as fools. We know what the outcome of that is from history.</p>
EM585	14-Feb-11	<p>i care for my husband [REDACTED].Iunderstand you need to remove people from dla who are claiming it for trivial ailments.My husband has Parkinsons and i think people with terminal illnesses should automatically receive it without having to fill in complicated forms.I am working part time at the moment to make ends meet but if dla was changed can you please tell us what will happen about our car,this is a lifeline ,as it means i can take [REDACTED] out to the beach or just to the shops.it would make life impossible if we had to rely on public transport as due to his condition his movements are sometimes ok then he can just freeze i can cope with this ,getting him to the car and in it but to be on public transport if this happens then trying to get him home from the bus stop would be impossible.please think carefully about this decision ,think about the people it affects.It affects the whole family not just the person being cared for. I receive carers allowance at the moment ,so i dont know how we would be affected by the change but like most carers this helps the day to day living the wages i receive from working pay the essential bills ,like heating ,phones, tvlicence,rent and oher bills.Carers allowance gives us a little bit freedom and buys the food pays the petrol if it was taken away we would struggle.*</p> <p>Please think of the whole family not just the person who needs caring for and the carer there is usually a family involved as well.</p>
EM586	14-Feb-11	<p>Hi, i have 3 points on updating dla to "reflect wider changes in society":*</p> <p>1. Current system too focused on care; independence more important to me.*</p> <p>2. These days people are more likely to be single + live alone; so</p>

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		<p>shopping + cleaning should be included.*</p> <p>3. To work from home +/- or my bed + communicate with my family i need a mobile and computer with internet with associated costs. Along with taxis, "communication" is therefore a key cost for me.*</p> <p>And i have a point on simplifying the form: state the criteria for each area being assessed, then say for example "does this apply to you?" a) people then wouldnt need an advocate to "know the right words to use" b) it would be simpler both to fill in + to process/administer</p>
EM587	14-Feb-11	<p>1.Poverty is a significant barrier to disabled people participating in society. For example, in my experience of working with learning disabled people, I have encountered many cases of people unable to attend social clubs because they cannot afford the transport and support staff costs. This is extremely regrettable as friendships can be made at social clubs which can reduce the need for paid staff support in the future. *</p> <p>2.I believe that the existing arrangements for DLA are reasonably sound and that the benefit is a cost-saving one which prevents many people from needing to use local authority social care services. *</p> <p>3.- transport - heating/laundry bills - attending medical appointments - aids and equipment*</p> <p>- home help - replacing furniture/household goods - leisure/holiday costs - home adaptations *</p> <p>- special diet - special clothing - safety equipment *</p> <p>4.It is very important that the lower rate of Disability Living Allowance is not lost. Many people receiving the lower rate of Disability Living Allowance are not eligible for local authority social care services. They nonetheless have significant support needs. If these individuals receiving the lower rate of DLA lost their entitlement to assistance I believe that the health and quality of life of many would deteriorate. This may well lead to them requiring a higher level of Government or local authority support in future. The lower rate of DLA is a stitch in time which saves nine. *</p> <p>5.Yes, some health conditions or impairments should mean an automatic entitlement. I would include in a list of such conditions:• Moderate, severe or profound learning disability • Dementia• Schizophrenia and schizo-affective disorders• Personality disorder*</p> <p>6.Your response:*</p> <p>7.Your response:*</p> <p>8.Your response:*</p> <p>9.Introduce an option to complete shorter form for those people who having existing recent documentation of their needs, e.g. in a social work or occupational therapy report. *</p> <p>10.The person who is most involved in supporting the claimant should be the person to provide supporting evidence. If supporting evidence from an independent professional is required, then I would suggest that a professional experienced in assessing day-to-day functioning, such as an occupational therapist or a social worker, would be best placed to do this. *</p> <p>11.Discussions with healthcare professionals who are strangers are likely to cause severe stress to some claimants, including those with learning disabilities, autistic spectrum disorders, mental health difficulties and fluctuating long-term conditions like ME and MS. I understand that the healthcare professional is likely to be medically trained and struggle to see that this kind of professional is best placed to assess a benefit which should be based on a social model of disability. What should be assessed is how the claimant is able to function in terms of activities of daily living and a functionally-trained professional who knows the claimant already is surely best placed to do this (by means of the provision of supporting evidence). *</p> <p>12.Your response:*</p> <p>13.Your response:*</p> <p>14.Your response:*</p> <p>15.I do not believe any such requirement is necessary. I don't believe</p>

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		<p>anyone prefers the kind of hand-to-mouth existence which goes with being on disability benefits. The majority of disabled people want all the advice and support they can get. *</p> <p>16.Your response:*</p> <p>17.Your response:*</p> <p>18.Introduce individual budgets combining funding streams and a genuine single assessment process.*</p> <p>19.A great deal more paperwork, stress and distress. *</p> <p>20.I am in favour of a system based on the individual budgets concept piloted by the previous Government, bringing all the funding streams which support disabled people together. *</p> <p>21.Your response:*</p> <p>22.To begin reform of a welfare benefit with the target of reducing expenditure by 20% is fundamentally wrong. This suggests that there are large numbers of current claimants who shouldn't be receiving the benefit and this is simply wrong. Disability Living Allowance is a benefit which makes life livable for disabled people. It stops many people's conditions from deteriorating and so prevents higher spending at a later stage. DLA fraud is absolutely tiny; about the same level as DWP administrative error. If the Government addressed the huge issue of tax avoidance, evasion and maladministration, cuts to DLA and to many other services and benefits would be entirely unnecessary (see Richard Murphy's tax research). *</p> <p>* The removal of the mobility component of DLA from people living in residential care*</p> <p>I am extremely concerned about the proposed removal of the mobility component of DLA from people living in residential care. My concerns are encapsulated by the Disability Alliance in its interim response to the DLA consultation, recently published on its website. Please see the text below and my comments on it:*</p> <p>* "We are opposed to the removal of the mobility component of DLA for people living in residential care.and potentially their families." As someone with a particular interest in the wellbeing of people with learning disabilities I would add that the removal of DLA from people in care homes would jeopardise the Valuing People agenda which the Coalition Government has endorsed. "The mobility component of DLA helps people to pay for things like accessible transport, requirement of care law." For empirical confirmation of this please see the report 'Don't limit mobility', recently published by a number of disability NGOs, including Mencap. "The Prime Minister and other Ministers DLA entitlements." *</p> <p>I would add that I believe disabled people who live and work in rural areas are likely to be particularly badly affected as they will simply not be able to afford the taxis which constitute the only means for them to get to work. "It also risks preventing implemented." We believe the Government must reconsider the impact of this proposal to understand the harmful outcome and should target reducing the national deficit elsewhere – Disability Alliance supports a financial transactions tax for example, with revenue raised hypothecated to tackle UK poverty</p>
EM588	14-Feb-11	<p>Dear Sir, Having read the DWP public consultation "Disability Living Allowance reform" in the course of conducting a piece of research into the relationship between concepts of disability and the benefit system, I wish to respond, specifically to question 4, part II (chapter 5) - "What if any, disadvantages or problems could having two rates per component cause?" *</p> <p>I notice the document makes repeated reference to the individual, better reflecting the individual's needs etc. (pg. 3, 4, 14). Under the current system of DLA there are two components, with a total of 5 rates between them, allowing for 11 possible combinations, depending on the</p>

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		<p>individual's needs. Under PIP, there will be a total of 8 combinations from the two components, each of which contain two rates. Surely this will only further hamper the system's already inadequate means of recognising and catering to the vast array of needs that are represented by the millions of individuals who comprise the disabled community? Undoubtedly this will result in simplifying the benefit (another primary goal of the reform), but in an especially clumsy way, with the cost far outweighing the benefit. I would be most interested in hearing your response to this issue. Yours sincerely</p>
EM589	14-Feb-11	<p>Question 1 – Problems/Barriers. The biggest barrier is the inability to include Disabled people within everything the community offers.* The Social Environment is not accessible for full inclusion and therefore discriminates – laws have been provided to be used so that organisations/work-places/leisure/and private organisations are aware of the need to make their organisations and buildings accessible but these laws and guidance are ignored on a massive scale and no Government yet has decided to use these laws to take these barriers away. Consequently Disabled People remain still unable to access work places of their choice, leisure activities, go shopping or even achieve voluntary work.* Good example is a Hotel in Leeds that realised 11 years after the DDA came out that due to not being fully accessible organisations were refusing to book with them for Conferences and overnight stays. They were starting a rolling program the following year to achieve this in the mean time they had lost around a million pounds worth of business the previous year. Not unusual this story to Disabled people.* There is little support for Disabled People to get back into work from Long term or short term Convalescence, support that was to be made available initially for a year was reduced and reduced till it is none existent to most Disabled people. The Government wants more disabled people into work but until the work places are made accessible they cannot and anyway where are the jobs for disabled people? Many Disabled people know of others who lost jobs at Remploy when they were closed down. In certain areas they were offered jobs, which only had support for 3 months and due to this lack of support when needed they lost the initial job and ended up either on the dole or working in jobs that made them feel of little value.* Disabled people are seen as easy targets for dismissal and are unaware of their obligation to disabled people morally in the work place. If it was possible to be counted those people with a disability would be the highest sector of the community who were out of work at the moment we would surmise.* Disability has no age limit and the Disability Movement has never understood the DWP's inability to accept this fact. Now with the added Age Discrimination the consultation gives the opinion that because of this the DWP will be reconsidering this fact. Of course the obvious fact now surely is that to limit this benefit given to those with a disability only up to the age of 65 would be against the law and only if they meet the criteria of the benefit should they be access and not by age.* Question 2 - anything that should stay the same? As no one is aware of what you are considering changing, other than what you imply in this consultation, then this question can never be answered fully, so we can only comment of the changes that we are consulted on and any other changes will be open to be challenged when we are aware of them in the future. Concerns from many on how this benefit will be able to be singled out for the hire of an accessible vehicle have been raised. If it comes with other benefits to the claimants how are they able to 'sign it over' to those whom they have the vehicle from?*</p> <p>Concerns have also been raised of what 'key activities' will the DWP expect the applicant to try to achieve that will answer the questions that</p>

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		<p>allow them to meet the criteria for receiving the benefit?</p> <p>Activities like lofting a bag of sugar in past have not been beneficial to meeting the criteria for the Mobility Section of this benefit for instance. It is felt that the area of 'key activities' should be identified in consultation with Disabled people and would ask that this be achieved.*</p> <p>Question 3 – Costs faced. Both sections of this benefit are given to the applicant because they experience EXTRA costs in their life because of their disability.*</p> <p>Until society is equal in what it delivers to all members of the public then this will always be the case – disabled people experience greater individual costs in their life and as is the case now....this benefit because of what it stands, for should not be included in any means tested.*</p> <p>Neither sections of this benefit meet the full extra costs of having a disability in this age. You could not buy a battery/electronic wheelchair or an electronic communication devise with either section and certainly the 'daily living component' does not meet the needs of those who should have assistance in their lives. No one is expecting either of these sections to be improved financially, but never the less it still has to be said.</p> <p>With the lack of accessible transport available and now the downsizing, by the cancelation of many routes, of even that which is accessible, means that taxis will probably be used more than ever, certainly in the rural areas, will this be considered?*</p> <p>Question 4 - 2 rates a problem? Will this mean that the DWP be developing 2 separate forms for people to fill in instead of the massive one now?*</p> <p>We would say that this can only be an improvement ONLY if the forms containing the questions are applicable to the outcome and that duplication of information does not keep occurring.*</p> <p>The Disability Movement in its many forms can never understand why the same information has to be sent again and again; that within departments and from others this part of form filling can be minimised a lot more than it is at present. Technology is available to do this so why is it not used for the benefit of Disabled people and the DWP? Departments should be working together to stop this duplication and we have been told for many years that this is occurring and will get better, but disabled people have seen little result from this claim.*</p> <p>Question 5 – some conditions mean automatic entitlement? This is another area that has always frustrated Disabled people. Some conditions should automatically ensure continuation of their benefit without further assessment of their benefit/s. It should be a decision that is taken in consultation with the client when they should return if the condition or impairment is progressive and of course the claimant can always call the DWP for an appointment for an update on their assessment at any time their condition has changed.*</p> <p>There should be more consultation with the claimant in this area and it is believed that if this happened then more people would be willing to work WITH the DWP and not feel that contact with them automatically means a drop in their benefits and ultimately their finances – which is certainly the way it is at the moment.*</p> <p>Would defiantly agree with ensuring that the person who is claiming benefits must be in residence in the UK before they are able to receive their benefit.....except that it is well known that many UK residents go way to a warmer claimant in our winter months. How will this new condition affect them?*</p> <p>Question 6 – activities essential to daily life? These are personal to each individual and should be part of the consultation with the claimant. The form probably is not able to identify everything – although it tries – and so communication with the applicant is necessary. Perhaps even a visit!*</p> <p>What is important to one person might not be for another and no assumptions should be made on what a person is capable of or should or</p>

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		<p>could achieve with their condition. NO ANYONE CONDITION ENABLES OR DISABLES A PERSON THE SAME WAY.*</p> <p>This also appertains to Question 7 on how new assessments can be appropriate?</p> <p>As it has already been mentioned that aids can be costly, especially the ones appertaining to speech, wheelchairs and the bathroom and that either of the benefits are not sufficient to pay for some of the items. For as individual budgets come in for all disabled people the use of aids is one of these extra costs cost that will need to be accounted for in the persons finances.*</p> <p>This continues further in to Question 8 when the consultation asks if the assessment should take into account any aids and adoptions? *</p> <p>All aids and adaption's should be included when considering this benefit as this is what this benefit started out to be for and should remain as – covering the EXTRA cost of those with a disability. *</p> <p>How can you take into account aids and adaptations that are already there when accessing for this benefit...they are there already!!!! This benefit is for what is to come – tomorrow, next week and next year.*</p> <p>Surely during the assessment and/or on the form there will be consideration for possible adaption's to the home and aids to assist in the life of the applicant for the future?*</p> <p>Question 9 – improve the process? The Form the way that it stands is very daunting to many and the availability of people to assist the applicant in the process of filling it in are few and far between.</p> <p>As already written no applicant is the same and therefore really no form can do the applicant justice in what their needs actually, as an individual, are. If the involvement of any other person does occur will the applicant be given a copy of any communication between them and the DWP – in case they might want to contest the actual financial or assessment outcome?*</p> <p>Occupational Therapist is one of the best people to assist in this assessment and the applicants Doctor should be the one person who is not involved. The Disability Movement is aware that the Doctor might know of the condition of the applicant but not what their aid and equipment adaptation needs are and have not wanted to be the person who has stopped the applicant from obtaining this benefit if it could help them in any way.*</p> <p>Question 10 – what evidence help provide and who to provide. As stated in the previous question the Occupational Therapist, as well as the physiotherapist are some of the best people to provide the information needed, along with any specialist that the claimant consults on their condition – this could be more than one.*</p> <p>When this comes to those with Special needs and those with Learning Disabilities, perhaps those who support them within any Day Centre could also assist with relevant information for this process.*</p> <p>Question 11 – important part for face to face interviews likely with health care professionals; what benefits/difficulties and are there circumstance inappropriate and what location?</p> <p>At any face to face meeting it should be strongly suggested to the claimant that they should have an independent advocate with them to support them. It is felt that this should not be their PA – personal Assistant and it is believed it should not be a member of the family either.*</p> <p>As for location – this should be up to the applicant. Most would prefer it was within their homes but others might not like this. Consideration should be given to their individual needs at the time of the appointment and were ever this face to face interview is held it should be in a place where private information cannot be overheard by others and all are agreeable with.*</p> <p>This also answers the part of the question about appropriateness of whether an appointment is needed – the answer being decided between</p>

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		<p>the applicant and the interviewer.*</p> <p>Question 12 – how reviews carried out; evidence and/or criteria of frequency of reviews; should there be different types of reviews? Reviews should be carried out in the place that the claimants would want/with the support (independent) that they desire and the frequency and criteria should be decided by the claimant, in consultation with the interviewer.*</p> <p>It seems a most inappropriate question to ask if there should be different types of reviews occurring depending on the needs of the individual and their impairment. The DWP and all those who are involved with these assessments appertaining to application for benefits should know by now that no disability or impairment is the same and therefore all interviews will be different just by the nature of the beast we are responding to. It is obvious that this question shows the lack of understanding from the DWP on Disability and Impairments and should not have been included.*</p> <p>Question 13 – how encourage people to report changes? The opinion within the Disability Movement and public is that reporting of any changes automatically means the withdrawal or reducing of the benefit they already claim and therefore there is reluctance in informing DWP of any changes in their lives. To change this perception will be very difficult and the assumption that the new system will automatically be welcomed, supported and accepted shows the DWP's inability to understand how the public view DWP in general. Nothing within the Consultation considers the effect that any change for those with Special Needs will have and the support they will need to come to terms with these changes and who will fund this?*</p> <p>Question 14 – what advice/information needed and provide this as part of claiming process?</p> <p>Any information on changes in benefits should be sent separately to those who already claim in their applicable requested formats so that within their homes they are able to understand it in their own time; also information should be sent with any future benefit process. This should be achieved as soon as is possible, advertising in the media of these changes in all forms; especially using the electronic media.*</p> <p>Question 15 – some form of requirement to access advice and support help encourage claimants?</p> <p>I do not think that making it a requirement to claim will encourage more claimants and certainly a detriment set. These benefits are available to those who wish to claim it and in a democratic society – which this is – we have a choice. If people decide not to apply for these benefits that is their choice.*</p> <p>Question 16 – how do Disabled people fund aids and equipment now and should there be an option to use the Personal Independence Payment to meet one-off costs? Whatever aids, equipment and adaption's are needed that cannot be funded by the NHS (equipment from Occupational Therapy), adaption's from grants locally and Nationally – if known off course – are funded by Disabled people themselves often having to do without because they cannot afford them. This of course has an effect on their disability, mainly to the detriment, which could then put extra costs on the National Health System. Some Disabled People take out loans, borrow money or get themselves into debt.*</p> <p>There might be an improvement of places that equipment can be bought – on the web, in magazines, catalogues, large stores for example - but most of them do not come with assessments and equipment is sold to people for the wrong reason and in the wrong size that also must put, in the long run, again extra costs on to the NHS.*</p> <p>The suggestion of this Consultation that there could be an option to use the Personal Independent Fund to meet the one off cost of equipment, aids etc is in theory a good one. But Disabled People would need to know what the criteria for this would be. Would this one off payment have to be paid back – if this is the case what benefit does this give for Disabled People when they then also have to live on a decreased benefit</p>

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		<p>or no benefit for whatever the period is of the repayment? This would reduce their independence in certain areas of their life, loss of assistance of going out for example.*</p> <p>Paragraph 38 – mentions whether changes to their Allowance will take account of this new Universal Credit. No matter what changes occur it should never be for the worse as these people save the Government/DWP a great deal of money and even if there is a considerable increase in their Allowance they are the communities and Governments natural saving and should not have to undergo any decrease in assistance.*</p> <p>Paragraph 38 – It is felt that this organisation is not as aware of what those with Children who have a disability are given in benefits to assist in their extra cost. But I am sure that it will not allow for the continual changes needed in; say a personalised buggy, for the growing child. If any changes that are considered for one off payments for items like the one mentioned, as when the Consultation speaks of adults – it surely should also appertain to children on equality basis. The parents of Disabled children have the extra burden of continual costs in all aspects of that child's life within the family structure.*</p> <p>Paragraph 40 – the child's extra needs do not stem just from the home but also appertain to all aspects of that child's life. There are extra costs for those children with a disability when it comes to the school uniform, going out on visits for example and these extra costs should be acknowledged in some way.*</p> <p>Question 17 – what key differences should be taken into account when assessing children?</p> <p>As this organisation normally deals with Adults it is felt that this question cannot be answered.*</p> <p>Page 24/figure 4 – shows the procedure for those already in receipt of benefits now claiming for the new benefit. The beginning of this process is all wrong. Why should those who are already in the system having to reapply – meaning fill in more forms when the majority of the information will be on the previous application. No matter what time has elapsed since their last assessment there should be no form filling in but a visit agreed to obtain any changes and for the collection of relevant information that will assist in the claimant being reassigned to this new styled benefit. This is one of those issues that have long frustrated Disabled people, the lack of ability for the department to use the information already at their finger tips. So it should be up to the DWP to contact those already on benefits and not Disabled people – it is the DWP/Government that has made these changes and not disabled people.*</p> <p>Page 25 paragraph 4 – within you're 'Glossary of Terms' there is nothing to explain the term "Passport". It occurs for the first time in this paragraph and you assume that this is acceptance of the new word and continue using it when to a greater section of the public will understand this as being the passport being used to get you into other countries. Also in this paragraph is the term 'in kind'. I have never heard of something that you have to be assessed for being given 'in kind' – my understanding of these words are that you do something or give something for nothing...the DWP does not!*</p> <p>Paragraph 5 – Disabled People would agree with the statement that benefits are overly complex and cause confusion. But the statement as quoted - 'consideration is to be given to what, if any, extra support may be needed in Universal Credits' is just as confusing when you then say nothing as to what they could be thus causing further confusion and concern.</p> <p>We hope that the changes could include the Freezer Benefit which are very confusing as to when they are to be given, who should get them and when this Benefit is sent.</p> <p>We also hope that the Annual Heating Allowance will not disappear in</p>

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		<p>these changes or be reduced as their benefit too many has been shown in the reduction of deaths of Elderly People.*</p> <p>paragraph 9/10 – whatever is considered under the section of Adult Social Care for Older and Disabled people within in their homes the Government/DWP should keep in mind the overall savings that happen when you either consider the cost of placing the people in this section of the public in specialist homes or on a ward in the National Health System. Staying at home for as long as is possible with the assistance of the care system still uses a great deal of finances but not as much and certainly with less physical and mental effect on the said people as well as the cost to other systems in the community. Confidentiality should be rigorously maintained within the departments of the Government that hold information about Disabled and Older People so that is may be passed appropriately between departments to save on time, cost and impact on Disabled People. There is a great need to minimise the paper work (bureaucracy) appertaining to the benefit system and this will be one way to achieve that objective.*</p> <p>Question 18 – how important DLA been for getting access to other services/what can be done to improve? DLA is not part of any assessment of any other benefit because this amount is given to people because of society's inability to have it accessible for disabled people and it covers the extra cost this incurs. For people on low income and with a person in the family with a disability this fact assists them considerably.*</p> <p>Apart from this we are at a loss to understand what other benefits you refer to? Just because people have put in for this benefit does not automatically mean that DWP send out information about other benefits, or show ways that disabled people can apply for other assistance. It is what should happen and it is what the Disability Movement have been asking for many a year but life is not made that easy by the departments of the Government. Usually Disabled People have found out from each other and other agencies of what is available once you receive this benefit. This is where joined up thinking of the Government departments would be beneficial and even though the Government says this happens, disabled people can categorically say that majority of the time it does not. It is thought that this answers the question about what improvements that you can make.*</p> <p>Question 19 – what are the implications if this benefit cannot be used as a means to get others? What a stupid question? Which of course you know the answer because you know what other benefits/services that can be used that ride on the success of the applicants of this benefit.*</p> <p>The sharing of information with other department in the applicant's local area is what should have been achieved when the idea of 'joined up thinking' was first mentioned years ago and still not achieved now.</p> <p>The amount of form filling in that disabled people have to endure could be radically reduced if departments used the information already in the systems and as you say, because of electrical links this can be achieved even easier now. It would save time in many ways and will allow the applicant to receive the benefit they have put in for a lot quicker, it would save finances for the DWP and the local offices, it would mean that Disabled People would benefit quicker in their own lives and because of this perhaps even save costs within the National Health. *</p> <p>Page 37 includes a table of conditions and impairments which currently lead to an automatic award of DLA. There is concern that the Double amputees section only mentions for legs and not the arm/s, or hand/s or part of the arm/s. Could this be added to this section for automatic award? *</p> <p>Other Questions 1/ How will the claimant, who has more than one other benefit, know which benefit is being paid and the amount? 2/ Will the claimant get monthly/3monthly/yearly notification of how the amount they receive is calculated? 3/ At the moment some benefits are paid weekly and some monthly – will this be changed? 4/ Will there be</p>

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		<p>support available for those who have always received weekly benefits to guide them into how they manage monthly payments – if this is how the 'Universal Benefit' will be paid in the future? 5/ No form can tell you what an individual can upon assessing, during a meeting with a person – and the consultation seems to imply that meeting the client is what in the future will occur upon reassessment – is this so?</p>
EM590	14-Feb-11	<p>I am conered about the changes in the reform of DLA benefits for some people with recognised long term dissabilities. There is no mention of the impact these conditions have, or consideration to those people with eg MS, Rheumatoid Arthritis, SLE Lupus etc. Autoimmune illness can take years to diagnose. I know this because I have had ill health for many years. Some of which I was very ill and virtually bedridden for 2 years after my children were born in my early 20`s. Yet there was no help or care available. I had no family living nearby to offer help and support. I didn`t get a diognosis till the age of 36 yet I had had problems going back to childhood.*</p> <p>Symptoms:- Pain always somewhere in the body, with varying levels of fatigue. At its worse have to rest after each task, eg bathing, doing any daily activities. Pain or shortness of breathe and pain that returns without warning. That can last for an unknown lenght of time. Increased worsening of symptoms after a cold, virus, strong sunlight. (extreme emotional stress can trigger flu like symptoms, extreme fatigue, headaches.) These are all ongoing sysmptoms. *</p> <p>Note - Chest pain due to inflammatory arthritis is extremely painful and leads to shortness of breathe and worsening fatigue. It can cause pleurisy, the muscles around the heart can become inflamed. The sufferer struggles with these symptoms on top of pain in joints or muscles. But many people have no understanding of how difficult living with these conditions is. *</p> <p>Equally, there are times when you may drop things or fall due to loss of sensation in feet or hands. Then there are depressive episodes that are present at lower or higher levels. Due to either desease activity, or due to the ongoing problem associated with living with these conditions. I have SLE Lupus all of these symptoms exist at varying degrees. But never go away. These conditions are ongoing and there is no cure.*</p> <p>For me my husband did not want a partner with such health problems that were ongoing and were an inconvenience to his and family life. I now live alone, my children are grown up and have their own lives. I fought to find out what was wrong with me for many years. I finally got a diagnosis at the age of 36. But had had health problems from the age of 5 when I nearly lost a limb with a bone infection. Sufferers have an impaired/faulty immune system a fault with cleansing the blood of impurities be it dying cells, hormonal changes when oestrogen levels are falling, or the result of an infection. The symptoms are many and varied.*</p> <p>Diseases of the Immune system are very difficult to live with for partners and their families. But even harder for the individual themselves. Having told you a little about the way these diseases impact on a persons life there is still very little understanding from official departments.*</p> <p>I may have Lupus. But I am not Lupus. ie I try to do the best I can with the sysmptoms that go hand in hand when living with such an unpredictable and ongoing long term illness. Because it is basically a faulty immune system that triggers auto antibodies that stick somewhere and then cause a full blown attack by the body`s immune system. It is circulated via the blood stream. It really is the "War Within". Yet there is no mention of such conditions in the proposed changes in the DLA reforms.*</p> <p>I for one, search job sites daily to try to find part time sustainable employment to improve my quality of living which also has the opportunity of meeting people. Plus increasing my financial situation. Which promotes the feeling I am still part of the society I live in. Yet many employers, I feel discriminate and do not want an employee with ongoing</p>

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		<p>health problems. In so many ways people with Immune system illness have to fight to make themselves be taken seriously. By not only their families and friends, but also healthcare officials.*</p> <p>They are groups of people who are let down by society. For me my long standing illness has blighted my life. If you see a person on crutches or a wheelchair, or in a plaster cast there are given consideration the general public can SEE something is wrong. But when a person struggles with ongoing symptoms that change because it depends which tissues in the body are under attack. The general public have little or no understanding till they or someone the know developes an autoimmune illness. Many non sufferers find it hard to believe the symptoms and the impact on daily life. Not all partners or their families can accept the symptoms. Nearly all sufferers have to fit in proper rest periods daily. To help keep the extreme fatigue to a lower level, also because pain increases when a sufferer becomes over tired rest is vitally important.*</p> <p>Because the symptoms are many and varied it can take years for a person to become diagnosed with these illnesses. Then to have to fight to get help to improve a persons daily life. eg blue badges, DLA benefits - also social consideration - understanding from non sufferers is an uphill battle.*</p> <p>Surely when diagnosis is not given easily, a person will have had to be monitored of long periods of time. For some it may be many months, in my case and my sisters who has MS it took years. A sufferer knows something is wrong but is often not believed until their grumbling symptoms become acute. Even then it still baffles some doctors.*</p> <p>Once diagnosis is awarded, the sufferers have to come to terms with the condition, yet people close to them find it hard to accept. Along with the limitations imposed because of the symptoms/conditions that cronicallly or acutely ill people endure. *</p> <p>There is no cure. Yet these individuals then have to fight to receive help from the system they should surely be entitled to long term which once awarded should be ongoing.*</p> <p>I know from experience how difficult it has been to be classed as being eligible for help. Whether with Blue Badges and being able to park in convenient places. Or to be able to obtain financial help from the benefit system.*</p> <p>Why don't you contact ARC (Arthritis Research Council) for more information about Autoimmune illness and how it impacts sufferers lives. It is not a matter of a simple operation or treatment will stop the condition. It really is a war within the sufferers own bodies. Of which there is No Cure. Don't you think it is time someone stood up and fought their case, and they were recognised as long term people with incurable disabilities? Because that is exactly what they are. *</p> <p>I read about the proposed changes to DLA and have been upset and dismayed that the system still continues this uphill battle to get the consideration and help that is so deserved. It states even those on DLA with indefinite awards will again have to face having to go through the process again. It was never awarded lightly in the first place!*</p> <p>Why are these illnesses not given the recognition that should be given by government officials? *</p> <p>If a sufferer is awarded indefinite right to benefit then why again do they have to continue the proces prove the right to their entitlement? *</p> <p>This is a group of society who are disadvantaged in so many ways, who in reality sufferer from a very lonely, disabling, incurable illness that has a devastating impact on their lives and their families. Also the consideration to employment by many employers. *</p> <p>Employers don't want to make changes to accommodate an employee with these conditions. They would rather give a job to someone without these conditions. Yet many suffers would like to find sustainable part time work to improve their own existance. Not just the financial element but also the social aspect of meeting people.*</p>

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		However way you look at it people with immune system problems are being penalised and let down by the benefit system if these changes are implemented. Or because of the lack of jobs and employers not wanting to employ someone with long term health conditions. I look forward to hearing your response. Kind regards,
EM591	14-Feb-11	<p>1.: • Lack of mobility• Problems accessing public places• Lack of assistance for going out • Fear of going out and lack of confidence• Dependency on other people• Lack of finances – those who are able to work are usually unable to complete a full week but earning a small wage can mean losing out on some benefits. However, pride means that some of us struggle on when our lives would be much more bearable if we could receive some help and work less hours• Concentration and memory problems• Feeling of letting people down when they have to cancel arrangements at short notice, as they feel too unwell to go out, leads to isolation and feeling of desperation as they want to go out but feel they have let people down too many times• Constant struggle for those who try to work, especially with invisible disabilities, to try to maintain a job when suffering pain/fatigue/concentration/memory problems etc• The effort taken to get ready to go out can be exhausting and sometimes lead to not having the energy to go out*</p> <p>• Sheer pain leads to a non-active life for many and depression leads to an inability to live a full and active life*</p> <p>2.: • The name should stay the same• The way it is paid • The way it is spent to remain a personal choice• Not be means tested or taxed• Applications should continue to be based on doctor/consultant's medical advice or someone who knows the person well• It should stay the same for people with terminal disease etc*</p> <p>• Keep the levels of care and mobility as separate components• Retain the standard levels of monthly payment and increase annually• Free access to an information line for help with applications• Retention of Motability scheme*</p> <p>• Higher rates should continue to include Blue Badge scheme, bus passes etc• Retain Christmas payment*</p> <p>• Continue to be assessed and administered by Central Government*</p> <p>3.Your response:• Heating and lighting as they spend more time at home• Special diets needed for some which are more expensive• Transport – especially on lower rate as this is not taken into consideration at the moment. It is impossible for some people to be able to use public transport without help even if they are on the lower rate – this means the cost of running a car or getting taxis or paying an extra fare for someone to accompany them• The cost of extra therapies and gentle exercise classes/yoga necessary for healthy mind and body. • The cost of paying for a carer, cleaner, home maintenance assistance, etc. • The cost of aids around the home if not available from OT. • Prescription costs for those not exempt• Herbal remedies which are sometimes recommended by consultants and are not covered by prescription costs*</p> <p>4.:• There should be 3 rates or there will be a massive difference between the 2 which will mean that those who are disabled and struggling will never be 'disabled enough' to reach the top level but are far worse than others on the low level.*</p> <p>5.:• Entitlement should be automatic for terminal patients and for conditions such as MS, muscular dystrophy, blindness, other conditions that will not change and are lifelong*</p> <p>6.Your response:• Properly cooked meals, feeling secure at home, clean home and clothes, personal care, social contact and activities. Being able to go out, having a phone and computer – enabling communication with the outside world and giving emotional support, TV for entertainment. Being able to keep a hearing/guide dog for some independence. *</p> <p>7.:• By getting reports from consultants, doctors and others involved in the person's care*</p>

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		<p>• Ensure that the person's worse times are taken into consideration*</p> <p>8.:• No – because some people are reluctant to use aids (such as walking sticks, crutches) even when they should be using them. Others use them when not really needed.*</p> <p>9. :• Shorter and less confusing forms, more to the point• Help from an adviser • Shorter waiting times for tribunals• Tribunals less formal and more friendly as we feel as if we are on trial and trying to get something that we aren't entitled to even when we are – they are very stressful• Information in GP surgeries and hospital clinics• Information in the media*</p> <p>10. Your response:• Consultant – reports and copies of results etc• GP – report from usual GP and any supporting written evidence – test results, hospital referrals, etc• Self – an explanation of how it is to live with the disability*</p> <p>• Other healthcare professionals – e.g. therapists (physical and mental health)*</p> <p>11.Your response:• The healthcare professionals don't see us outside of clinics and therefore, although their evidence is needed, they do not always see us in our normal environment• The healthcare professional may not have sufficient experience of the disability• It can be very stressful for the person with the disability• I can't see any benefits from seeing a healthcare professional who is not involved in our care• CAB should be allowed to attend as support*</p> <p>• Partners should be allowed to attend for physical and moral support• They can be very intimidating*</p> <p>• Whoever is present needs to have empathy and not appear to be 'grilling' the patient as it can be a very daunting experience• The healthcare professional must have previous experience of the disability involved• The process needs to be informal and friendly and the patient not made to feel uncomfortable or as if they are in some way cheating the system – the majority of disability claimants are genuine but it doesn't always feel that way• If their own consultant and GP has supported the application, it should be unnecessary for a further healthcare professional to make an assessment – this is wasting time and money• Terminal patients should not be put through this process*</p> <p>12.Your response:• Terminally ill should not be re-assessed• Certain illnesses should not need to be reviewed as they are at present• Some disabilities never change or only get worse and these should not need review*</p> <p>13.Your response:• Those who do not report changes now, will not report them in the new system• Send a reminder*</p> <p>14.Your response:• The same advice as they currently need with DLA• A free helpline would be useful*</p> <p>15.Your response:• Leaflets in GP surgeries• Suggestion by consultant on diagnosis*</p> <p>16.Your response:• OT/supplied by hospital• Self funded• Loan from hospital• Charitable loans*</p> <p>17.Your response:• The child should never be assessed on their own*</p> <p>18.Your response:• It has been very important regarding travel – eg railcard• Important for social life – eg cinema discount• Lowers living costs enabling people to have a better quality of life – eg council tax reduction, cavity wall/loft insulation which reduces heating bills• Access to cheaper bus travel for those on lower rate as most of us are unable to travel alone which means we have to pay for a carer as well</p> <p>19. Your response:• It would mean that people may not be able to go out as often due to travel cost• It would possibly stop people from going to the cinema as the cost is high without help*</p> <p>• Limit social life leading to isolation• Increase depression if unable to go out*</p> <p>20.Your response:• Sick leave taken at work – with the claimant's agreement*</p>

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		<p>21.Your response:• There should be choice of male or female interviewers for reason of ethnicity, religion, a past sexual abuse issue*</p> <p>22.Your response:• PIP should continue to be administered by Central Government and awarded on ground of disability only and not means tested• An advocate should be allowed to help with assessments etc• There should be 3 levels of award, thus making the gap which exists currently to be narrowed. • DLA allows the patient to have a better quality of life and more independence and relieves the pressure on family finances• Applications should be administered by Central Government and not a private company. • Current claimants of lifelong DLA awards should not be re-assessed as these have been given for a good reason. Re-assessment would be expensive and would cause unnecessary stress to the claimant.</p>
EM592	13-Feb-11	<p>1.Your response: Attitudes of society. Employers being willing to adapt fully to the needs of disabled. Adaptations not being made to make outside spaces available to all needs.*</p> <p>2.Your response: It should be paid directly to the disabled person.*</p> <p>3.Your response: In my case having to run a car as I am unable to use public transport. Higher fuel costs as I am mostly forced to remain indoors. I cannot use supermarkets so pay premium prices for food in the small local shop I can access. I am unable to cook so have to pay for expensive ready meals. I need the internet and mobile phone as I cannot use the phone except to contact close family. Internet is for clothes shopping etc. I pay towards the cost of my care. These are a few of the hidden costs that my disability costs me.*</p> <p>4.Your response: The subjectivity of determining which rate is applicable to a disabled person. It's always a judgement call... usually not in favour of the disabled person.*</p> <p>5.Your response: Same as now.*</p> <p>6.Your response: Being able to move freely... whether due to physical or mental problems these should not impinge on ability to get out, get shopping, meet people for health or care appointments, see friends. Everybody should be able to get out if they want and see another human being every day and not be restricted.*</p> <p>7.Your response: Seek gp/consultant advice.*</p> <p>8.Your response: You should consider need for aids and adaptations and not just if the person has been able to access them. My car is an aid... one I pay for myself.. but it is absolutely essential to my ability to get out at all or even buy food. Walking aids and wheel chairs obviously, and prosthetic limbs. Household aids such as bath boards, grab rails etc*</p> <p>9.Your response: Naturally making it shorter and less deliberately repetitive would help.*</p> <p>10.Your response: The person should be able to nominate someone who knows their condition and needs best whether that be a gp, consultant or carer. It is not always the gp for example who would be best suited to make a judgement... it is not a one size fits all situation.</p>
EM593	14-Feb-11	<p>11.Your response: The healthcare professional will not know the person or indeed necessarily the condition/s in any detail. If the person is naturally nervous they may not give a full account of the deprivations caused by their illness. Would the healthcare professional be a generic, DWP employed Dr or a specialist in each person's condition?*</p> <p>Face to face meetings are appropriate if they take into account the fluctuations in a person's condition, and that a person might be too unwell on the day of the appointment to be seen. This shouldn't be held against the person. The person should also have the choice where to be seen.*</p> <p>12.Your response: Naturally a person should not be disadvantaged due to their condition. My disability means that I am often unable to communicate effectively to people I don't know, especially if I deem them to be in 'authority' mode and/or are male. This should be taken into consideration during assessment. Long term, degenerative and enduring</p>

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		<p>conditions which would not normally be expected to change or improve obviously should not require such frequent reviews.*</p> <p>13.Your response: Ensure that any loss of finances due to the changes are phased out to enable the person to find work etc.*</p> <p>14.Your response:*</p> <p>15.Your response: A requirement???!! How draconian. If people CHOOSE not to take action then that is their right. Why are you always so intent on compelling people to bend to your will? Disabled people have little enough power in our society, that you would try to take even this little amount from them.*</p> <p>16.Your response: Social services pay for some. Disable people fund others. Don't know enough about the PIP to form an opinion.*</p> <p>17.Your response:*</p> <p>18.Your response:*</p> <p>19.Your response: People would lose out.*</p> <p>20.Your response: Enough information is shared already.*</p> <p>21.Your response: *</p> <p>22.Your response: That this is a pointless paper exercise. That you've already made your mind up but that this 'consultation' is helpful for your propaganda.</p>
EM594	14-Feb-11	<p>This is my response to your consultation document. My wife is 55 years old woman and suffers from Huntingtons Disease, and will be directly affected by any changes. I have concentrated my response to 4 questions:-*</p> <p>*</p> <p>Question 5 - I think some illnesses do need to automatically qualify, certainly at least once a certain stage in degenerative illness has been reached. My condition has only one ending, there is no cure or treatment which will halt the disease. Because of the very nature of my illness I gat extremely anxious about assessments or tests, it causes great stress and at times I am sure irrational decisions. I may come across to someone carrying out a short assessment of an hour or so as being quite independent, able to walk and get about quite freely, and although my speech is slurred they may say I can be quite easily understood. Superficially that may seem true, but underneath it all I am unconfident about many things, I don't retain information and my ability to use technology that I would have had no problem with say 2 - 3 years ago has now deteriorated so badly that I could not use a computer in the workplace. *</p> <p>*</p> <p>Question 7 - This really depends on someones health condition. If they have a temporary problem that treatment or physio will improve over time, then there may be a case for re-assessment at periodic intervals. Where the illness is such that it will only deteriorate then there is no need for re-assessment.*</p> <p>*</p> <p>Question 10 - It seems to me that at a time when greater trust is being placed on GPs, that persons own GP or specialist consultant is the best person to tell you what someone can and cannot do.If the assessments for the new allowance were similar in any way to those currently conducted for Jobseekers Allowance then I would see them as hardly independent and driven towards ensuring as few people qualified for the new allowance as possible rather than a genuine attempt to help people with disabilities. My wife sees a specilaist in Huntingtons disease about every 6 - 8 weeks or so, as part of a drugs trial. That person is far better qualified to decide what my wife can and cannot do, and not to seek their opinion would be manifestly unjust.*</p> <p>*</p> <p>Question 11 - Meeting people who are there to assess you, can be very stressful for someone with a disease such as Huntingtons. I remember how anxious and upset my wife was when she was told she would need</p>

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		to undergo a driving assessment if she wanted to retain her driving licence. It caused her tremendous worry, sleepless nights, and resulted in her surrendering her licence rather than undergo the assessment. I'm not sure having the assessment at home is much better than having to attend a surgery. I would also question how independent any assessor appointed by the DWP would be, because surely that depends on what their remit is. My own experience of Atos Origins medical assessments is that their approach is to seek to disqualify claimants at every opportunity. There are loads of message boards out on the internet which will say much the same. If you do decide to go down the road of independent assessors then you will need to be very transparent about how independent they really are. 14 February 2011
EM595	14-Feb-11	<p>I work as a Specialist Social Worker in a Multi interdisciplinary team at Icanho, the Suffolk Brain Injury Rehabilitation Centre. I am very concerned on the impact on Carers and Clients of the new proposals for DLA.*</p> <p>As you may be aware, head injury is known as 'the hidden disability' and as such, not only is it not recognised by the public, but also by some medical professionals. The cognitive issues related to brain injury are not visible, and it takes insight for the client to recognise their issues. The client may confabulate, and when asked questions about their ability, they will assure people that they can manage very well. An interview with a brain injured person can give an incorrect picture of their abilities. Fatigue is often a major issue with the brain injured, and so their condition changes. It is difficult for professionals and/or medical practitioners to gain a realistic picture of the issues facing someone on a day to day basis.*</p> <p>The impact of losing Carer's Allowance could be devastating to the many people supporting those with Brain injury. Often the brain injured person needs constant supervision and support because of their lack of insight, their impulsivity and their fatigue. To leave them alone all day is a risk to themselves and others. It would certainly be a necessity to keep Carers allowance outside the universal credit. It should not be means tested, as the 'test' alone is so stressful and time consuming, that Carers would decide not to claim to save themselves time and energy. I would like you to consider these points before making the proposed changes. Thank you</p>
EM596	14-Feb-11	<p>Question 1 Lack of Mobility. Inaccessibility of places. Lack of a carer if you need one. Social isolation. Dependency on others. Low income — sometimes lifelong - unable to build up a pension because of inability to work) The prejudice & stigma attached to both visible and invisible disabilities, leads to unreal expectations equals either too high or too low - from both employers or others making success at a job application or interview for example impossible in many cases. Depression & mental ill health are difficult enough to cope with conditions in themselves but the extra stress caused by a physical disability often leads to - depression and breakdown. - *</p> <p>E.g. Form filling, problems in the system of claiming together with pain & sometimes lack of mobility or social isolation, can all further contribute to mental health difficulties. School separation-many disabled children are separated from in mainstream schools or because they have to attend special schools-this does not help with social integration or stigma.*</p> <p>Hospitalisation and medical appointments as well as the follow up from them, often take up a great deal of time and energy. This prevents regular commitments either to social or work activities.*</p> <p>Question 2 Keep DLA name as it is well known We agree that DLA IPIPs should not be means tested or taxed and it is most important that the choice of how it is spent also remains.*</p> <p>Applications for PIPs should continue to be based on the claimants own, Doctors and Consultants medical advice or from information gathered from other health workers or from the wider community e.g.</p>

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		<p>friends and carers. Entitlement should remain automatic for terminal disease and also for certain other conditions e.g. blindness, hearing disability, M.S. Muscular Dystrophy.*</p> <p>Keeping the different levels for care and mobility is essential-and adding to them by one level to the mobility component highly desirable.*</p> <p>Awards should continue to be assessed and administered by Central Government, retaining the standard levels of payment at regular monthly intervals. These awards should increase annually to keep pace with the increase in the cost of living.*</p> <p>Responsibility to advise the administering department should remain with the client. Easy continued free access to an information line for help with filling out forms and, guidance through the application process and forms should continue to be available in different languages. Retention of the Motobility scheme-which could be widened to include other form of transport.*</p> <p>The higher rates of awards should continue to act as a gateway to other benefits, e.g. Blue Badge Scheme, Council Tax rebate and free bus passes.*</p> <p>- Question 3 Extra heating and lighting costs, as disabled people are often at home more both in the day and evening.*</p> <p>Special diets and nutritional needs e.g. diabetes, vitamin B or D deficiency.*</p> <p>Provision of suitable transport e.g. the cost of purchase and running of a including any necessary adaptations-this might mean using the Motobility scheme or for others being able to have a free bus pass rather than having to pay to take more bus rides. Taxis are costly and often do not have ramps. Taxis with ramp adaptations are often not easily available.*</p> <p>Disabled people often benefit from having extra therapies and these can act as a way of "keeping going" or/and maintaining mobility e.g. physiotherapy, osteopathy, gentle exercise /hydrotherapy. However, because of the health problem concerned the person is likely to need more of these therapies and sometimes they will be ongoing - all of which increases cost.*</p> <p>The extra cost of paying for a cater cleaning, gardening, decorating, D.L.Y. and the many odd jobs that cannot be carried out by somebody with a disability e.g. moving heavy items, changing the curtains, going into the loft as well as other household! support-ironing, washing and shopping for example.*</p> <p>Paying for either ongoing physical care or ad hoc personal care during or after illness or after periods of hospitalisation.*</p> <p>Clothing suitable for people with a range of different disabilities can include front opening or Velcro fastenings, plastic protective coverings or special footwear and hose.*</p> <p>Personal care supplies e.g. incontinence pads, nappies and special creams for skin suppleness and to prevent bedsores.- \$*</p> <p>The cost of home adaptations e.g. having an extra room or W.C. added on the ground floor or having a shower or wet room installed. In addition there may also be the high cost involved in moving to a ground floor flat, bungalow or sheltered accommodation.*</p> <p>There are costs incurred from wear and tear on the home and furniture or bedding e.g. more frequent washing of sheets, clothing as well as wheelchair damage to floors and walls. It follows that special flooring and adapted furniture/furnishings are also sometimes required*</p> <p>Holiday are extra costs for disabled needs e.g. transport and accommodation.*</p> <p>Prescription costs are likely to be greater because more prescriptions are often required for complex health conditions. ! -*</p> <p>Question 4 There should be three levels for mobility and care so that a person can work to improve their health, so as to go to the next level down, thereby reducing.*</p> <p>dependency. !To have just two levels would represent to big a gap and</p>

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

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		<p>face to face or on a free telephone line. The process should have shorter waiting times.*</p> <p>Tribunals should be less, formal*</p> <p>There should be leaflets/forms at all GP Surgeries social work Departments and Post Offices.*</p> <p>Put information about the new benefit on TV and Radio before and when it is first introduced, and then as part of an ongoing information service.*</p> <p>Train OPs and hospital Doctors, as well as other health professionals to mention this benefit.*</p> <p>Assessing doctors should not just turn up without warning.*</p> <p>Question 10 By allowing the claimant to use supporting evidence for their application for example using medical information from their OP or Consultant, and reports and social/community evidence e.g. from carers or diaries-of symptoms or medical appointments.*</p> <p>By allowing the evidence of employers, teachers/ complimentary therapists, social services, Occupational Therapists into the assessment process, but ensuring that the clients worst days and times be taken into consideration.*</p> <p>Question 11 An important part of the new process is likely to be a face to face discussion with a' health care professional. (What if any) benefits or difficulties might this bring?*</p> <p>A doctor should be used where complex cases are involved nurses and other - professionals e.g. O/T could be used for less complex cases providing they were given adequate training with regard to the nature and difficulties caused by disability.*</p> <p>An assessment would probably take pver an hour, or in some cases more time and second appointments needs to be allocated for more complex or distressing cases.*</p> <p>Carers-or an advocate, or supportive person should be allowed to be present at an interview*</p> <p>- This would help as claimants cant necessarily articulate very easily. A translator or signer may also be necessary.*</p> <p>There should be a choice of where the interview should be held-at home or in an office-but if in an office it should not be up flights of stairs unless there is a lift. The cost of a taxi or other form of transport should also be provided.*</p> <p>These sessions should be as informal as possible to take account of peoples pain, stress and anxiety-and should not be about ticking or filling in a pro forma. Nor should the claimant feel that they are on trial.*</p> <p>Question - And are there any circumstances in which it may be inappropriate to require a face-to- face meeting with a health care professional-either in an individuals own home or another location? -*</p> <p>Yes-the following t be circumstances in a face-to-face interview would be inappropriate. If someone is terminally ill or in hospital; or is unable to communicate for themselves. -*</p> <p>Some religions don't allow women-to speak to males for example.*</p> <p>It is not appropriate to interview a young child regarding a claim, this would have to done by an adult responsible for their care. - Similarly, an adult with learning difficulties for example might either need to have an appropriate adult present to answer the questions and/or represent them.*</p> <p>Question 13 The terminally ill should not be re-assessed. - The claimant should be allowed to report if they are feeling better or worse, this is a matter of personal responsibility.*</p> <p>Reviews should be variable-someone who has a serious condition e.g. - Multiple Sclerosis should not be reviewed unless they request it, but claimants with other conditions might be reviewed after a standard period, or again if they request it.*</p> <p>Question 14 .Don't change the name of DLA as it is well known The claimant should be allowed to report if they are feeling better or worse, this is a matter of personal responsibility-a telephone help line should be</p>

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		<p>free ,and easy to access in order to do this.*</p> <p>It should be recognised and acknowledged that some claimants would have difficulty in reporting a change in their circumstances-because of their condition e.g. bi-polar or other mental health conditions especially, but not exclusively. In such cases perhaps a box could be ticked on the application form asking if they wish to be sent a pro forma at intervals to help them to do this. THERE SHOULD HOWEVER BE NO QUESTION OF PROSECUTION IF SOMEONE FAILS TO REPORT AN IMPROVEMENT BECAUSE OF THE ABOVE. +*</p> <p>Question 15 Yes, it would be helpful to have advise and information about the application process, this could include:- a leaflet with every application form, explaining the whole application process and saying how to contact a free help line who would say where to get advice, or give advice and help to fill the application form in*</p> <p>Questions 16 A leaflet and application form should be available in all Gp surgeries Social Workers Departments Post Offices and noted on all communications from Government, e.g. at the end of a tax return form- Put on the such forms - do you! need a DLA or other benefit application form? or include a leaflet about the benefit; with the forms*</p> <p>THERE SHOULD BE NO REQUIREMENT OR COERSION to take or agree to a medical opinion on how to treat a claimants disability or other health condition. as this infringes personal freedom, and the right to treat any health problems in the way an individual may choose.*</p> <p>Question ! 17 By grants from the Local Authority for housing adaptations Social Services — Occupational Therapist provision*</p> <p>Motability Hospital loan, Own savings Charitable loans *</p> <p>Question 18 Yes, there should be provision for one off costs under the new PIP scheme for large expenditures e.g. moving home, computers or a costly item to help with disability such as a mobility scooter, but not instead of or included as part of an award, it should be over and above any regular payments.*</p> <p>Question 19 The Government might also use the new assessment for children. What are the key difficulties the Government should take into account when assessing children? It is not appropriate to interview a young child regarding a claim, this would have to done by an adult responsible for their care.*</p> <p>Schooling — special needs children often have extra cost.eg.aids ata mainstream school or the cost of special schooling e.g. transport to and from school for the child, but also for the family to visit if the school is residential.*</p> <p>Personal care supplies and needs e.g. nappies, rubber gloves, transport, relief care and special diets.*</p> <p>Question 20 PIP would be most important to disabled people as a gateway to other services and benefits*</p> <p>1) High rates of mobility awards should equal a free bus pass and a Blue badge entitlement*</p> <p>Higher award rates should equal automatic access to council tax discount. These gateway benefits should be put on the DLAJPIPs information leaflet. The above keep people mobile, independent and also help with mental health- it follows that without them people would become more dependent and isolated.*</p> <p>Que 21 When a claimant applies for sickness type benefits information could be shared (only with claimants agreementijt could go towards a DLA application. The reverse would also be true.*</p> <p>Question 22 A monetary award could help a disabled person to be ,and feel more integrated into the local community.*</p> <p>Help with the costs of schooling — special needs children often have extra costs. eg.aids at a mainstream school or the cost of special schooling e.g. transport to and from school for the child-this could help integrate disabled children more into the educational process. With face-to-face interviews there should be a choice of male or female interviewers</p>

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		<p>for reasons of ethnicity and religion. Cultural, religious and gender differences should also be taken into account to help alleviate the problems of minority groupings. The forms should be in other languages and a translator should be provided where necessary.*</p> <p>Question 23 Is there anything else you would like to tell the Government about its plans? An advocate should always be allowed to help with assessments and reviews etc.*</p> <p>No one should be coerced take medical treatment or advice etc this is an important issue with regards to personal freedom and erodes the individuals right to treat their condition in the way they.-feel best including the use of complimentary therapies.*</p> <p>PIP should not be administered by a Local Authority, but continue to be administered by Central Government and awarded on grounds of disability only, and not in any way means tested.*</p> <p>There should be three levels of award for both mobility and care. Keeping the different levels for care and mobility is essential-and adding to them by one level to the mobility component highly desirable.*</p> <p>DLA represents a real lifeline to many people-it is the difference between having self respect (or not) and between having a reasonable lifestyle and level of mental health rather than having to live on a very low income for long periods. It stops claimants being dependent on others and also on Government provided services.*</p> <p>This independence end would continue on the condition that a claimant would have the freedom to spend the money as they would choose-it treats people with the respect and dignity that they should have. It keeps costs to the authorities down especially with regards to mental health, as having a physical disability and all that that entails can easily cause mental ill health and breakdown. Extra stress can be caused from dealing with forms, hospital situations and the illness or disability in itself.*</p> <p>Allowing one off payments under the new PIP's scheme for items of large expenditure would help with financial stress and long term low income issues, but should not be instead of or included in an ongoing award. Receipt should be provided by a claimant after the purchase of the item in question.*</p> <p>A claimant in a care home should not be deprived of financial assistance to get out and about as this is really important for the maintenance of mental health, and having a full and active lifestyle.*</p> <p>PIP's should continue after age 65 for everyone-this would save on the cost of changing to Attendance Allowance for example.*</p> <p>Applications and assessments for Pip's should not be processed by private companies, but instead continue to be administered by Central Government, and to take into consideration the claimants choice of supporting evidence.*</p> <p>Claimants of DLA who have been given lifelong awards should not have to be reviewed-there is good reason for the awards.</p>
EM597	14-Feb-11	<p>1. This is a very broad question - the government should review all relevant research findings relevant to this issue*</p> <p>There are inherent problems for disabled people in seeking to participate and lead independent lives.*</p> <p>The mechanisms and vehicles in place are not promoting the full options available to people with disabilities for example the utility companies do not make it easy to access information in respect of social tariffs, which is a significant disability related cost. These include lack of facilities</p> <p>Attitudes of society towards disabled people Appropriate adjustments made for people to access services – Disability Discrimination Act compliance. There is the potential to use ICT - http://ftp.jrc.es/EURdoc/eur22352en.pdf The rate of the Disability Living Allowance (DLA) payments do not allow people to participate full in society. This is often seen as tokenistic recognition of the disability and there remains a lack of social engagement for people with disabilities.*</p> <p>2. The consultation paper sets out some of the advantages of DLA at</p>

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		<p>paragraphs 8 to 11.*</p> <p>Under the current system there is little stigma of claiming Disability Living Allowance as compared to other benefits (Job Seekers Allowance/ Income Support).*</p> <p>Professional Advisers have clarity in the understanding of the current legislation with a significant body of case-law developed over many years. The new proposed process of medical assessment will deter claimants from making claims and also undermines the current right to claim this benefit.*</p> <p>The concept of "essential daily living" introduces a new legal concept which will have higher threshold of needs compared to the concept of "reasonably required."*</p> <p>The three tiers of award should remain there is concern that people who currently receive the low level of care component will be the group that loses out under these proposals. There are groups of people with low level of disability who manage and maintain their condition without the need to access local authority services and the loss of this level of award is likely to push people into seeking local authority assistance. There is a particular concern for people suffering with mental health problem they are more likely to be affected by the proposed reduction of the levels of benefit available, causing a detrimental impact for their health condition and needing increased levels of professional medical input at a cost to the NHS. *</p> <p>There is a need to clarify the rules concerning scheduled accommodation to provide clarity to the claimant, decision makers, local authorities and advisers.*</p> <p>3. The key areas of additional costs faced by disable people include:*</p> <ul style="list-style-type: none"> • Costs related to the disability e.g. incontinent pads* • Costs relating to maintaining the property heating a maintenance, hospital visits* • Additional cost relating travel, leisure, participating in ordinary family activity.* • Cost relating to excess washing* • Need for sign language interpreters for people with deafness* • Heating costs related to disability and being housebound* • Costs of disability equipment* • Privately paying for care not funded by a local authority* • Costs of short breaks* • Special equipment* <p>4. There are potential advantages of having two rates of each component; this will make understanding of the system simpler. This will reduce the number of permutations of benefits.*</p> <p>The three tiers of award should remain there is concern that people who currently receive the low level of care component will be the group that loses out under these proposals. There are groups of people with low level of disability who manage and maintain their condition without the need to access local authority services and the loss of this level of award is likely to push people into seeking local authority assistance. There is particular concern for people suffering with mental health problem are likely to be affected by the proposed reduction of the levels of benefit available causing a detrimental impact for their health condition and needing increased levels of professional medical input at a cost to the NHS. *</p> <p>The key disadvantage is that there is a very strong risk that fewer people will meet the threshold to qualify for the new payments benefit and some people will lose their current entitlement to benefit. Local authority demand for services is likely to increase and demand made for low level services.*</p> <p>Professionals administering the system will need training and support to properly administer the new system. There is likely to be increased costs of administration in introducing the medical assessment to be conducted</p>

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		<p>by the medical professional. *</p> <p>5. Entitlement should remain for some health conditions based on rigorous assessment for these disability needs which has resulted in the inclusion of these condition being included in the DLA criteria e.g. terminal illness and kidney dialysis, severe mental impairment. To change these provisions will result in many severely disabled people being put through an unnecessary process which may result in loss or reduced level of payment.*</p> <p>Include other conditions to make adjudication simpler?*</p> <p>6. This question is again a very broad question similar to question 1.*</p> <p>A full assessment similar to the one conducted prior to the introduction of DLA.*</p> <p>The second part of this question is also far too broad to adequately respond in this consultation. There needs to be a review of the research in this area before a definition of “essential” is established. A change to the new definition will make it more difficult for a person to qualify for the new payment. The response to question 4 also deal with this question, as the current system attempts to allow people to participate in daily living with support of others.*</p> <p>7. One option to consider is to have a self assessment form completed to which takes account of the variable nature of the condition with a requirement for and change of condition to be notified to the department. This would in principle be no different to the requirement of a person to notify any change of circumstances within the wider benefit system. This would remove the current approach of adjudication where the benefit is awarded for a fixed period with no obvious requirement to advise of a change of circumstance. This would be specific to variable condition to ensure that people with a long term and enduring condition are not having to be repeatedly go through the adjudication process.*</p> <p>8. The assessment should not take account of the disabled person’s ability to make use of aids and adaptations. If they were to be taken into account there could be a perverse incentive not to use aids and adaption’s to retain entitlement to the payments.*</p> <p>It is vital that evidence of carers is properly considered in these cases all too often the medical view is preferred*</p> <p>When considering the use of aids and adaptations needs to a take account of the disabled person’s ability to make use of these facilities, often the facility cannot be used without the assistance of the carer, for example when assessing the need for bath rail the persons ability to grip and lift themselves needs also to be properly to be taken into account.*</p> <p>There should be environment created by the DWP so that people do not have a fear of being ‘punished’ when they advise the department of a change of circumstances. For example, the experience of claimants often is that a change was advised in respect of an improvement in mobility resulting in the whole of the DLA award (mobility and care) being removed.*</p> <p>9. How could we improve the process of applying for the benefit for individuals and make it a more positive experience? For example:*</p> <ul style="list-style-type: none"> • How could we make the claim form easier to fill in?* • How can we improve information about the new benefit so that people are clear about what it is for and who is likely to qualify?* <p>Process It is vital that there is clarity in the new legislation, regulations and guidance to ensure the clarity. It is also vital that the process is also clear and less bureaucratic and less intimidating for vulnerable people, in order to make effective use of the system.*</p> <p>This change will require having highly trained and experienced staff to deal with enquiries from claimants making first contact. This is vital poor initial contact will deter people from making use of the system to establish confidence in officials and the system. The current practice of screening questions acts to deter disabled persons from their right to apply for DLA*</p> <p>Form filling Proper and effective use of the Working with Representatives</p>

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		<p>Guide would assist in the whole process from beginning to end where representatives are involved. This policy has been adopted but the experience of representatives across the country is that the policy is not known to DWP staff working on the front line taking calls on the front line.*</p> <p>The forms need to provide clarity of the question and encourage the person to qualify the answer.*</p> <p>Engage with professional and third sector groups and organisations (national, regional and local groups) that support people with disabilities.*</p> <p>Information Evaluate the current use of information to establish the most effective use of printed information, to include content, language requirements brail, use of video's with signers for people with hearing problems.*</p> <p>Effective marketing of the new system, to provide positive images in the press and use TV advertising with of examples where and how disabled people may make use of the PIP. This needs to include social media including dvds and leaflets.*</p> <p>10. There needs to be a greater weight being attached to the disabled persons and their carer's evidence. The constant request for medical evidence is often unnecessary and significantly burdensome for people with disabilities. The use of medical evidence should be limited to special cases. There needs to be greater responsibility on General Practitioners to provide relevant and full responses to requests for information by both the DWP and the claimant.*</p> <p>11. The proposal to use a healthcare professional in a face to face meeting goes against the whole ethos of the current system of assessment. The use of the medical professional is likely to disempower the individual.*</p> <p>Here the comments of Professor Harrington very significant and reflect the experience of many disabled people when attempting to claim benefits "In broad terms the pathway for the claimant through the Jobcentre plus is impersonal, mechanistic and lacking in clarity". (An independent review of The Work Capability Assessment November 2010). *</p> <p>The report went on to say "the claimant needs to feel that they have been fairly treated and thoroughly assessed. They need to know that the object of the whole exercise is accurately assigned to them to.... ensure that those who cannot work receive the full support from the state."*</p> <p>All too often this is not the experience of people claiming DLA.*</p> <p>Disabled people do not recognise their own need and rely heavily on carers and professional to help with the identification of care needs. The use of the medical professional will not assist in this process unless a carer is present and given a formal status of being allowed to contribute in the face to face meeting. The current experience is that the carer is marginalised in this process by the examining doctors.*</p> <p>12. The current proposals for the change to DLA are due to be introduced between 2013 and 2016 this overlaps with the migration of Employment Support Allowance which will take place during 2011-2014. It is crucial that disabled people are not put through a DLQ review and IB migration at the same time.*</p> <p>Long term and enduring conditions which are unlikely to improve, for example severe and profound learning disabilities, are cases where it would be wholly inefficient use of resource in reviewing these cases. These cases need to remain long term fixed awards. Conditions which are likely to change need to have time limited awards. Where a condition improves it is right to expect a person to inform the DWP of any improvement in the condition, similar to the requirement for means tested benefits. However, this may give rise to difficult judgements to be made by claimants who are not specialists in the area of benefit administration and there is an assumption that the benefit rules are fully understood –or request a new assessment.*</p>

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		<p>13. The government can encourage people to report any relevant changes in circumstances in reminding the importance of all citizens in their rights and responsibilities to society. These responsibilities extend to wider society not just the benefit and taxation system. The system needs to remove focus on 'policing' and bureaucracy.* The government needs to recognise that there will be groups of people who do not have the ability (physical or mental) to inform the department of changes.*</p> <p>14. It is crucial that information is provided at the point of claim and where an adverse decision is made. There is also the need to have advice and information in relation to social care needs.*</p> <p>15. Disabled people and carers need clear and concise information and access to assistance from independent organisation who provide advice and information and to represent the person where required.*</p> <p>16. The current levels of DLA do not meet the financial needs of disabled people. Aids and adaptations are already available but not always as easy to access from the local authorities, the health service, the social fund and charities.* There could be a role for PIP's to provide for aids and adaptations but this provision should be seen as a supplement and not a replacement for weekly payments.* The government needs to recognise that there are also likely to be on going costs of maintenance of aids and adaptation e.g. a stair lift, which need to be provided for under PIP. The government also needs to recognise the limits of aids and adaptations they are not suitable alternative participating in society assisted by a carer.*</p> <p>17. The key distinctions in the use of DLA between adult receiving DLA and the parents of disabled children's were illustrated in the Impact of Disability Living Allowance and Attendance Allowance: Findings from exploratory qualitative research, by Cordon, Sainsbury Irvine and Clarke, DWP. These findings set out the key differences which should be part of the decision making criteria, p41. * The report also demonstrated that for child recipients of DLA, parents were using the benefit in ways that enhanced the child's future life chances and opportunities. There were useful examples of what the money was used for including:*</p> <p>Tuition fees – Physiotherapy - Speech and language therapy - Equipment to encourage learning and development*</p> <p>These are features which need to be retained in the new system for the assessment of PIP for children.*</p> <p>Too often the current system places great emphasis on a need for a diagnosis and claims often are refused on this basis. Care assessments should be carried out on the basis of need rather than a diagnosis.*</p> <p>18. The current system is an essential means of accessing other services including other benefits (e.g. tax credits). It also provides a gate-way for carers to claim Carers Allowance. There are also a number of services which can be accessed:*</p> <p>Blue Badge Scheme - Local authority leisure pass - Bus pass - Energy efficiency grants - Warm front services - Access to the Family Fund - Motability*</p> <p>The DWP need to better inform disabled people of the availability of these services and this can be information can be provided with decision notices.*</p> <p>19. If PIP were not to be used as a passport to other benefits and services there would be additional costs borne by the disabled person of funding. There is also the likelihood of service provider may be asked by disabled people to provide these services which again will involve cost to the person.*</p> <p>20. Financial assessments – share information once – build on pilots which have been run over recent years. There are a number of assessment processes (DLA/means tested benefits [Pension Credit and</p>

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		<p>Income Support] local authority financial assessments and disabled facilities grants) currently in place for people to access benefits and services. A single assessment process can help to avoid bureaucracy for the disabled person and cost to the DWP and local authorities, improved data sharing systems with local authorities will provide this efficiency.*</p> <p>21. This is again a very broad question which to respond comprehensively would require significant time and resource which is not available this authority.*</p> <p>The new system needs to be sensitive to the religious and cultural needs of diverse groups of people with disabilities, as an essential part of social integration and engagement.*</p> <p>The government also to examine the findings of DWP research of the experience of minority ethnic groups and in the benefits system and adopt the recommendations*</p> <p>22. General observations: • The impact in Sandwell – 31,900 DLA claims in Sandwell – 20% loss of claims will have significant economic impact for the borough*</p> <ul style="list-style-type: none"> • There is no qualification in the consultation document concerning the rationale for extended qualifying period and whether this is appropriate. There is little or no evidence of disabled people becoming entitled to DLA for a less than 12 months.* • GP factual report needs to be improved with a stronger obligation on GP's to provide considered responses.* • Appeal rights need to be made clear on all decision notices* • There are clear strains currently being experienced by claimants and advisers since the introduction of Employment and Support Allowance, these can only be increased with the implementation of these proposals. The current proposals need to be properly planned before implementation and likely to manage the pressure on the DWP and the Appeals service in implementing this change.
EM598	14-Feb-11	<p>To whom it may concern, I am a carer for my 16 year old son who has autism and severe communication (speech, language etc) difficulties and severe learning disabilities. It is extremely worrying to me to hear of the proposed changes, as I am concerned that my son is not able to explain his difficulties at all. *</p> <p>There are many hidden complications to his condition that even people who know him quite well do not understand. He is very vulnerable and may lose benefits that he is not able to claim under the new system, but are essential to him. *</p> <p>*</p> <p>My son has been assessed, and awarded DLA on the present system. This is essential for his extra needs, as there are a great many ways which he is not able to live a normal life, but they are not instantly obvious. A reduction in his benefits would mean his life becoming even more difficult, as we would be pushed further into poverty.*</p> <p>*</p> <p>I returned to part time work several years ago, but even with understanding bosses who will allow you to be flexible, I cannot be in two places at once. It is often clearly inconvenient for me to regularly take time off work, or change my working hours for my son, as he cannot get himself around or be left alone in the house. During the past few months I have been close to becoming ill myself from trying to juggle so many commitments. It is not possible for me to work full time at all, so my ability to earn is directly affected by my care responsibilities. *</p> <p>*</p> <p>At present there is still Carer's Allowance which means I can at least receive a basic amount of money and have NI contributions paid for me even when I am at home with my son, or only working one or two days per week. This is the maximum I am able to cope with while my son is still at home.*</p> <p>*</p>

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		I am very worried that the proposed cuts to DLA will make our life, which is already challenging, truly desperate. I am sure I speak for many other disabled families when I say this. Yours,
EM599	14-Feb-11	<p>Dear Mr Cameron PM, Mr Clegg and Ms Miller, I am writing to you in relation to the government's plans to change the DLA system. These changes could be detrimental for the genuinely disabled and ill if carried out in the wrong fashion or without genuine knowledge of people's needs. I know there are people who cheat the system but there are so many genuine needs and cases who wholeheartedly depend on the system.*</p> <p>For example, I have a high level of spinal injury (I broke my neck), which has had other effects on my physical and mental wellbeing and life in general. Since my accident, some of my physicality's have deteriorated so much so that I have often considered going to Switzerland as things are so unbearable and not other options.... If you were to ask people with genuine disabilities and illnesses, most would tell you the same thing – that they would rather be healthy, contributing and active. Unfortunately, when the choice is not available it is so much more difficult. It is genuinely terrible to have a chronic disability and not be able to control choices over otherwise mundane day-to-day tasks for able-bodied people.*</p> <p>It is exasperating to be told what to think and believe. So, I hope no to be patronized. When you are considering points, please remember that disabled people have real emotions and feelings well as needs. There are decent honest people do not want luxurious homes with swimming pools, holidays abroad and so forth but means to survive and have a quality of life. *</p> <p>If the DLA is altered and the Motability scheme lost, this really would be a truly bleak outlook on an already poor enough quality of life. To be in a position of getting myself from 'a to b' is such a practical necessity and feeling of independence and empowerment. It really would be harmful for me and the people around me. A lot of my hospital appointments are in Belfast – which is over 21 miles from where I live to the hospital. If I was without a car there is no way I could afford a taxi every month to and from the hospital and that is just one of many medical appointments. As I mentioned, the practicalities of this can have a strong and positive effect on a person's mental wellbeing and therefore has an optimistic effect on mental health.*</p> <p>*</p> <p>Although I do not claim to be an economist or know enough about budgets, politics etc. – I do appreciate that savings need to be made. Bearing this in mind, any reduction in a genuinely disabled person's financial support will not make their life improve if they are unable to act upon it. *</p> <p>It is infuriating to see on the news and hear stories of how people have been cheating the system- by claiming benefits whilst working with another income or acting as a linesman at a football match etc. but obviously I have pointed out that this is not the case with so many like me.*</p> <p>There was also frustration to see an article on 'The One Show' last week regarding unused prescriptions being discarded. Figures were given as to how much is wasted and it is worrying to know that this waste is happening but the disabled have to fight for everything, cancer patients have to go to court over medication etc while a lot of people take prescriptions and don't use them.*</p> <p>If any money is to be reduced while a disabled person has to go to hospital – electricity bills etc. still need to be paid for regardless of whether or not a person is in hospital or a home for a period.*</p> <p>I have a heavy, non – negotiable reliance on nursing staff. *</p> <p>With the nature of my disability, I would frequently be in a position where I would need to phone the nurse back to the nature of the attention being needed. If unattended the condition can lead to a potentially life threatening condition called 'autonomic dysreflexia'. Please see link</p>

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		<p>attached: http://en.wikipedia.org/wiki/Autonomic_dysreflexia*</p> <p>With the nature of the condition, I cannot afford to be somewhere and not be able to get back to my home (as I need to be lying flat on an accessible bed) so there is a real medical urgency to considering peoples needs with a matter of seriousness.*</p> <p>Mr Cameron, I hope not to cause offence and I say this with the utmost respect to you and all your family. When you read anything from the last paragraph or within the rest of the letter, please take into account your own grief from the past. *</p> <p>So, if I could politely insist that you think carefully about your intentions and consider how people's lives could be affected. Thank you very much for your time. I have written to all three of you if you wish to discuss my concerns*</p>
EM600	14-Feb-11	<p>Dear DLA Reform Team, PLEASE DO NOT ABOLISH DLA AND REPLACE IT WITH PIP.*</p> <p>*</p> <p>I have severe Myalgic Encephalomyelitis (ME), a neurological disease that affects multiple systems of the body, and I am severely disabled. There is no known cure for my disease. Severe ME brings profound cognitive problems as well as functional disabilities, severe ongoing malaise that is amplified on even minor exertion, and many other complex symptoms that can make life a torment.*</p> <p>*</p> <p>Disability Living Allowance (DLA) is an essential payment that people with severe ME rely upon to help meet their care and mobility needs. There are no compelling grounds to abolish it. The suggestion that the DWP can justifiably slash the welfare budget under the banner of replacing DLA with a system of 'Personal Independence Payments' (PIP) that is 'simpler' and 'fairer' is fundamentally flawed and disingenuous. It would appear that many people who face additional costs of living as a result of having a long term disabling disorder will no longer qualify for help when DLA is replaced with PIP. The predictable impact of the PIP system on people with prolonged ill health and disabilities will be enormously detrimental and unacceptable. *</p> <p>There are also potential adverse knock on consequences. If a person loses their benefits under PIP, then their carer may lose Carer's Allowance, then making it impossible to pay basic bills and to carry on caring.*</p> <p>*</p> <p>The administrative costs of replacing DLA with the new system will be hugely expensive and a poor use of taxpayer's money.*</p> <p>*</p> <p>The Ministerial foreword to the consultation paper states: <i>"We are steadfast in our support for the principles of DLA, as a non-means-tested cash benefit contributing to the cash costs incurred by disabled people."</i> If this support is to progress beyond lip service then the government require to radically rethink their legislative plans for a new system. *</p> <p>I ask you not to abandon the Disability Living Allowance and replace it with Personal Independence Payment. The government's plans amount to the introduction of an inferior, unreasonable and unfair system. The introduction of PIP may act to reduce the budget deficit but unlike DLA it will not meet the needs of people who are chronically sick or disabled.</p> <p>Yours sincerely,</p>