

Disability Living Allowance reform consultation – email responses 601 to 700

Respondent Number	Date Received	Response
EM601	14-Feb-11	<p>1. : Lack of support, slow reaction by statutory services. Having a variable condition such as Multiple Sclerosis. People in power not listening. Money, if you are disabled particularly raising a disabled child you are more likely to live poverty. Mobility equipment and cars.</p> <p>*2. There should be more rates not less - My son needs 24/7 care as he has complex medical needs and challenging behaviour. Our neighbour (paralysed by a stroke) also needs round the clock help but can entertain himself, watch TV etc. They both get high rate care . Surely there could be super high rate, we literally cannot leave our son because he has no awareness of danger.</p> <p>*3. Heating, washing clothes, mobility (a WAV is still far more expensive in terms of down payment than a normal car on Motability, also they are more expensive in terms of fuel.). Those with learning difficulties and challenging behaviour breaking things. In the last 12 months our 11 yr old has pulled down curtain pools, broken a radiator, thrown a DS console, scratched the TV, broken the toilet flush, broken the doorbell, threw over a chair which damaged flooring. He chews clothes, wets the bed. Hospital appointments travel, food whilst he is in hospital - we cannot leave him as nurses can't provide the specialist care he needs.</p> <p>*4. : It demonstrates the lack of understanding again of the people who run the system. I would like to see three rates of mobility not two, the middle rate acknowledging those who are able to walk but so limited that they cannot shop, or take part in society without help. I for example can walk a little in the morning but due to neuromuscular fatigue can only make a few steps at other times - I am unable to walk - depends when you see me!</p> <p>*5. Your response: Difficult, I feel the decision makers should listen far more to the local medical team who know the patients. I also feel that some awards should be made indefinite. our son is severely affected by Tuberous Sclerosis Complex, He is not going to get better.He will need lifelong care and mobility support, but I have to fight to get an award of longer than two years - its soul destroying! Especially when a bright spark at the DWP tells me he might get better.</p> <p>*6. : Accept that disability is not a choice. Rates of DLA are low compared to increasing living costs. When our son first received DLA we were told it was to cover the additional costs of disability. In reality we used the money to pay the bills. This was necessity as I had given up work in a high paid job to care for him, our income was less than half of what it had been - we</p>

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		<p>had to eat and pay the mortgage! Now I have been diagnosed with rapidly progressing Multiple Sclerosis but was told at DLA tribunal I couldn't possibly have so many issues myself as I care for a disabled child. We are not benefit scroungers just darn unlucky, I can barely walk but still can' ignore the fact that his Inco pad need's changing, I will crawl across the floor to do it. Essential activities include personal care, socialisation, mobility, education. Also the impact on the family needs to be considered. Our lives are hard enough without the system making it harder. We have to fight for nappies, respite, wheelchairs, why?</p> <p>*7. : Listen to the medical professionals who care for people with these conditions. Be realistic.</p> <p>*8. : YES YES. Again I was penalised for living in a Bungalow (which we pay for and spent a lot of money making it liveable.) If we had stairs I would have scored higher on the DLA assessment. All aids should be considered, without a crutch I can barely walk but I am only 40 so if I was 'normal' I could still climb Snowdon.</p> <p>*9. : I have no problem with the DLA forms but I do have issues with the way the system responds to the answers. You can't make it a positive experience - you have to catalogue what as a disabled person you can't do: not nice but a necessity.</p> <p>*10. : Why not use communication from medical professionals?</p> <p>*11. : Again I have no issue with a face to face meeting, but the healthcare professional must be adequately trained. Currently they seem to make decisions that are dubious and show a lack of understanding. However I feel it is a waste of resources to do this for everyone. Neither my so or I will 'get better' thus why waste money and time assessing us. Also both of us have a team of professionals involved in our care - listen to them rather than adding in yet another appointment. ██████████ would be very difficult to assess due to his severe learning difficulties and challenging behaviour - I would be rather disturbed if the system was adamant they wanted to assess him - Why not take some of the information from the most eminent neurologists (Great Ormond Street) and Psychiatrists (Maudsley) who treat him.</p> <p>*12. : As Above : Use existing information rather than duplicating work and information. These reviews may be useful where an individual has a bad back or something that is not quantifiable but in our case what's the point -we aren't getting better!</p> <p>*13. : Sounds like a load of tosh. People won't let you know if they are swinging the system. How will you deal with something like Multiple Sclerosis? Pips sounds like another great on paper but useless in reality piece of legislation.</p> <p>*14. : The system never works together and until it does it won't work.</p> <p>*15. : Good idea, but the framework has to be there. I am in</p>

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		<p>urgent need of Neuro Physio, but am on a waiting list. I took it upon myself to join a gym to help myself as much as possible (at a personal cost). One of our main complaints is that we are pigeon holed, no one looks at my son and I together. We have now demanded that they do - but as usual the more you help yourself the less help you get.</p> <p>*16. : With great difficulty. We had to raise £30k to match the 30k from the local authority DFG to adapt our bungalow for [REDACTED]. The system is long winded and slow Over the 11 years of [REDACTED] life we have paid out more than £5K on mobility equipment (mainly from charities). I had to fund a mobility scooter. These things are not cheap and are in no way comparable to the costs of children without disability. Finally I may be assessed for a wheelchair but after a fight. *17. : Disabled children cost a fortune to raise, at the same time the families income is often halved. Whilst Child Tax credits make up for some of this we are still 'poorer' than we should be.</p> <p>*Mobility : PLEASE DON'T TAKE AWAY MOBILITY CARS FROM CHILDREN AT RESEDENTIAL SCHOOL YOU WILL BE REMOVING ALL ASPECTS OF NORMAL FAMILY LIFE DURING WEEKENDS AND SCHOOL HOLIDAYS. PLEASE SEE SENSE, SURELY ITS A BREACH OF THEIR HUMAN RIGHTS!</p> <p>*Care : Please be realistic about severely disabled children in hospital too. We can't leave our son alone in hospital, so we still provide all his care. We left him for one hour (whilst he wasn't under anaesthetic) on the neuro surgery ward at Great Ormond Street. Even with their wealthy of expertise they couldn't cope with him. So don't take care away from children or adults with severe learning difficulties in a medical setting. It already costs us more (e.g. eating 'out' three times a day and the system wants to impoverish us more - cloud cuckoo land!) We often sleep in chairs, on floors just to be there for our child - don't make it harder.</p> <p>*Please allow us to save a bit for our future. Everything is means tested, we have a few thousand in the bank from my critical illness payment but it will be counted against us for mobility cars etc. I have no pension as I have cared for [REDACTED] - its not fair that we have no right to try and improve our lives.</p> <p>*18. : It is vital but not perfect. Whilst we get increased tax credit etc the system is a muddle.*I cant get any premium on Tax Credits for my own disability as I am a carer not employee - Erm so I am saving the state money by caring for a pittance but its not 'proper work' - gee that makes me feel valued. I am also making myself worse by working so darn hard for my child but again the system treats me like a benefit scrounger - thanks for that!</p> <p>*[REDACTED] is not the householder so we instantly miss out on Warm front etc - He will never be a householder as he is too disabled.</p>

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		<p>*We get no help with water bills as we are a tad to wealthy - [REDACTED] has a hole in his stomach so has to be bathed daily, He is also incontinent but we still get no help as it is a social tariff.</p> <p>*The only good thing is we get our season tickets for football cheap.</p> <p>*19. : It would make a difference and make a complex system even more complex*20. : As I keep saying use the existing evidence.</p> <p>*21. : Consult with support groups such as MS society, TSA, Autism UK, they are specialists within their own field.</p> <p>*22. : There will always be abuse of any system, but please don't make it harder for people who would rather not be in this situation, we are already struggling to get a little bit of help. We have two confirmed diagnosis in one household. My husband still works and I try to carry on with help from my parents yet the system judges us. Neither [REDACTED] or myself are getting any better. The help we need is the help we need it would just be nice if we got it.</p>
EM602		
EM603	15/02/2011	<p>Dear Minister, I am responding to this consultation in my capacity as: A former carer for my late husband who was severely disabled; An Accessibility Officer for Disabled People at Football Club; A consultant on disability and accessibility; and</p> <p>*A former decision-maker (adjudication officer) for the administration of Disability Living Allowance.</p> <p>*I welcome this opportunity to provide commentary and hope you will acknowledge that I have a breadth of knowledge and experience from the last 21 years and consider my insight and comments as constructive and valuable to the consultation process. I am sorry that at this late stage I have not been as thorough with this review as I would have liked and so have identified 10 key points listed in the table below. My first thoughts that I would like to share (and forgive me for including some personal examples but I believe it is the real stories that are critical in changing perceptions)are as follows:</p> <p>*DLA is awarded supposedly to severely disabled people; - I'm not sure this has always been the case;</p> <p>*DLA is supposedly to help with extra costs incurred by disabled people, however it is difficult in some circumstances how that can be;</p> <p>*DLA does not look at the whole picture – originally domestic and social requirements were not considered only personal care and yet social and domestic matters affect everyday living but the title of the benefit itself did not reflect that – more disability existing allowance;</p> <p>*There is no correlation between DLA and the DDA (now the Equality Act). Should the recipient of DLA be severely disabled on a day to day basis? WE should be mindful of course of</p>

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		<p>fluctuating conditions and people who manage their condition well should not be penalised.</p> <p>*I was shocked at the culture amongst colleagues when I first started work. It was a totally negative view of disability and disabled people. From then until my husband's death five years later I couldn't bring myself to tell anyone I worked with of our circumstances – that my husband was severely disabled due to a stroke. A family man a professional musician with three young children who had lost everything as a result of a severe impairment down his right –hand side because I feared we would be labelled the same. I kept it to myself because I knew we would be judged – wrongly but judged. I didn't have the guts at that time to speak out This was a view shared by many in society and to this day sadly it still prevails. I was told recently that disabled people should stop at home. I resolved when he died to help disabled people by helping to remove barriers and to try to change people's perceptions and culture.</p> <p>*It needs to start with a statement about encouraging people to be independent and be able to play a role in society without being judged.</p> <p>*My husband never received the rate of DLA to which he was entitled (middle) because he told the examining Doctor he could undertake all his personal care himself. He could do some bits but not properly and I had to re-do most things e.g. fastening shirt buttons and trouser zips and shoe laces, belts, baths hair washes and shaves, carrying things, cleaning up all the water all over the floor and cutting up food – he'd make a good attempt but I couldn't have let him go about unless I did it myself to make sure everything was right. That was the truth of the matter but how could I disagree with him in front of the Doctor when he felt so wonderful having had to start all over again learning how to undertake simple tasks and felt so independent which I spent each day trying to get him to be and find he was penalised for trying. On a scale of 100% we were talking about 20% here. I couldn't possibly discourage him by saying to the Doctor he couldn't actually do these things – result no DLA and so no CA and me having to give up work for seven years to care for him and three small children.</p> <p>*To sum up how do we ensure the people really entitled are awarded the benefit. How do we deal with understating as well as overstating? Even the new medical assessment which I agree is correct – it should not be self-assessment – is not wholly reliable unless Doctors / Health Professionals learn to pick up on examples like the one I've used above..</p> <p>*During my time as a Decision-Maker for DLA in which I applied the criteria to the applications I witnessed many examples whereby applying the law meant that people who I felt did not 'fit the bill' as it were, were awarded and those who I felt did were not. I had to demonstrate professional judgement and</p>

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		<p>keep emotions in check whilst discharging my duties but felt right from the start the benefit was flawed and whatever the policy intent may have been it was not happening in practice. If the benefit was for the extra costs incurred I could not see how a child who had to be helped to have 3 puffs of an inhaler could be awarded thirty odd ponds a week to help with extra costs in the same way that it also applied to a para or quadriplegic whose costs for care bore no comparison. The benefit was not fair or equitable. Relying on an individual's judgement does not bring consistency and disabled people have different perceptions of how their disability affects them.</p> <p>*How do we ensure that if the benefit is for extra costs that is what it means? Should the claim form ask?</p> <p>*Why not in some cases grant the money to a Local Authority to make adaptations to the home? *No.</p> <p>*Comment</p> <p>*1*“Better enable them to lead full active and independent lives...providing cash support to help overcome the barriers which prevent disabled people participating fully in everyday life” This is a great statement but what does that mean in practical terms? One of the biggest barriers I see in the work I do is the culture and perception of disabled people by members of society – the message needs to go out from government that disabled people who are encouraged to be independent and live as full a life as possible should not be penalised financially for doing so. We should be rewarding independence not penalising it. People should not be scared of going out in case it's misconstrued.</p> <p>*2*“I want as many disabled people as possible to benefit from employment”. Again we would all want that but first we have to create an understanding by employers that for some disabled people they are not always able to get up every day and feel able to go to work. How are we going to manage employers' expectation and encourage them to employ disabled people? We need to look at the skills people with particular disabilities have and harness those skills particularly for those people with learning disabilities. Changing perceptions is as much a reasonable adjustment as a special desk or chair.</p> <p>*3*“The Personal Independence Payment ...will support disabled people who face the greatest challenges to remaining independent and leading full and active lives...What about those who sadly are not able to – won't we be supporting those people as well?</p> <p>*4*“We will prioritise support on those individuals who face the greatest day to day challenges and who are therefore likely to experience higher costs”. Are we talking costs for respite, getting to work, equipment, and personal care?</p> <p>*5*The only difference here is an extra 3 months qualifying – so the waiting time is longer before putting in a claim - not sure how this will ensure that support will go to those who face the</p>

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		<p>greatest challenges.</p> <p>*6*A welcome move to use a healthcare professional I long thought that GP and hospital reports sometimes were of no value as the GP / Consultant is not aware how someone functions on a daily basis. The new arrangements regarding GPs would only increase this and so an in depth analysis like a case meeting is a positive step.</p> <p>*In the majority of cases evidence will already be held by for example a Local Authority, a school and a Deaf / Blind Society which negates DWP having to request it all again. I expect this move will harness the evidence already available thus reducing the cost of evidence for the new benefit.</p> <p>*7*Use of aids etc – this is a direct contradiction of the former DDA where the use of aids is discounted so how can this be justified? However I take the point and suggest an innovation would be in some cases a commission to the Local Authority to make adaptations to the home rather than provide a cash payment to the disabled person. Could there then be different options for the Independence Payment (Award?).</p> <p>*8*The government needs to learn from previous mistakes and ensure that all recipients understand the basis of an award and stress that it is not just because the person is disabled but as a result of their needs. When DLA first came out it was said they were practically giving it away. At that time people were awarded on the understanding it was because they were disabled. There was little emphasis about it being for need – therefore I suspect there are a lot of people in the country who are in receipt who may well not now be entitled if we measure the award against the criteria but who believe they are genuinely entitled because that’s how it was sold and awarded to them.*Why not have an amnesty to see if anyone wants to relinquish it?</p> <p>*9*What a good idea – we should be providing a one stop shop for disability and provide advice on healthcare, adaptations, mobility vehicles and work and provide a holistic approach rather than just pay benefit. However the title of Personal Independence Payment would not be appropriate. Regarding the title for years DLA has become a bit of a joke – replacing it with the acronym PIP is not a good move. I Ws disappointed in this although the reference to independence is good.</p> <p>*10*Whilst supporting people who are not always able to be independent and lead active lives we should also reward independence not penalise it. DLA does not encourage independence. In the former DCS we talked about “enabling independence” and yet we still have a culture in society and the media that if a disabled person gets in a car and goes to work or to a football match or on holiday then “they can’t be that disabled”. Whilst acknowledging that there are some individuals who take advantage for financial gain we have to dispel this myth and say to society actually it’s ok for a disabled person to</p>

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		<p>do these things – they have the same desires emotions and feelings as everybody else-it’s just that sometimes they need a little more help and we should be giving it them whether it’s advice adaptations or finance to help independence wherever possible.</p> <p>*I hope you will find these comments helpful. Thank you, Kind regards, [REDACTED]</p>
EM604	15/02/2011	<p>I strongly agree that the Disability Living Allowance needs reviewing and i am pleased that you have decided to ask disabled people for there opinions.</p> <p>*1. I find that i cannot take part in society at all. I am isolated and excluded the majority of the time. My father and finace have to go out to work which means i have to be left alone in the house all day. I have a care phone so i can get help should i need it in an emergency but i do not see any one else. While i can be left alone, i cannot leave the house alone as i am very unstable on my feet and cannot do busy situations without support or assistance. The first barrier i face is being able to leave to house alone. This means i cannot attend any hobby groups, i cannot attend medical appointments, i cannot go to town, i cannot go to the library, i cannot take part in sport or leisure, i cannot work and basically all i can do is sit on the sofa and watch the rubbish day time tv or look on the internet and doing this day in day out is boring! I cannot make new friends or socialise. So i do not lead an independant, full or active life. My life is restricted.</p> <p>*2. The mobility car scheme should stay the same because it means my father and finace can take me out to town on a weekend as public transport is not possible. It means on an evening they can take me out for a drive which cheers me up.</p> <p>*3. Mobility aids – wheelchairs, walking frames, mobility scooters. Care packages. Medication. Heating bills, Phone bills, paying for someone to take us out of the house to any event. Longer parking tickets as it takes longer to get around places.</p> <p>*4. I think the current levels work well. Having 3 levels of care is good as i am only middle and even though i get told to apply for higher i will not because i do not need this but i do need the middle as per what the sheet says you should be.</p> <p>*5. I think that if someone needs any form of walking aid should get low mobility. People who need wheelchairs or walking frames should get higher. I wobble from my bed to my bathroom 5 steps and have to sit on toilet to get my breath back. I find i wobble to my mobility car and have to stop twice along the way to get my breath back to prevent me going dizzy. If you do not want to walk at snail pace (1 hour – 150yards) it is to your best interest to push me in my wheelchair rather than me using my walking frame with seat attached.</p> <p>*Care i need washing and dressing in a morning, a sandwich making for lunch and meal preparation in the evening. Just eating and talking has me breathless. I wobble due to low</p>

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		<p>muscles and with these struggles i only ask for middle care because i can manage in the night even if i do at points crawl to the bathroom (5 steps). I do think how you do them at the moment works. But maybe you should get people to do a video diary for a month so you can get an overall picture rather than filling in forms. Because a lot of people know how to word the forms rather than how they are actually affected and this does make me cross. I would quite happily video my life for a whole month for you to show you what i struggle with so you can judge my claim fairly. I do not like asking for more than i need. I think it should be done on an individual basis because every condition affects a person differently there are no two identical people.</p> <p>*6. The most essential parts of every day life – personal hygiene ie daily wash and dress, Food and drinks, being able to live the house to get some fresh air and to see other people to help remain cheerful. I think these are basis human rights anyway. I know that if i did not have my care package i would not get these basic requirements – infact i am not getting out to get fresh air daily or meet other people which is why i am trying to make a difference!</p> <p>*7. Video diaries to get a true picture of how you live your life or maybe going to a centre for a week but that may cost too much money and require too much organisation. I think video diaries.</p> <p>*8. I think the assesment should take everything in to account. All parts of the story build up a full picture. I think that whether a person has something or not should not count. I think the social services should actually work with NHS not separately it would make it better. The way it currently is done is not right at all. I guess the only way to get a full picture of what it is like to be disabled is to spend a week in the life of that disabled person. It is like me i never get a full nights sleep because of the side affects of my medication. I have to wake at set times for more medication in order to breathe. I cannot do any task in the same amount of time as my father it takes me often triple amount of time. I find this hard because i am younger than him. I think the assessment should include all affects of a disabled persons life!</p> <p>*9. The form you have to fill in should require a lot more detail and it should be more tick box rather than wanting poeple to word it in a set way. Maybe use pictures for people that struggle with words. At the moment the form you haev to word in a set way. This is very unfair. I think it should be tick box. ie can you lift a mug? can you lift a pint glass? do you use a straw? can you stand to have a shower? do you sit to have a shower? can you get in a bath? can you get out of a bath? do you use a bath chair? can you walk up the stairs with no handrail? do you have one handrail on stairs? do you have two handrails on stairs? hope you see how much detail i mean? i know that may seem over the top but to a disabled person this is relaiity! Can you understand a printed letter? do you require pictres to help you</p>

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		<p>understand? can you do a telephone conversation? can you get yourself to the doctors? i could go on but think you will have the picture by now.</p> <p>*To improve the information you need to use short sentences with pictures. An information booklet with loads of text is not helpful! Infact to me no use. Audio versions, braille versions maybe even dvds! Use all media! I think there should be a very strict criteria for each level and it should depend on evidence not just how you word a form. Anyone can tick on a form but a video diary cannot be faked!</p> <p>*10. Family and Friends are the best people to give a clear picture because they see the person in there daily lives. A medical profession will only see a person at max weekly and they do not see them in there home enviroment. Home care people would be able to give a clear picture as would support workers. It needs to be people who see the person on a daily basis. Medical people can only say what medication and hospital visits they cannot say how you are affected on a day to day basis they do not see your pain, your lack of sleep.</p> <p>*11. Getting to the healthcare professional would be my main problem. Also the health care professional never know what it is like living with it every day. They only know what medication you take. I think social services are a better indication because they help you on a daily basis. Or they do in my case. If you do not need home care or a support worker why do you need money for care? You are not being cared for so why do you need money to be cared for? this has always annoyed me. People get higher care yet they do not have a carer – whether a member of family or a social services one.</p> <p>*I only get middle care and i have home care twice daily and a support worker and go to a day centre so i am being cared for. And my father comes to help me get food shopping and my boyfriend comes to help me get my medication and ready for bed. So i am cared for so need money to pay for my care.</p> <p>*I could not get to another location alone. I would need a carer to take me. and then they would not get a true picture because no one ever can in one meeting.</p> <p>*12. Reviews – this is difficult because it depends on the individual is there condition deteriorating? is it the same? does it change day to day? If it is the same no review needed, if deteriorating possibly very frequent and if it changes lots then poss frequently. Maybe yearly reviews would be best?</p> <p>*13. Give incentives to people – like social activites or gifts</p> <p>*14. A real person coming out to your home to explain the process.</p> <p>*15. do not understand question</p> <p>*16. Personally i have had to fund all my aids and mobility items. – i think they should be provided for because it is not my fault i am disabled i did not ask to be. I miss out on so much in life and to haev to pay for things is not fair really. Yes i should</p>

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		<p>pay for what normal people do but not what others do not need.</p> <p>*17. All parents care for children to some degree. No parent leaves a child alone who is under 12. No parent expects a child to cook unattended under 10. Think of the role of a parent for a normal child then base it from this.</p> <p>*18. I do not think it has made any difference or certainly not i am aware of. I think if you need social services help then you should get money for care. Just like if you need mobility aids you should get mobility money. It is common sense really.</p> <p>*19. Not sure</p> <p>*20. Why cant if you need help to do daily tasks can it not mean you need all disabled stuff? le i need the basics personal care, hygiene, food and drink, fresh air and socialising So why cannot this mean i need everything.</p> <p>* My personal thoughts are why have lots of different benefits? Why not just have one fund for disabled people? If you are disabled you get money to cover all your needs. Basic needs are Hygiene, food, drink, medication, aids, fresh air, socialising, housing, transport. Why can you not just have one package? Keep it simple. Make it really simple! Disabled people need it simple why not just have one benefit for disabled people that covers everything! Yes have criterias like low middle high but just one benefit!</p>
EM605	15/02/2011	<p>I am responding to the consultation process as an individual. I have 10 years' experience of working in the Civil Service, administering benefits in the DHSS, where I worked as an insurance officer (what would now be called a 'decision maker', adjudicating doubtful claims for contributory sickness and incapacity benefits. *I have 20 years experience of working as a local authority solicitor in the social services field, relating to both adults' and childrens' services. This has involved responding to consultation processes in an official capacity. I was pleased to note that the consultation relating to the new Volume 1 Guidance to the Children Act did result in considerable changes to the draft guidance to take account of the comments made by practitioners involved in social services and care proceedings, therefore I am cautiously optimistic that it may be worth contributing to this consultation process. I am now the carer for my husband, who has become disabled, and no longer able to work, following a severe stroke two and a half years ago.</p> <p>*THE CONSULTATION PROCESS</p> <p>*1. The abbreviated period of consultation, including as it does, the Christmas and New Year period, is likely to limit responses from the public. The proposed changes will affect the quality of quality of life of numerous vulnerable people and their carers, who, as a group, generally have less energy and / or time to consider their responses than the able bodied and persons without caring commitments. It could have been hoped that this would have been taken into account if the consultation was</p>

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		<p>really intended to obtain the views of as many of them as possible. Not to do so, and to rush the consultation through, could be seen as potentially discriminatory. Further, the fact that the consultation is on 'general principles only' in fact makes it more important, rather than less, for those affected to have time to give a considered response, as it is easier to understand how a definite proposal may affect your case, than it is to make a guess at what the implications of a response on a general principle are likely to be: e.g. a response to question 4 would be easier if it was made clear whether or not it is proposed that there would still be payments under the PIP system for the level of personal care required by people now receiving the lowest level of personal care component of DLA.</p> <p>*2. The decision to replace DLA has already been taken and this is clearly anticipated to save money (a major, if not the primary aim (paragraphs 14 and 15). It is said that more people are in receipt of DLA than had been anticipated. If what is going to happen is that the criteria will be made more stringent, it will result in many vulnerable people and their carers enjoying a very much reduced quality of life. If that is the case, it is fudged in the way the consultation is presented (e.g. paragraphs 3& 4). If not, perhaps this could be stated as the proposed change is bound to cause anxiety to disabled people receiving the benefit.</p> <p>*3. The use of the word, 'reform' suggests that the benefit is seriously flawed, if not corrupt, according to the dictionary definitions, whereas in fact it helps a lot of people with major physical and mental problems to live lives of more dignity and independence and to maintain their friendships and interests.</p> <p>*THE SPECIFIC QUESTIONS</p> <p>*1. What are the problems or barriers that prevent disabled people participating in society and leading independent, full and active lives? These will, of course, vary according to the type of disability from which the individual person suffers.</p> <p>*However, these can include: being unable to use public transport other than taxis, which means that if, for example, you wish to visit friends or relatives, or just go for a day out, to somewhere half an hour's drive away, it will cost you £45 to £50 just to get there and back, and to go further afield is not really an option</p> <p>*having to be careful where you go, since as a disabled person you will probably appear vulnerable and / or different from other people, and more likely to be attacked and / or robbed than a person who is not disabled, and it is also not that uncommon for the disabled to be subjected to verbal abuse or audible comments by ignorant people</p> <p>*being unable to go out to new places, or at all, without a companion to support you and prevent your coming to harm</p> <p>*worrying about going out because, due to slow movement and / or medication, you may need to use toilet facilities urgently,</p>

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		<p>and these may be absent or inaccessible *having difficulty in sitting for a long time, or conversely being unable to stand for long, which makes it hard to attend theatre, concerts etc</p> <p>*coping with incontinence which makes it difficult to get out</p> <p>*needing help to cut up your food, get dressed, go to the toilet, have a bath, switch on appliances because the plugs are too low, etc etc</p> <p>*being unable to prepare food for yourself and depending on others to cook for you</p> <p>*being unable to clean your house or do the garden yourself</p> <p>*being unable to do even simple diy jobs yourself</p> <p>*being selfconscious about your disability (probably especially if you have not always been disabled),depressed about your inability to participate, spontaneously or at all, in outings and activities which people without disabilities can do routinely, and unhappy about having to request / accept help from others, can make it more difficult to interact positively with other people, however nice they are, as no one wants to harp on and on about their disability but it is difficult to contribute to a conversation about e.g. skiing holidays.</p> <p>*in many cases, no longer being able to work and lacking any income of your own (apart from benefits) to enable you to engage in activities or follow interests</p> <p>*suffering from cognitive difficulties, either congenital or acquired, which make it difficult to comprehend instructions or cope with financial, business or legal matters</p> <p>*impaired memory impacting adversely both on personal life and capacity to manage practical affairs *if you have a mental illness, your behaviours can make it inadvisable to go out alone in case you offend people etc, or you can be prevented from going out by agoraphobia etc</p> <p>*2. The new benefit should continue to be paid to all the people whose disabilities are at a level that now attracts the payment of DLA. While it is clearly sensible to review entitlement from time to time, and therefore it would be exceptional for an award of the new benefit to be made for life, to exclude people whose lives are impaired by their disability to the level of the lowest award of DLA, which is still at a relatively high level, would condemn them to living without help. In any caring, or even civilised society, help would be given to the vulnerable according to their needs and they should not be deprived of assistance for reasons of financial expediency, when billions are spent e.g. on a high speed rail link.</p> <p>*The main expenses disabled people face will vary according to the disability but are very likely to include:</p> <p>*High transport costs, using taxis or a driver</p> <p>*Cost of tradespeople to do household tasks, gardening and repairs*Cost of personal care*Cost of aids, adaptations and gadgets*In some cases, additional clothing and washing costs due to incontinence</p>

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		<p>*There is insufficient information in the question, which is therefore difficult to answer. There seems to be no reason why it should be easier to understand two bands rather than three in relation to care, it would rather seem that, if the level of disability attracting payment will remain the same, then there will be more disparity rather than less between people in the same band. If the reason for substituting two bands for three is that is proposed to delete the band altogether, this should be honestly and explicitly stated and a genuine opportunity given for consultation; the drawback would obviously be that people who were disabled enough to need help, as in (3) above, would not get it and would suffer both practically and by diminution of their independence and ability to live in a decent environment.</p> <p>*The conditions attracting automatic entitlement are currently severe. If it is planned to assess each person when this was not done before, it will attract additional costs which may well not be justified by what could be anticipated would be a small number of people who would not qualify for the benefit or who would qualify at a lower rate.</p> <p>*and 7 I would agree with the description of activities in paragraph 25 with the addition of : comprehending instructions and being able to perform household tasks to maintain a person's environment, and cooking. There should be an assessment of individual needs and it should be a genuine, not a 'tick box' assessment, and the assessment should be holistic and not based on adding up points (I am reminded of some of the decisions made centrally in respect of the former benefit of Housewives' Non Contributory Pension, for example a case where the benefit was disallowed for a woman who had lost both hands in successive actions, but was still of course able to do some tasks such as communicate with tradesmen, plan shopping etc).If a condition is variable and fluctuating then, unless of course the episodes when the condition is worst are very rare, the support should be geared to the condition at its worst. However, it is clearly appropriate to review entitlement and a sustained improvement would clearly affect this.</p> <p>*The aids and adaptations should be taken into account and how the person is able to manage with the assistance of these. Aids could include e.g. a stick, prosthetic limbs, mobility scooter, etc. However the assessment should also, as it does now, take into account the difficulties that the person has, with the aid, in excess of those which a person who did not have to use them would have. E.g. it is not as quick or easy to get around on a mobility scooter (e.g. going between narrow lanes in a market) as it would be for an able bodied person to go to the same places. It would be wrong to take into account an aid which a person does not have unless they had been given the opportunity, or assistance, to get it, and had declined to do so without good reason.</p>

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		<p>*The process of applying for a benefit of this kind must inevitably be depressing as it involves declaring what the person cannot do. In my experience, most disabled people tend to minimise their disability and to concentrate on what they can do. However negative the experience may seem, the right information must be given and I think the only way to elicit this is to ask the type of detailed questions which are on the current DLA form. While this may not be the most positive of experiences, to be refused benefit for which your disabilities would entitle you because the right questions have not been asked, would be still less positive. If the form were to encourage one word answers, it is likely that inappropriate disallowances would follow due to inadequate information being given. The best way to make the claim form easier to fill in is to ensure that there are sufficient health professionals, CAB workers, welfare rights advisors and social workers available whose job it is to assist. Prospective applicants should be directed to the source of such assistance.</p> <p>*The best supporting evidence will come from:</p> <p>*The applicant (who should be able, as now, to submit reports from anyone they deem appropriate, though these would carry variable weight)</p> <p>*The applicant's carer</p> <p>*The GP</p> <p>*Any other health professional involved, e.g. occupational therapist</p> <p>*Any social worker or other professional involved</p> <p>*If the advice of all health and other professionals who know the applicant well is sought routinely, it would seem unnecessary to involve a healthcare professional in all cases. To insist on this in all cases would greatly increase the cost of administering the benefit, especially as the assessment work would be likely to be contracted out to a private company doing the work for profit. This would, of course, reduce the amount of benefit available for payment to disabled citizens and could even result in the threshold's being set artificially high. Many people with disabilities are likely to be depressed, fearful and inhibited in trying to express themselves in a short meeting with a complete stranger who has no responsibility for their welfare, and are unlikely to give a true picture. In cases where supporting evidence is inadequate, or there is doubt, there should be such an interview, but as these would be held less often there could be more time allowed, and hopefully a better picture could be obtained.</p> <p>*The criteria for a review could be set, on medical advice, according to the nature of the condition affecting the disabled person, and whether it was likely to change, if so within what timescale, with regard to variables such as the person's age and the individual prognosis already given. It would seem reasonable for reviews to take place initially by requesting</p>

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		<p>reports, and following this up by a medical review in cases where there was doubt.</p> <p>*The changes which have to be reported should be set out very clearly and if my suggestion that everyone should have a right to help with completing the form is accepted, the person giving that assistance could emphasise the need to report changes etc.</p> <p>*It would be hoped that disabled people would have contact with health professionals and / or social workers who would have given them assistance already in relation to their disability. If they had not had such assistance, the benefit authority should make a referral to the appropriate source of assistance. However the benefit authority should not attempt to set up a rival system, which would be costly and would not work as well as an appropriate local source of support.</p> <p>*I feel that the majority of people do want support and will access it. However the autonomy of the individual should be respected and a person could not be forced to access it.</p> <p>*Disabled people will fund their aids and adaptations in various ways, in some cases Health and / or Social Care will provide them. However in many cases people will have to buy their own, e.g. if they want a bath lift rather than just a bath seat which the occupational therapist will provide. If they are getting DLA this will help them to pay for the odd item of their own choice. I am not sure what the question means, as it would always be possible to save up to buy a bath lift etc. If it means that an additional grant could be made, one would need to be sure that this did not simply shift responsibility e.g. from Health to the benefit authority, with added administration costs, but no benefit to the applicant. If it means that the benefit could just consist of a one off payment without continuing benefit, this would represent a diminution of the assistance currently available and would be unlikely to help people.</p> <p>*The differences would seem to be the changing needs of the child, the intensity of the child's needs as time, to a child, seems longer than to an adult, and the fact that the child is less able to make informed choices or communicate his or her needs. Advice should be sort from paediatric experts.</p> <p>*It seems to have been helpful as a passport to very useful services, such as the Blue Badge scheme and transport assistance, and, if the person is able to drive or has access to a driver, the Motability scheme is life enhancing. It also saves public money as there is no need to perform multiple assessments.</p> <p>*Obviously it would be a retrograde step which would make life worse for disabled people if the new benefit were not to act as a passport to other benefits and services. There would have to be multiple assessments and this would be intrusive for the disabled people and would waste public money.</p> <p>*This would seem sensible, however care would need to be</p>

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		<p>taken that assessments made for each benefit covered only matters relevant to that benefit and that information was shared only for the purpose of establishing entitlement. The assessments for EASA and DLA are currently rather similar and might possibly be combined.</p> <p>*The benefit needs to be administered fairly to all and to give help to all who need it. That there has been greater take up than anticipated is surely a reflection of the needs people have and the fact that professionals working with them have informed them of their rights. People should be able to have some independence and dignity and to live in their own homes. Comments made, as by the Chancellor, relating to claiming disability benefits as 'a lifestyle choice' bear no relation to reality for the great majority of disabled people, who sadly have no choice about their condition.</p> <p>*22. No thank you.</p>
EM606	15/02/2011	<p>I am registered blind and use a white cane to help when getting around. I have had the same eye condition since birth, although I chose not to get registered blind until 2000, I am now [REDACTED]. I have worked most of my life until 2004, when I parted company with my last employer on Disability Discrimination grounds, I have not worked since. I regard my DLA as essential to my independence and to enable me to lead as normal a life as possible. I am extremely concerned that the re-assessment process from DLA to PIP will not reflect the special needs of those with sight loss.</p> <p>*The purpose of disability benefits like DLA is to assist people with the extra costs associated of living with a disability. Blind and partially sighted people are facing the prospect that vital financial support will be removed from underneath them, when so many other public services, such as social care, are also being further rationed or cut. Local bus services are continually being eroded, particularly in the evenings and at weekends, adding to the social isolation of the visually impaired. Working age people with a visual impairment feel particularly vulnerable because entitlement to DLA and ESA will be tightened just as cuts in local authority services are taking effect and the employment market becomes far more difficult with the recession impacting on all areas of employment.</p> <p>*Blind and partially sighted people are more likely to live in relative income poverty. Blind and partially sighted people of working age are also significantly more likely to be unemployed than the rest of the population.</p> <p>*The long DLA forms are difficult for blind and partially sighted people to complete on their own. Getting independent assistance to complete such forms is becoming more difficult with the decline in the availability of CAB advice due to funding cutbacks.</p> <p>*DLA reform will cost the Government considerably more in administrative terms due to the assessment process. The</p>

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		<p>“objective” assessments carried out by independent healthcare assessors, would appear to be cost-driven, as the Government’s objective is to significantly reduce the number of claimants and save around £1billion. I expect the number of appeals to increase significantly, further adding to the administrative burden.</p> <p>*The PIP assessment process needs to take account of:- the specific barriers to mobility and daily living experienced by people with sight loss.· recognise the unique difficulties blind and partially sighted people face accessing written information and the costs this can present in terms of aids and equipment for communication, and in applying for the benefit.· need to be based on an effective approach to gathering the medical evidence already available about an individual’s impairment.*Automatic entitlement to DLA/PIP for people who clearly ought to have it, including the higher mobility component for people who are severely visually impaired, should be retained. It is counter-productive therefore to insist that all disabled people, including individuals who evidently have severe needs, undergo an assessment. To assess (and repeatedly reassess) claimants where there already exists clear and objective evidence of entitlement to the benefit will not only be costly to Government but will be highly stressful for the individual.</p>
EM607	15/02/2011	<p>1. Your response: 1. I worked with disabled children & adults for many years in a healthcare professional role in the 1980’s, “thinking I was fairly aware” (because of my own training for specialised health professional role and my personal attitudes of fairness & justice for everyone) of the problems/barriers that prevented disabled people from participating in society & leading full & active lives, However the true nature of the barriers/problems for disabled people only really became apparent to me properly as I became more disabled in the 1990’s due to a neurological medical condition & by the restrictions imposed on me by society as I tried to participate in everyday activities needed in society. There are many barriers that are the same for every disabled person, and others more related to their individual impairment.</p> <p>*Examples of problems/barriers- Physical barriers that do still exist, restricting access into & within buildings even since the DDA & Equality acts came into place. Lack of appropriate equipment. Extreme extra cost of being disabled in today’s society.</p> <p>*Negative attitude/emotional response barriers that come from people’s fears about disabled people. Lack of awareness of what disabled people are capable of, & restrictions in allowing people to fulfil their potential. Lack of/ limited awareness training for employers. Funding restrictions for adaptations necessary for disabled people to be fully included as a customer or employee. Disabled parents often fall between</p>

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		<p>adult & child services when wanting some support to fulfil parenting role.</p> <p>*Discrimination against people applying for jobs etc</p> <p>*Physical barriers E.g. I tried to look at a first floor flat to rent with my spouse and son for a few months, as had to move out of my adapted home due to a major flood, to allow repair work to take place. The estate agent assigned even took us to view a flat seeing I am a wheelchair user, but thinking it would be fine, because there was a lift! The 3 level blocks of flats had been built in the last 2 years, and therefore had been passed by planning department whilst being built under DDA & equality regulations. However as I tried to access the lift, we found it was not to be seen on the ground floor as it didn't start until the first floor level.</p> <p>*You may think this is an exception to the normal experience of access, but I assure you, the regulations that should be there to reduce the barriers, seem to be "got round" too often, by</p> <ol style="list-style-type: none"> 1/attitude of planners accepting even big companies excuses that adaptations would be too/difficult expensive, 2/not enough disabled planners employed or on town planning committees to advise 3/limitations on funding available to help small companies to train on benefits of fully including disabled people as employees & customers. 4/limited opportunities for people with hearing impairment, visually impaired, or learning disability to access information easily. You often have to request it, and it is not always forthcoming. <p>*2. Your response:2. The new benefit should start at 3months and not 6mths. People who have been disabled for 3 months & would expect to be disabled for at least a further 6mths should be able to apply for the new benefit, rather than wait for minimum of 6months, because some of the biggest costs as people adapt to being disabled, are in the first few months, and so without a benefit at 3mths they would have no provision of money to pay for these extra costs.</p> <p>*3. Your response:4. The main extra costs are extra money needed to fund:-* i/paying for care/support at home -for help with daily living skills to assist with tasks that cannot be done by myself; aids that were a few years ago given to disabled people e.g. kettle tipper, helping hand, wheelchair cushion covers/back supports, now have to be purchased by disabled people due to cut backs in all depts. Help has to be purchased if not able to carry out simple repairs to essential home equipment due to physical impairments. Help was needed to enable me to fulfil my parental role in caring for my child & helping to make sure he was safe, well fed & warm.</p> <p>* ii/ food & dietary needs- I require a diet that covers needs for 5 medical conditions that I have. This is not unusual, as often one illness can predispose one to related conditions, & hence there are complex needs & increased costs in many areas. The need to pay for help with shopping as not able to go out</p>

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		<p>independently to get to shops.</p> <p>* iii/Electricity/Heating-As I feel cold more & home for more hours than those out at work, I need to spend more on heating to stay warm, even when put on more clothes & try and have limbs moved with help. I also need to power a pressure relief mattress with electricity 24/7.It is more expensive now that fuel in general has gone up.</p> <p>* iv/transport & travel –Where it is not possible to access public transport through bad design of buses, or taxi’s, greater cost are involved in getting out to buy anything, or to go to dentist, doctor, physiotherapist,, shops to buy clothes, food etc. Extra transport costs are incurred to adapt a car &put in specialised controls, if people are unable to use standard cars. Hiring specially adapted vehicles is more costly for a wheelchair use than a non-w/chair user using a taxi or van. There is also a greater cost on petrol, as there is greater dependence is on vehicles to do essential journeys when not so mobile. In the early days of being disabled, I could drive an adapted car very short distances with help& had to pay extra costs to make that physically possible. Some disabled people who do drive independently, often use a car as an essential means of mobility to go everywhere. I am now not able to drive an adapted car at all & therefore I am totally dependent on others to take me &my wheelchair everywhere. Therefore the extra costs now are on employing someone to take me & w/chair to appointments, shopping, and other essential journeys.</p> <p>* v/chemist items-extra amounts of bathroom items, creams, medication etc.</p> <p>* vi//laundry-extra w ash loads due to incontinence, paying someone to assist with getting clothes washed & dried.</p> <p>* vii/ clothing- purchase of specific items relating to specific needs, extra warm clothes that cope with frequent washing, and work with bladder control systems.</p> <p>* viii/ Gardening/property exterior support, I initially thought this was not an essential, but realised had to be purchased when it began to be a health hazard e.g. presence of rodents!</p> <p>*ix/ extra phone costs, communication equipment- as well as physical impairments, I have memory/cognitive difficulties, and for both of these reasons I need to spend more on different pieces of essential equipment, to be able to do basic tasks for daily life.e.g. to avoid missing essential appts, not requesting medication etc.</p> <p>*x/ Adaptations to home - adaptations to a disabled persons home to make them internally accessible and also accessible from the public highway, is very costly & there are few if any DFG grants that people can try to apply for to help with costs</p> <p>* xi/holidays-anytime away from home over night is a holiday for me. However this incurs high costs to try to find somewhere that is accessible for a wheelchair user with a son. They are not often geared for disabled people with a family.</p>

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		<p>* xii/Insurance for a wheelchair, house contents or a holiday is very expensive. When disabled people try to book any insurance for a holiday, there is always an increase in the cost, which goes up related to number of conditions you have & how many different types of medication thy need to take regularly. For me it is several medical conditions & a large number of different types of tablets & other necessary items etc. so this is very expensive even if I shop around and compare companies.</p> <p>* xiii/miscellaneous sundry general items that are all linked to consequences of impairment & how I cannot fully be involved in society e.g. counselling/therapy costs; parking penalties e.g. have incurred 2 fines from parking attendants when parked in a disabled bay displaying my blue badge but)it had the wrong side of name badge facing out, an error made because I had just had radiotherapy & surgery & b)the badge was a month overdue being renewed, I had not noticed partly because my home had been flooded a few days before. I challenged both these to explain difficult circumstances, but fine upheld costing me £75 at the 50% reduced rate in a six month period!</p> <p>*5. The new benefit will have two rates for each component.....: Your response:4a) DLA has 3 levels for care and a range for mobility. Whether the 2 rates per component would be easier to understand & administer, depends on clarity of criteria for each rate and whether they will cover the wide range of needs people have.</p> <p>*b) If they just restrict to moderate or severe levels of need after 6mths, many people with moderate/severe needs from 3mths would be excluded from new benefit and they would have no access to any help or support from social services by their entry criteria of providing for only those in urgent need, & other services. These people would fall through both systems that are meant to provide support for people in need & it could result in more people developing more severe & costlier difficulties later for health & social services later on e.g. short sighted “short term saving” for government would develop longer term greater costs later on, which doesn’t seem good use of money. Also big disadvantages of many benefits for disabled are that they do not put sufficient emphasis on the psychological effects of illness and impairment, and the disabling impact it has on someone’s life, and their inability to function in all areas of life at home, work & ability to care for self. The new benefit needs to include in its assessment, the impact of memory, concentration & language difficulties & mood changes on people’s ability to carry out normal everyday tasks as well as physical needs, learning &/or psychological difficulties.</p> <p>*6. Should some health conditions or impairments mean an automatic entitlement ...? Your response:</p> <p>*5. I would expect some health conditions & impairments to have automatic entitlement to new benefit. E.g. Cancer, Multiple sclerosis, Parkinson’s Disease etc. this is because they</p>

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		<p>are conditions that would have been diagnosed by a health professional e.g. GP/consultant etc. following several tests, & with identified consequent difficulties in daily living tasks specified and they are often regularly reviewed & in touch with several health professionals often on a weekly basis. This would be less costly for health, social services and the disabled person, and they are already regularly tracked and monitored routinely by numerous healthcare professionals.</p> <p>* For me as a disabled person with many conditions, it is extremely tiring & draining to make lengthy applications for any assistance & benefits or to even respond to this consultation. I have had to do this in many stages & only with the help of others to support me. Doing the initial DLA assessment was exactly the same, and the thought of having to do an assessment like that again & regular reviews terrifies me, to the point of feeling desperate. Living with our conditions & the impairments that result, is bad enough. Having to state & repeat at regular intervals how very difficult/impossible daily living tasks are to do & stating how limited life has become is depressing and something we often have to do when see a GP or other health professional as part of monitoring the conditions! Depression is something that often results from long term illness, & the things associated with it e.g. applying for assistance to help with a whole range of basic daily living tasks & stating how limited life has become! Therefore the thought of being put through this assessment trauma again scares me. The stress of the process has caused me to be more depressed before, and I am very fearful that it could cause that again. It is liked being kicked on the floor when you are already down not coping with everyday tasks and almost out of any hope it will get better.</p> <p>*7. How do we prioritise support life? Your response: 6 a. Prioritising support to those least able to live full & active lives, means accepting evidence from the disabled person or a person they recommend who should know them well e.g. perhaps their G.P or equivalent professional they are in regular contact with. This person would have immediate records, & could indicate whether they have need for assistance with daily living skills during the day or night, & whether they are able to go out of their home without assistance. If the disabled person receives a service from social services e.g. Homecare, they would automatically have undergone a rigorous assessment for this, and therefore evidence of this should be proof in itself. The tasks they need help with are officially recorded professionally. However the context for each person's help still would need assessing. Often disabled people are initially seen by 5 or more professionals to get them set up over a period of time. This time period varies from one local authority to another, depending on staff resources and which equipment/services are required, but after this is done, they are left under continuing care of GP.</p>

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		<p>Therefore this person would probably in the best position to provide evidence as sees the individual most regularly.</p> <p>*6b The activities most essential for daily life are getting washed, having medication, getting out of bed, dressed, toileting, shower/bath, help to prepare & have hot meal/drink, help to buy food, help to mobilise indoors as much as possible, help to go to shop for essential food & drink, appts for Dr, dentist, church, & if they are physically & mentally capable to carry out employment /work role. Another essential activity is to fulfil their disabled parenting role to get child fed, clothed, taken to school, take them to appts (where parent is not supported in this, it restricts child's right to education, health & individual's right to be responsible parent in human rights acts & equality act 2010, producing often damaging physical & psychological effects on parent & child. It is also essential that if a disabled person is married that they have funding for a respite arrangement, where their spouse is given a break from their caring duties, especially if they are trying to both do employment & care for the disabled person. Without this there is a very high incidence of marital & family breakdown which adds more costs on society in general & lowers even further a disabled person's ability to participate in everyday life activities.</p> <p>*8. How can we best ensure fluctuating conditions?Your response:</p> <p>*7a A new benefit assessment would need to have an allowance for variability of a person's ability during the same day or week. Living with severe M.S & other conditions mean that help is needed at night, & to help dress, use wheelchair & other aids, help with washing, & other bathroom tasks, prepare hot/cold drinks, medications & food everyday. There is variability though between different people and even for the same person e.g. For the same disabled person, during some parts of the day transferring may be easier from chair to bed etc, but later in the day or on another day, this same task may not be so possible. Indoor powered wheelchairs help with leg weakness to get about indoors, but for same person again at other times may need to be pushed in a manual wheelchair which requires additional care staff time. I also do essential prescribed passive movements several times a day to prevent further problems and reduce pain felt always every day. My general condition is therefore variable always needing support and wide range of equipment to meet all my needs. Many neurological conditions are like this. However, when I was Chair of a charity for parents with a disability, I often found that with visual or hearing impairments, mental health, and learning difficulties there is also a fluctuation of needs and support necessary. Therefore, a new assessment cannot be given on just how an individual is at just that particular moment/day. Consideration must be given as to how that person would be later that day or tomorrow as well. The use of a scale of</p>

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		<p>variability of need during a typical week, as opposed to a fixed statement of what a person is able to do at any one moment, maybe a workable way forward for this point.</p> <p>*9. Should the assessment ... adaptations they use? Your response: 8.a)Assessments can record what aids adaptations & individual currently uses, but often people can be on long waiting lists to be referred to see an OT or a Physio and in the first six months may not have the equipment that would assist them. Therefore. it should not be assumed that someone does not have a bath hoist, indoor/ outdoor wheelchairs, or adapted shower room, that they do not need them. I had to wait 2 ½ yrs. to be able to have shower in my own home with a DFG ,and had to wash with a bowl of water in the bedroom while I waited. Disabled people even with the support of other people e.g. M.P's, G.P's D.N's campaigning for them are powerless to do anything else other than wait!</p> <p>*b)As stated already assessments can note what a person is currently using, but an individual should not be penalised for not having a wheelchair/hoist/stick/or guide dog, they may be on a long waiting list to obtain them. No pieces of equipment are easily obtained unless you have lots of money and the specialist knowledge to know what piece of equipment is most suitable to meet ones needs. People who do fundraise for pieces of equipment without the right advice & assessment do it because they are desperate, but it may not meet the person's needs adequately.</p> <p>*10. How could we improve experience? For example: Your response:</p> <p>*9a) The process for applying for a new benefit would be a more positive experience if it could i/focus more on what a person can do in a scale of variability of need, or ii/ would like to do given X assistance.</p> <p>*b)Claim form This should be provided in various formats. For some it could be made easier for a person to fill if there is an option for at least some of the form to be filled in using a computer on line, or facility for someone to form a response & copy & paste this onto a form sent electronically for at least some parts of it. This would allow some disabled to be more actively involved. However everyone's needs are different, and one solution would not be suitable for everyone.</p> <p>*c) Information about the new benefit could be improved, if more details are given about who would qualify re certain ranges of levels of care needs,&/or mobility needs including fluctuations in abilities of each. Appendix 1 covers specifics for some impairments but a greater proportion of disabled people with other impairments would be looking for and needing similar clarity too as a guideline to know who would qualify, even if each individual case is assessed on an individual basis.</p> <p>*11. What supporting? Your response:</p> <p>*10a) Supporting evidence providing clear assessment of ability</p>

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		<p>could be provided by person assessed, their G.P, or social services if they receive a social care package. b)The G.P maybe best placed to provide this because an individual always has to be known to a G.P to receive any support from health services or elsewhere, as opposed to social services where each council operates a different system with different criteria, and people don't see their care manager that often even if they have one. Similarly Physio's,O.T's don't see everyone as there are long waiting lists & if they do see someone, they may only see them for an initial assessment, short period of treatment if qualify, but then often discharged until next crisis episode, they are not people who have an on-going regular professional contact with someone.</p> <p>*12. An important part? Your response: 11) a)Benefits – If the face to face discussion is with a healthcare professional who understands the social model &known to the individual in a professional context &discussion is in their home setting , it would result in a more accurate realistic assessment of an individual's needs & constructive for both person assessed &purpose of assessment. Difficulties-If it is with a healthcare professional that doesn't use or understand the social model,& is new to person assessed, then it will be harder to establish the full needs &impact of disability/impairments on daily life activities without a considerable amount of time being spent with person on several occasions in their home setting. There would be an increased risk of individuals appealing their assessment, which is costly and time consuming for disabled people & professionals involved.</p> <p>*b) It may be inappropriate to have face to face discussion with healthcare professional -if person assessed is in too fragile state emotionally, psychologically or physically either in own home or other location. I know when I have been too depressed suicidal infact with combination of severe physical impairments due to MS,IBS,Osteoporosis &other conditions, not coping with bereavement from parents death &waiting 2 ½ yrs. for a house adaptation to be completed to give me an opportunity to have a shower &/or wash in sink, I was in no way able to tolerate a new benefit assessment discussion with anyone as this would have just made me more ill physically as stress exacerbates many conditions, more desperate psychologically, with feeling no point in life.</p> <p>*13. How should the reviews be carried out? For example: Your response: 12) Reviews- a)These could be carried out by perhaps GP of disabled person receiving benefit at an agreed interval. E.g. a standard letter/ short questionnaire could be completed by GP about any changes in circumstances every 4yrs,for initial 12yrs, and then every 5-10yrs or less often depending on nature of impairment.</p> <p>*b) Where medical tests have identified a person has a long lasting progressive neurological condition e.g. motor neurone</p>

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		<p>disease, progressive M.S with on-going severe impairments affecting all daily living activities they do not need to be as frequent as someone who has perhaps a mild stroke who initially has a weakness on their left leg but should be able to drive & work after a period of intensive physiotherapy. G.P's reports could perhaps provide evidence for this. For some individuals the effect of their condition/impairment could be reviewed by another professional agreed by person receiving benefit, if it is felt that person knows the assessed individual better. Reviews or assessments by a health professional who is a stranger & who doesn't know the person at all will not provide accurate information of the needs of individual assessed, and be misleading, & confusing for all concerned.</p> <p>*14. The circumstances? Your response: 13) Individuals to report changes in needs & circumstances. a) People could be encouraged to report changes in circumstances if they are warned that a penalty could be given for people who continue to claim i/when they moved home & not given change of address, or ii/ married & not given change of name etc. or iii/their assessed needs have been shown to have significantly improved i.e. such that the benefit would not be given if assessed/ reviewed again. e.g. they were not able to walk following car accident but after rehab have regained this ability and adapted to carry out several other skills for daily activity tasks. This may mean they could be eligible for a lower level of benefit or no benefit at all.</p> <p>*15. What types of advice ... process? Your response: 14). Disabled people & parents of disabled children would need advice about collecting information on nature of condition/impairment from the health/social care professionals that are involved with them. It would be helpful if they had the support and advice of people who had experience of completing the form e.g. key worker, CAB advisor, to help them describe to what extent they can attempt daily living tasks, and what assistance they need to do different tasks. If the individual could use this information with appropriate support to complete a benefit claim form, then the information could then be verified by a GP. Hopefully this could be instead of a face to face discussion with any healthcare professional unfamiliar to them. It is a face to face discussion with someone, the individual has not met before & who does not have the time ability to gain the trust of the person, and therefore not able to gain adequate information, that is most feared by people, because of the greater likelihood of a faulty judgements being made, which then could lead to lengthy costly appeals in time, money and stress.</p> <p>*16. Could some form ... need to be avoided? Your response: 15a). It would not be realistic to assume that every person claiming would have access to advice & support for making a claim, because it easier for some people to have contact with</p>

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		<p>relevant people than others, and for some this would be impossible because of their circumstances. Therefore I don't feel it should be a requirement to make a claim, but strongly made clear that it is in their best interests to do so if possible. Each person should be certainly told that it would definitely make the process easier for them, if they seek advice & support from their local CAB, &/or OT, SW, Key worker if they have one. There will be great variability of who would be available to whom, as this varies so much from area to area, as priorities, time to help in this way & skills of relevant people all vary enormously. It is unlikely to be on the job description of any of these professionals. Those that do it probably would only do it as a favour, and this cannot be enforced</p> <p>*b) One definitely needs to avoid a disabled person trying to make a claim for this benefit, without any support and advice at all, but I do not think it will routinely happen until assistance completing benefit claims forms does become part of a health/social care professionals job description and the time necessary is set aside to do it.</p> <p>*17. How do disabled people ...one-off cost? Your response: 16a) There are a great variety in ways in which disabled people try to fund their aids & adaptations. E.g. If people need a stick, kettle tipper, helping hand, grab rail, monkey hoist or wheelchair and are on a waiting list to see an OT or Physio or have a wheelchair assessment, they may hire some equipment from the Red cross at a charge & if it is available while they wait to see a professional. In some areas, equipment can be loaned by the health service, but in others it has to be purchased. This is dependent on policies of trusts & community health budgets. Social services used to provide more equipment than they do now. Everyone's funds are being restricted, including social charity funds etc. and it is a lot harder now to obtain many pieces of equipment. A lot of people cannot obtain the funds adequately and really have to struggle in very difficult circumstances.*If people have the money some they can purchase them, or take out a loan to fund them. People try and raise funds for specific pieces of large equipment, from friends, family, local firms, but this can take years to save enough for large items e.g. for a pressure relief mattress, powered w/chair etc. I would hope that a person is assessed fully to ascertain which the right piece of equipment is for them first..*The high rate mobility allowance has enabled many disabled people to have the use of an adapted car for 3yrs or 5yrs if a WAV. This has been a life saver for many people allowing them for the first time to have the possibility of either driving the car themselves if able, or being driven in the car with their w/chair to go to a Dr appt, shop etc. I am concerned that if this benefit is stopped that Motability may not be able to carry on in the same way, and people will be confined to the 4 walls of their own home.*Withdrawing DLA from people in care homes is again,</p>

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		<p>taking away any possibility that the individual is enabled to go out with a carer to a location of their choice. This is going backwards to days of institutional living where a disabled person only came out of their care home, as part of an adapted coach group of disabled adults to a set location, and the individual is denied the choice about where to go, with whom and when. Choices which for non-disabled people is seen as part of normal life. Not to allow this freedom is penalising disabled people not supporting them.</p> <p>*b) The option to use a PIP to meet a one-off cost of expensive equipment would be useful, but a regular amount should be included to meet increased everyday disability costs including purchasing, insuring and maintaining aids and adaptations.</p> <p>*18. What are the key ... children? Your response: 17) Many things are important when assessing disabled children, and ensuring they have the opportunities to have an education that a)meets their own individual circumstances and that b) changes as they get older maybe getting more severe as they grow e.g. often with children with cerebral palsy. It's also important to ensure that the disabled child's parent's opinions are given sufficient weight, as they are often the best people to see what is the greatest difficulty for a child, and to know how the siblings interests may need to be addressed as well as parent/ child relationship factors. Assessing children is often more complicated than assessing adults as there are many more variables to consider, and it needs clear interagency working where one key professional is the link with the parent, to avoid parents having to repeat the same information 10 times over gain.*It is also vital that there is continuing care from children's services into adult services especially during the adolescent years.*It is also true that assessing a disabled adult with growing children is complicated too. It is wrong that child and adult departments often try and play one department off against the other e.g. and say for a disabled adult, that it is not the adult team of social services that needs to fund the support to a disabled parent to help his/her parent with his/ her child appropriately, but say it is the child's team that should pay for the support. They in turn often try to refuse request for funding saying it is not the child that is disabled.</p> <p>*19. How important arrangements? Your response: 18) It has been vital to receive DLA as a disabled person, because without this I could not apply for a blue disabled Badge for parking; nor apply for a Motability vehicle; nor apply for a council tax disability discount; nor receive a child tax credit. Providing a standard letter of entitlement may ease the process of applying for this benefit, because at the moment the only way is to photocopy a record of the last DLA payment rate I receive as the disabled person. This requires asking someone else to photocopy this information which is not always easy, and does not mean the information is kept confidential.*It is vital that</p>

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		<p>Motability are given assurances that a disabled person will receive an equivalent benefit to mobility allowance of DLA for 3-5yrs, otherwise there would be no incentive to them to lease disabled people a car for the 3 yrs or 5yr period depend on whether it is a saloon, estate or WPV car.</p> <p>*20. What would be ... benefits and services? Your response: 19) There would be very severe implications for disabled people & service providers, if a PIP could not be used as a passport to other benefits & services. The extra costs in time money & effort for disabled people would be horrendous to apply for each benefit separately . Also the amount of extra administration work & professional costs for a service provider in having to establish each individuals eligibility for a service would be extensive and very expensive for service providers, whilst also being absolutely unbearable for the disabled person waiting without money needed while decisions are considered. Life even with the existing provision is really tough, many days only just bearable, and then to even consider asking a disabled person to seek out a service, provide additional evidence of their everyday needs, for a disabled badge, Motability car, & other services is terrifying, too awful to imagine.</p> <p>*21. What different assessments ... duplication? Your response: 20. From my experience each local authority in England has different eligibility criteria for who can receive an adult or child social care service or not. Therefore although I can see some logic</p>
EM608	15/02/2011	<p>1.Society is based around the medical model of disability which makes the problem the persons. If we work to remove the barriers to facilitate real inclusion which is more than just ramps and switches but a state of mind that accepts and celebrates difference in all areas of our work and life things will improve and incidents of hate crime will reduce.</p> <p>*2.The fact that my daughter can spend it to facilitate her inclusion without having to ask permission from anyone. Direct Payments and social care have a lot to learn from the light touch applied once the award is made.</p> <p>*3.Always having someone else with you immediately doubles the cost of daily life, support costs and paying for support workers to do activities alongside our daughter costs a fortune but if we don't we deny her the opportunity to do things with someone other than mum and dad</p> <p>*4. there is nothing wrong with what we have now that's easy. Someone may need a lot of support during the day and not so much at night so middle rate at the moment covers that leap</p> <p>*5.Should be based on need yes but once someone has had it for a while – some things are going to reach a maximum of development e.g if someone has CP and are in a wheelchair the chances of that always being the same are high. Once its secured there could be a judgement that means you don't have to keep applying e.g. my daughter will always have Downs</p>

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		<p>Syndrome and therefore always have some developmental delay</p> <p>*6.Do not underestimate the importance of sustaining friends and relationships those sustain all our health and well being. Most people understate the support they need there are only a few people who wrongly claim most don't claim at all,</p> <p>*7.Ask once and trust that's how it is.</p> <p>*8.no because they need changing and maintaining. Don't make it too complicated</p> <p>*9.Its really hard because it is such a deficit assessment and feels very disloyal describing what my beautiful daughter cant do. The fact that she ahs Downs Syndrome and therefore is developmentally delayed should mean that we perhaps don't need to fill in all the questions over and over with the same answer</p> <p>*10.If someone has a funded package of social care support, if DLA has been approved before, and statement of educational need.</p> <p>*11.Our experience of health or social care professionals is that they hang on to their power over our lives and misuse that at times. People don't often over egg the support they need and this could be done for many people where there is already a names key worker e.g. social worker. Maybe the person could identify the most appropriate 'professional' if that was necessary?</p> <p>*12.Ask if someones circumstances have changed and if the answer is no maybe trust that and no need to fill in the form again. If the person was signing to say they declare this is the truth like passport/ child benefit etc that should be enough. People could be made aware of the consequences for false declarations</p> <p>*13.as above, make sure people are aware of the consequences of falsely signing a declaration</p> <p>*14.Local support and information/ peer support organisations to help with the form</p> <p>*15.Not sure requirement is right but a pointer would be useful*16.yes, DFG's are so limited and people have to wait a long long time. How people choose to spend it to meet their needs should not be the question</p> <p>*17.It would of helped us to have a way of applying for the blue badge when she was little without really needing the mobility component just because we needed to be able to park in the bays close to where we were going or she would be too tired and need carrying before we got there.</p> <p>*18.One assessment that believes us and is not repeated so often</p> <p>*19.It is really hard and depressing constantly focusing on what you or your child cannot do and all the assessment focus on deficits which is very painful and feels disloyal.</p> <p>*20.combine social care/ DLA and point to cinema cards and</p>

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		<p>other supports that use DLA as a qualifier</p> <p>*21. People find it very hard asking for support now and the form is so difficult and disheartening. Trust people to tell you the truth and have a light touch like there has been with child benefit. Chase the people who deserve it and leave those of us who rely on it alone please</p> <p>*22. Please do not introduce more bureaucracy make it easier and less painful to get the support our daughter is entitled to and needs and share the assessments with education and social care so we only have to tell the story once</p>
EM609	15/02/2011	<p>1. My personal problem is transport, I have MS and have mobility problems. I have sticks and a rollator but if I need to get to the town I have to wait for my husband to come home from work. When I need to attend hospital appointments my husband takes me, he is self-employed and on a very low income so when he does not work he does not earn. I would like to go back to work, even on a part time basis but transport will still be an issue.</p> <p>*2. I have applied for DLA three times and three times have been refused because I can manage with the assistance of my husband and the aids I have to assist me. Granted my MS is not as serious as some I know, but I am still reliant on my husband to help me, there are days where I am unable to do anything myself, personal hygiene, cooking etc and my husband loses money to stay at home but I am not entitled to anything. Health checks should be maintained from patients consultants and followed through. Although there is a section in the form where consultants are contacted it is not followed through, because in my last attempt at applying for the DLA my consultant was not approached.</p> <p>*3. In my case Extra petrol costs, Heating and Electric for the home, because I have problems with the cold and I need to use more electrical equipment to give me a little more independence</p> <p>*4. How can you rate disability? I did not ask for this condition and would welcome the chance to get back to work to interact with people. Too look at me you would think there was nothing wrong, until I started walking or I started having tremors or my muscles go into spasms or I temporarily forgotten what I was to say. MS is the most cruellest condition on this planet. A person is blind they need help, a person with cerebral palsy, they need help. How can you rate disability. These will never get better, that's the only rate you can go by.</p> <p>*5. It should be left up to the integrity of the individual applying. I would have hoped that there was still some honesty out there, but obviously there is not, hence, this change. I started applying when my MS worsened. When I need that extra help, no matter how small.</p> <p>*6. Interaction with other people is most important, it's bad enough when the active life you have had previously has come</p>

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		<p>to a full stop. I used to run, do latin and ballroom dancing, cycle and swim, yes, I can swim but not as much as I could and even the pool prices are going up so we can't do that often anymore, because of council cutbacks.</p> <p>*7.Means testing.</p> <p>*8.I have aids to assist me to walk and lead a more independant life around my home and garden, it does not improve my condition, Sometimes I cannot use my aids because the MS affects my arms and because I don't have a wheelchair I stay at home although there is talk of a motorised scooter now. That will cost extra money we have not got.</p> <p>*9.Stop repeating the same questions. Get some people with disabilities to devise the questions, especially with a permanant disability or a neurological condition. They have more knowledge and understanding.</p> <p>*10.The persons own Consultant. Medical profession.</p> <p>*11.I have no problems with it being face to face but the staff must be educated in the many fields of disabilities. There are alot of ignorant people out there that don't understand they only recognise external disabilities, things that the can see, they don't recognise neurological disabilities.*You must be very careful. You are playing with peoples lives.</p> <p>*12.Your response: Reviews should be carried out on the severity of the condition.</p> <p>*13.Your response: Tie this in with the answer to question 12.*e.g. If the severity is likely to improve , review in 6 months with a medical and discuss changes at the interview.</p> <p>*14.Your response: When people have been told that they have a condition that there is no cure for, or they lose limbs, or a child is born with severe disabilities. They will need someone understanding to speak to, who is knowledgable about various disabilities and can assist in advising them over the phone, I never received anything like that in fact the only person i spoke too did not know what MS was. So what hope is there.?</p> <p>*15.Discrimination</p> <p>*16.I have done one of mine through a charitable donation. Which I had to find the money for , and the gift was so miniscule I felt guilty. I dont think the PIP should meet the one off payment, because i was under the impression that was what the original DLA was for to meet the extra costs.</p> <p>*17.You are joking, how can you put children through the assessments, surely a child, needs all the help that can be given, let them have it done automatically with their medical consultants, the people that they know and trust.</p> <p>*18.Yes discuss options over the phone not send info in the post, only on request.</p> <p>*19.CAB would be inundated with questions or people would suffer because they would not know who to ask.</p> <p>*20.Sharing information from housing benefit.</p> <p>*21.It could create alot of anger if the different equality groups</p>

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		<p>were not looked at individually and bunched together , which is happening now.</p> <p>*22.I am speaking on behalf of those honest people with Neurological disorders who are struggling to exist from day to day as well as live with a chronic disability which is unpredictable. This is a cruel condition which we did not ask for, most of us have probably led healthy lives and worked hard, and some like me have been refused DLA because of our honesty but we can't go on. I am watching my husband struggle from day to day and tell me not ot worry, our debts are slowly mounting and we can't cut back anymore. We need help.</p>
EM610	15/02/2011	<p>I am writing this e-mail with regards to my concerns over the proposals to change DLA. I work for Crossroads Care as the [REDACTED] for the Leicester Mental Health Carers Project providing emotional and practical support for carers of adults with mental health problems. I am concerned about the implications that a change in DLA will bring to carers in terms of their eligibility for Carers Allowance. Currently carers will only receive Carers Allowance if the person they are caring for is in receipt of the high rate for the care component of DLA. This looks like it will change when a new system is put in place meaning a large number of carers will not be eligible for Carers Allowance anymore. This will impact on their financial situation as well as impacting on the carer and service users' mental and physical health through the stresses and strains a reduction in their monthly income will bring. Carers Allowance should not be means-tested and should 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 for some carers by means-testing it. Carers contribute to society by saving the government huge amounts of money and should be recognised and supported for their role in society. Providing all carers with Carers Allowance would show that carers are recognised for their contribution to society.</p> <p>*I am also concerned that when disabled people will be assessed by a medical professional to establish their eligibility for the new benefit the assessment might not provide a true picture of their illness on a daily basis. People with mental health problems will struggle to even attend the medical assessment appointment due to their mental health difficulties and when they do attend this will probably be on a good day and not reflect the true nature of their illness. Mental health problems can vary from day to day and the person suffering from this will feel and behave differently from day to day. People with mental health problems often struggle to engage and attend appointments due to the nature of mental health and how they might feel on the day. Often they may feel too depressed to even eat or drink let alone leave the house and be examined by a medical professional. It may be that they are hearing voices or feel that people are out to get them therefore</p>

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		<p>leaving their house would be extremely stressful and difficult. People with mental health problems often struggle to attend to the daily activities of living such as getting out of bed, attending to their personal hygiene, making food and drinks. They also find it difficult to discuss their mental health problems with others and in particular would find it very difficult to discuss their own personal lives an levels of functioning with a perfect stranger who will be making decisions about their entitlement to benefits or not. Also often the carer is the person who truly knows how a person with mental health problems functions on a daily basis and may need to prompt, support and encourage the service user to attend the appointment in the first place.</p> <p>*The changes in benefits and possible loss of Carers Allowance would have an impact on the daily lives of millions of disabled people and their carers. It would mean that carers may not be able to pay their bills, buy basic essentials such as food and drink or even have a life of their own away from caring. It would impact on the carers' physical health as well as their own mental health needs. It may even impact on their ability to look after or care for their loved ones. It would also impact on the physical and mental health needs of the person they are caring for. It would also put extra strains on the relationship and may mean that some carers will decide they no longer are able to care for their loved ones. This would in turn have implications for the government who would then have to pick up the costs of supporting the individual with the care needs.</p>
EM611	15/02/2011	<p>I am responding as an individual to the consultation. I am a disabled person (I am tetraplegic as consequence of a spinal cord injury) I also work for a charity that provides a range of services to disabled people throughout the country.</p> <p>*I must regrettably start by expressing disappointment at the brevity of the consultation. Ten weeks is a fortnight less than the minimum recommended by the Government's own code of practice. This has been justified on the grounds that the consultation is on general principles only. This raises the question why has the consultation been pushed through in this manner. It is my view that it would have been better for you to extend the period of the consultation and to have asked for recommendations on how, if it was felt to be necessary, to amend the existing arrangements.</p> <p>*There is an expression "if it it's not broken then why try to fix it? This could certainly apply in the case of Disability Living Allowance where the consultation document fails to make the case for change. Indeed the main argument being made for changing the present system is that more people than expected have been granted DLA settlements and as such the cost is higher. The other issues raised are easily resolved.</p> <p>* There is no suggestion that the recipients are not entitled to the allowance, simply a concern over the cost to the exchequer. Given that this allowance is intended to cover the extra costs of</p>

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		<p>living with an impairment or health conditions this seems inappropriate.</p> <p>*A number of disabled people with whom I have discussed this consultation expressed concerns over the proposed change in assessment criteria. The mobility and attendance components of DLA are to be replaced with a revised mobility allowance and a daily living element. There is great concern among wheelchair users that mobility allowance will look at their ability to get around rather than their ability to walk. They fear this would see many of them lose their mobility allowance which they use to fund power wheelchairs or other vehicles. Equally there is uncertainty about how the ability to carry out other key activities necessary to be able to participate in daily life is to be measured. There is uncertainty about how this can be measured without taking into account the lifestyle choices of the individual concerned. Greater objectivity and consistency do not appear to be likely outcomes of the proposed changes to me or those I spoke with.</p> <p>*Following on so closely from the announcement to take away the mobility element of Disability Living Allowance from those in living in residential homes this consultation has provoked unease among recipients in these establishments. Already the attendance element of their DLA is withheld by local councils as part of the cost of housing them. They therefore fear losing out further if there is an element based on their ability to carry out other key activities necessary to participate in daily life. It would seem that there is a presumption about what residential care homes provide which does not meet with reality.</p> <p>*I would urge the DWP to reconsider the need for this reform.</p>
EM612	15/02/2011	<p>To whom ever it may concern, Firstly I think that the DLA system seems to work well for those people who actually need and are entitled to it. the problems arise when those who maybe once needed it but still claim after they are well or those who are wrongly awarded it. Important factors to me are, regular checks on those who get it, costly maybe, but less so that paying DLA to those who aren't entitled and making sure there is enough information gathered and 2 grading for each I feel is too little. Disabilities are varied and even two people with the same condition can have vastly differing needs, this HAS to be taken into consideration.</p> <p>*I suffer from Fibromyalgia, this for me means that I can no longer walk without having severe pain and discomfort, I have widespread pain, I can no longer drive my car, my husband has had to stop working so he can look after me and our 5 children and due to my medication and symptoms I have had to withdraw from my degree with the Open University, thus my previous career choice of teaching is no longer a short term possibility. I am also very depressed and my self confidence is damaged beyond repair, perhaps seemingly less important to the onlooker I have gained over 4 stone in weight in the last 12</p>

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		<p>months due to inactivity and immobility.</p> <p>*I am just one person but above is a mere overview of the complex multifacets of my personal symptoms with one condition, a condition that is incidentally widely misunderstood and mistreated by the general public <i>and</i> the medical profession.</p> <p>*I think to put categorisation of disability or illness into such a stringent stranglehold is dangerous and will lead to many people not receiving the help they are entitled to, more thought needs to go into this change, simple might be easier for the government but I am not convinced it will cure the problem of individuals fraudulently claiming benefits or of ensuring everyone gets what they need.</p>
EM613	15/02/2011	<p>I am the Father 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. We 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>”. 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 case for a non-disabled child.</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> <ul style="list-style-type: none"> *Mobility – our children are less mobile, tire more easily and lack road safety awareness: *Transport to appointments & parking; Specialist buggies for older children; *Road safety equipment for older children; *General Health and Safety – our children lack safety awareness: *Road safety equipment for older children;; Locks, stair gates and similar for older children Night safety equipment for older children; Need for constant supervision in each room in the house, which will often involve extra paid for childcare; *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: *Sleep Apnia alarms – for breathing problems affecting sleep; Decongestants;

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		<p>*Additional night laundry – up to 6, 7 times a night; Bed rails for longer than children of the same age; Greater breakages; 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; 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; 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; 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; Chewy Tubes; Computer programs; SLT resource books and materials;</p> <p>*Adapted bikes; Adapted swimming kit; Trampolines; Specialist chairs / tables / pens / writing slant; 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> <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</p>

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		<p>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> <p>*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;</p> <p>*It is exceptionally rare for a person with Down Syndrome not to have expensive additional support needs as an adult;</p> <p>*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:</p> <p>*Reduced earnings – diminished by 1/3 with a child with disability;</p> <p>*Greater incidence of marital break up and divorce;</p> <p>*Negative impacts upon siblings, often necessitating additional sibling childcare, if a principal carer has to attend additional appointments.</p> <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</p>

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		<p>the capacity of both parents to attain full time employment, thus reducing family 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>
EM614	15/02/2011	<p>PLEASE DO NOT ABOLISH DLA AND REPLACE IT WITH PIP. Euthanasia is illegal in this country - but 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.* 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. To do so effectively makes many of us feel so depressed to keep battling on . 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 loose Carer's Allowance, then making it impossible to pay basic bills and to carry on caring. The administrative costs of replacing DLA with the new system will be hugely expensive and a poor use of taxpayer's money. The Ministerial foreword to the consultation paper states: "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." If this support is to progress beyond lip service then the government require to radically rethink their legislative plans for a new system. 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</p>

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		disabled. Yours sincerely,
EM615	15/02/2011	<p>1.Suitable/affordable transport options available 7 days a week. Inability to use public transport due to disability.</p> <p>*2.Ability to purchase Motability Scheme.</p> <p>*3.Transport (ie Taxis)</p> <p>*4.Interpretation by officials as to eligibility especially for people with variable symptoms.</p> <p>*5.Certain conditions like disablement from birth or imminent end of life through cancer even though timescale cannot be totally accurate.</p> <p>*6.Access to support centres and other public buildings.</p> <p>*7.Look at worst case scenario.</p> <p>*8. Just because someone has an aid that helps them and they are able to pay for it should not stop them being awarded benefit.</p> <p>*9.The questionnaire should not be so rigid. It should ask a general question on how their disability affects their life. If someone takes an hour to dress that has a big impact on their daily routine.</p> <p>*10.Their GP should be well placed but they have limited time resource to answer questions and they may not know the full extent of someone's difficulties. Charity sector may be useful.</p> <p>*11.Location of assessment centre and access difficulties. Someone in a wheelchair struggles to travel even short distances. Some people will feel intimidated or anxious and so will not attend or continue with the application.</p> <p>*12.NHS or GP consultations can provide evidence over a period of time with a simple 'Has the patients condition changed since the last time?'</p> <p>*13.Offer a freephone telephone line or yearly prepaid reply card</p> <p>*14.The most common statement I always hear is that they were not aware that they could apply. *15.Local Authority Benefit Events involving the Charity sector.</p> <p>*16.If they have the funds they buy it. If not they don't. Some Councils will have grant systems but you have to know about them and may need support to access.</p> <p>*17.They may be no improvement in the condition and it will be more likely that there will be a deterioration of the condition.</p> <p>*18.It is important but again a lot of people are unaware of the entitlement.</p> <p>*19.It will create another barrier to people with disability.</p> <p>*20.If someone is getting ESA or vice versa, information could be shared.</p> <p>*21.Your response:</p> <p>*22.This exercise is looking at reducing the costs of this benefit. I firmly believe that if all people with disability knew of their eligibility you could actually see an increase in costs. There are a lot of people who do not apply because they feel it is too</p>

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		difficult or they can't possibly be eligible.
EM616	15/02/2011	<p>1.It should be mandatory that all Planning and similar departments at all levels should consult with their local Disability Network or similar volunteer body to arrange for blind, deaf, elderly, wheelchair users and others, to review and test arrangements at the opening, middling and almost completed stages, to avoid money being wasted on things not really fit for purpose. Slowly but surely the physical barriers should come down. My irritation is that buses are allowed to continue to display the wheelchair accessible sign when the gear is out of order. Covering it with a "Sorry Out of Order" sign may encourage maintenance engineers to deal with the problem.</p> <p>*2.In general, the conditions for which it is granted. I fear cuts for cuts sake.</p> <p>*3.As a wheelchair user, I face the costs of taxis for distances that previously were a healthy twenty minute or so walk. There is the cost of the accessories that make our lives easier. There is the cost of carers (in my case 30 minutes each Monday to Friday, Meals of Wheels but I would have to eat anyway, and a cleaner once a week.</p> <p>*4.I fear the box ticking of "administration". There are rarely simple answers with disabilities. I fear being penalised by making the effort to overcome barriers that prevent disabled people participating in society and leading independent, full and active lives.</p> <p>*5.A former Archbishop of Canterbury had FIVE Police Background Checks, one for each of the organisations he was joining. One good one should suffice. Some health conditions or impairments, like mine, are permanent and will get worse. The specialists say so. If the specialists say so, why do administrators need to doubt them? :</p> <p>*6.LISTEN to the Voluntary Organisations that look after the people with such disabilities, We do need to encourage their abilities.</p> <p>*7.LISTEN to the Voluntary Organisations that look after the people with such disabilities, I am a representative member on my local Disability Network and respect their knowledge, experience and commitment.</p> <p>*8.Circumstances alter cases. I am told a "wheelchair voucher" is easy to obtain. 36 months on and I am still waiting. What will your rules say?</p> <p>*9.Plain English forms and leaflets. Give the information to the appropriate support groups and networks and medical centres etc.</p> <p>*10.Probably the Carer or visitor or close friend should be involved as well as an assessor, as both a witness and an advocate.</p> <p>*11.As a representative member of our Social Inclusion</p>

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		<p>Network, I appreciate that mental problems can go with physical disabilities, and this can be a very sensitive and difficult area. The area assessor should be able to identify the appropriate cases of potential problems through the local organisations. .</p> <p>*12. • Reports by specialists or advocates• Yes, definitely.</p> <p>*13. The GP will be aware of changes in circumstances. :</p> <p>*14. Clear and complete. Helpful:</p> <p>*15. Consult with the appropriate voluntary groups and networks. :</p> <p>*16. Varies. Yes.*17. No experience. :</p> <p>*18. Very useful. No, if these other entitlements do not change their rules. :</p> <p>*19. Why spoil what is working well? :</p> <p>*20. That depends on the bureaucracy, which is currently changing.:</p> <p>*21. Your response:</p> <p>*22. Consult fully with all the appropriate Voluntary Local Groups, by phone where possible.</p>
EM617	15/02/2011	<p>Here are some comments. I hope you find them useful.</p> <p>* 1. I am the mother of a 15 year old boy with profound and multiple disabilities Problems:Inability to work and earn a living, poverty, inability to express their needs and wishes if they have multiple and profound disabilities.*My son is limited to 4 hours outside the house. He is doubly incontinent and too big to place on a baby changing table. We have now given up changing him on the urine soaked floors of public conveniences. We need to have more public toilets where there is a hoist and changing table. My son cannot use public transport, if you take away the mobility component of DLA because he has to attend respite nights away from home then you may as well lock him up. His horizons which are already limited will become just his home and school environment.</p> <p>*2. children and adults where there is no hope of improvement in their condition please don't make them fill in regular DLA reviews, keep the system of indefinite awards. It is too cruel to keep asking parents of severely disabled children how different their child is from one of the same age who does not have disabilities.</p> <p>*3. Definitely transport. It is just not possible to use public transport. My son had instances of turning blue on the bus needing the ambulance service to be called out. We now carry oxygen with us. It was very distressing not just for us but for the children and adults on the bus who had to witness the incident. We also have increased heating bills, he cannot move and is at risk of respiratory infections. We have to keep the house warm and if it was just me I would turn the heating off. .I am dreading the next gas bill. Travel insurance was sky high because my son had been on the high dependency unit. We cannot make use of cheap holiday options because the facilities</p>

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		<p>are not geared up for severely disabled children. My son is incontinent, I pay out for wipes and extra nappies. My laundry costs are increased because he regularly vomits on clothes and bedclothes. Although I have had a disabled facilities grant it does not cover the extra costs of making the house appropriate for my son (e.g. flooring for the wheelchair) and landscaping the garden. It is impossible now for one person to care for my son, it needs two, if we go out or go away I have to pay the additional costs of a Carer e.g. their travel, accommodation, meals, entrance fees to attractions etc.</p> <p>*Toys for disabled children are expensive.*It is not a cost to my son but the major cost to our whole family has been the extreme drop in income caused by having to give up work to care for my son.</p> <p>*Having said all this I do recognise and am grateful that the state has stepped in financially with DLA , Carers Allowance and Child Tax Credit and my local authority is very supportive.</p> <p>*4. My son under any system would qualify for the higher rates of both so I cannot comment on this</p> <p>*5. Yes see above. You should not focus only on terminal illness. Someone with quadriplegic cerebral palsy, blind, tube fed incontinent, unable to talk etc should be automatically entitled perhaps with one letter or certificate from the GP.</p> <p>*6. For a child; to play , to interact with other children, to be part of family life, to explore their environment and participate in their community. Please don't make us go back to the old days when a disabled child was sat by the fireside and was not taken outside the house.</p> <p>*7. Your response:</p> <p>8. Your response:</p> <p>9. Your response:</p> <p>*10. The GP or the nurse at the Special School</p> <p>*11. A face to face discussion with a DWP health professional would be a waste of resources. My son is already seen regularly by more than ten health professionals, why add in another one?</p> <p>*12. I would recommend that children and adults with profound and multiple disabilities are not reviewed. I would like there to be a miracle but unfortunately it is not going to happen.</p> <p>*13. Please see the end for my comments on reporting changes. I feel that sometimes you just have no idea what it is like to be chronically sleep deprived and just about keeping everything going when looking after a severely disabled child and other children in the family. I have had difficulty remembering whether I had just given my son his evening medicine let alone remembering that I have to report a change in circumstance. If you provide a blanket stiff sanction to encourage people who are "mentally incapacitated" to report a change in circumstances this could be very cruel. Are there any circumstances where people cannot be expected to identify</p>

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		<p>and report changes?</p> <p>*14. Your response:</p> <p>15. Your response:</p> <p>*16. I have had to apply to charities for certain items. The Variety Club kindly supplied my son with an adapted tricycle which he used until he could no longer do so, Newlife supplied us with a Dreama sleep system. I struggled to pay the £1000 deposit on the motability WAV , I did not fit their charity criteria. The Family Fund have been very good in helping my son.. I feel very embarrassed to approach charities</p> <p>*17. See some of the comments above</p> <p>*18. I am in favour of passporting benefits. There appears to be no co-ordination between the people dealing with DLA, Carers Allowance and Child Tax credits disability component.</p> <p>*19. I would feel like pushing it all on to my son's social worker to cope with.</p> <p>*20. See the end for my experiences regarding the interaction of DLA and Carers Allowance</p> <p>*21. Your response:</p> <p>*22. Yes. I would like to share with you my experience of the link between DLA care component and respite care and Carers Allowance.</p> <p>*Should severely disabled children who need respite care be issued with an electronic tag? My son's medical needs are very high and after suffering from chronic sleep deprivation my son began boarding at his school 4 nights a week to give me respite and the strength to provide care for him at weekends and to minimise the distressing travel experiences he had. The recording and reporting of this I found it an absolute bureaucratic nightmare. For Carers Allowance I had to record the exact time he came home and left for school and any time he spent with his father to meet the requirements of caring 35 hours a week and also for the DLA Care component I had to record each night he spent at home and each night away. On the bus one day I saw a young lad with an electronic tag on his ankle and it struck me that the state is monitoring the whereabouts of two groups in society on a daily and timed basis, namely the whereabouts of disabled children and young criminals. I find this unacceptable, stigmatising and intrusive. I know that you have to check for eligibility but this is just too bureaucratic.</p> <p>*If you are going to introduce a system whereby severely disabled children not only lose their DLA care component when in respite but also the mobility component then you might as well slap a control order or its equivalent on my son.</p> <p>*Under the current system there is a rule which can kick in to prevent removal of DLA care component but this assumes that going into respite care can be controlled by the Carer rather than seeing that respite care is in some cases is designed to meet specific needs of the child.</p>

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		<p>*Also the reasoning behind removal of the DLA care component in relation to respite care is flawed. Yes, the state is covering some care costs but the care component of DLA does not just meet "running care costs" but one off care costs too.</p> <p>*There is an issue also with what happens to parents who are not eligible for means tested benefits when their disabled child reaches 18 and is no longer eligible for child benefit and they cannot claim child tax credits. A lone parent who has given up a career for say 15 years will find it very difficult to enter the job market to earn a living and they will still have their caring responsibilities.</p>
EM618	15/02/2011	<p>1. Hidden disabilities such as fatigue and pain prevent people from wanting to or being able to leave their homes. We do not want to end up causing a scene or other people difficulty "just because we are crying out in uncontrollable agony or have fallen asleep or feel drowsy at an inopportune time causing loss of concentration". The hidden symptoms can also make you feel like other people are judging you and deeming you a hypochondriac because they cannot see the cause of the problem, thus preventing us from wanting to mix with the rest of society and causes emotional strife.</p> <p>*2. The Motability scheme helps people to afford cars and other wheels to allow attendance at appointments and to visit family, buses and trains are fine if you can access the stations and stops, but when there are stairs stopping you, your own wheels make the difference. The travelling time is also significant to people with hidden symptoms, 10 minutes in a car compared to 40 minutes by bus can change a person's outlook and ability to leave their home.</p> <p>*The care element of disability living allowance enables help to be brought in when the local council charges for services that are not means tested; doing the laundry, preparing and cooking food, cleaning the bathroom and kitchen are impossible when you cannot afford the extra cost of maintaining your home and in turn, your health. This allowance also enables those of us who cannot trim our nails, which unless you have problems with your feet/hands such as hard skin etc, is not available under the NHS or council (carer's are forbidden under health and safety), the ability to pay someone to do it for you.</p> <p>*3. Transport to appointments, servicing bought mobility aids, prescriptions, paying someone to do what you cannot for yourself (laundry, dishes, floors, dusting, nails, shopping, cooking and preparation of food), electricity and gas in the winter; wheelchairs don't go in snow meaning you can be confined to your home during periods of snow and ice on paths. In addition, the final main cost can be food, especially if you need a specific diet to enable wellbeing.</p> <p>*4. There is, in my opinion, no problem with the current system of rates, therefore, I do not envisage a problem with the same again, as long as the qualifying criteria is as clear as the current</p>

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		<p>system.</p> <p>*5. Yes, some conditions should have automatic entitlement to basic benefit, then the rates change from there, determined by the persons needs, conditions with no cure that also are degenerative should qualify for automatic entitlement.</p> <p>*6. The ability to have contact with people past the four walls of their home is essential, socialising with other people, even if doing grocery shopping helps with mental health.</p> <p>*7. Get advice from all qualified medics and what the patient is saying before setting the assessment criterias.</p> <p>*8. Aids and adaptations can make it easier for a person to get about or use a shower, but it does not get rid of the condition. Some aids are not available to every person; electric chairs are not given to every person needing a wheelchair, only to those who will never be able to walk, and they need serviced regularly. For people who need the electric chair when they cannot push themselves manually, and can perhaps take only two steps, use the mobility component to buy an electric chair or lease one, and this would need serviced annually, adding additional expense. In addition, fluctuating and degenerative conditions can take hold of a person abilities quickly or slowly, how can future aids be determined if it has not yet happened.</p> <p>*9. Ensure the appropriate training for the staff who process the forms as they arrive to enable continuity of the process and the interpretation of what has been written down (there are many ways to read a book!).</p> <p>*10. GP's and Consultants do have a vast array of knowledge, but they do not live with the person or see the daily fluctuations. Family can be useful, if you have any, but perhaps a combination of qualified evidence (diagnosis etc) and an assessment within the home to show how they dress, wash, use the toilet, change the bedding etc could find a happier medium.</p> <p>*11. The assessor must be open minded without any prejudice about that person before they meet them, an assessment at home will allow the assessor to evaluate the needs of the patients problems more easily than within a sterile environment.</p> <p>*12. Your response: The emotional wellbeing of the patient is paramount, you cannot differentiate between emotional and social wellbeing. But when a condition has no cure and is degenerative, common sense should prevail! This person, unless a cure is found and administered will obviously deteriorate, and should be placed on re-evaluation without a view of removal of benefit but to ensure their needs are still being met.</p> <p>*13. Give the power of assessment review to the consultant so that they may determine any changes and report this in their letters. If the patient does not attend the appointment, then this is also reported.</p> <p>*14. A layman terms sheet informing people how to interpret the</p>

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		<p>questions being asked of them within the application form, putting the questions in plain english and uncomplicated would also work.</p> <p>*15. Refer to above answer!</p> <p>*16. All equipment at some point needs serviced or replaced, do you expect a person to keep an electric chair for 30 years? All equipment degenerates like a few conditions I could mention.</p> <p>*17. Allowing them to mature into their condition.</p> <p>*18. The importance speaks volumes, we are no longer hidden behind closed doors to be excluded from the rest of society, we are able to go grocery shopping when there are disabled bays not being used illegally, we feel included and emotionally feel independent.</p> <p>*19. Are we to be behind closed doors again?</p> <p>*20. Train up the people who process the forms to focus on specific disabilities and have teams to process them e.g. neurological teams, mental health teams, amputees, youth, old age and working age etc etc</p> <p>*21. Listen to those who have the conditions.</p> <p>*22. Trust is not given, it is earned, let us trust you by not putting up barriers and fuelling discrimination.</p>
EM619	15/02/2011	<p>Please find attached my responses to your questions. Kind regards</p> <p>*1. Need to be visible in everyday society, eg local schools, local transport, usual meeting places. All this takes time of carer, whether paid or unpaid, vision and commitment of carer, and enough money to finance both individual and carer. Many family carers have not had the opportunity to continue with a career and this lack of finance and independence leads to disabled people remaining in the family home once they reach adulthood.</p> <p>*2. People with severe cognitive impairment should still be entitled to a mobility element as this impacts on their ability to participate.</p> <p>*3. Paid support to access everyday situations which most take for granted, both in and out of the home. Transport, accommodation – private landlords will not take on benefits supported tenants even if good references because their experience is late payment/difficulties with rent, daily living costs eg heating, washing, clothing, bedding, more frequent replacement of major items eg washing machine, floor coverings, holidays in adapted or convenient accommodation</p> <p>*4. Don't see the problem. Quirk of present system is that you have to be in receipt of highest care in order to claim higher mobility. Why? Also, in order to claim highest care, you had to have someone get up to you at night. Surely, the fact that you have severe mental impairment and cannot cope when you do wake up should be one of the criteria?</p> <p>*5. My daughter has Down's Syndrome and there is an</p>

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		<p>argument that all DS should receive some DLA. But there are many people with DS who are very able, so probably no. In our case, I am fed up with having to prove lack of ability on behalf of my daughter and one piece of paper not being good proof to another agency. Eg I am deputy under Court of Protection and manage her property and affairs. Yet, this is not enough standing re the local Health Trust for me to manage a personal health budget on her behalf (we are not in pilot area). The government needs to be joined up and not have different systems in place for different circumstances, especially in something like mental capacity.</p> <p>*6. Most essential is difficult concept here. First there are the things without which one would die or become ill, eating, drinking, sleeping, warmth, washing, clean clothes. Then, there are the things which impact on people's mental and physical health, eg support to go out into the community, access swimming etc which require paid support or special transport. If you are not eligible for social care because of FAC eligibility in your local area, you lose out as against another area. Not fair. Should be universal benefits not dependent on whim of your local council.</p> <p>*7. In some cases, perhaps like my daughter's, with a lifelong condition of Down's Syndrome and an order under the Mental Capacity Act, it is unlikely that her situation would change and therefore it would seem reasonable and fair to all that she be given an award indefinitely, as she currently has. Were her condition likely, or possible, to fluctuate, then it would need to be subject to review. How long would depend on age and other circumstances</p> <p>*8. People should at first be assessed without any aids and adaptations. At the same time, it would be reasonable to note what difference aids and adaptations make to a person's life, or, what difference they might make. This should be subject to review. What you don't want to do is to penalise someone for doing their utmost to improve their situation, and reward those who have not made the effort and are still relying more on others for support. It is vital in these proposals that you reward people who do the best for themselves. For this reason alone, if there is doubt over this, I would not take into account the effects that aids have</p> <p>*9. I last filled the form in over 15 years ago for my daughter approaching 16 years. A lot of it was irrelevant to a younger person or someone whose main disability was a learning one. Better guidance directed at different ages and disabilities might help. Information about where the DLA fits in with other benefits eg income support, and payments for support such as direct payments as part of an individualised budget, or personal health budget, would also help. There are too many sources of income for disabled people, and some action is needed by government to unify them. As my daughter's deputy, I have to</p>

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		<p>account to several bodies for how her money is spent. This is onerous on me, and poor value for money by the government.</p> <p>*10. Individual, family, respite carer, support worker, school, other professionals who know them well, GP</p> <p>*11. Good. Will save time and money. I had to appeal to tribunal to get higher mobility. This was then obvious. Written description not the same as seeing someone.</p> <p>*12. Should depend on needs and impairment/condition. May be able to award indefinitely still. Some conditions will never improve so why waste everyone's time?</p> <p>*13. Time set for review must be smart. If a condition is capable of improvement, review date should be sooner, or get person who verifies or supports their application to write with an update after one year. Ask GP by annual form to say if they've seen individual in last 6 months, and if not, then activate a review.</p> <p>*14. Information re other benefits and local support.</p> <p>*15. Your response:</p> <p>*16. Own money, or through health trust, or equipment and adaptations of local council. One off payment good idea for large items.</p> <p>*17. Conditions may change, including family support. Families can often do more, and expect to do more, when their children are young, but when they become adults, they expect their disabled children to become more independent of them. Families need to be encouraged to do this, as all too frequently they become trapped and tend to rely on the income the family gets as a whole from their children's benefits. Families, and parents who stay at home to care for disabled children, need more financial support to encourage them to be independent of their own children.*</p> <p>18. This is improving. Need to amalgamate more benefits and income.</p> <p>*19. Surely you should know this. It just shows how complicated the whole system is when you ask questions like this!</p> <p>*20. I would amalgamate the lot. I run 4 different bank accounts for my daughter to deal with her various benefits and income. I have to account to all for this. To COP to purchase property with housing association, application for mortgage, Income support interest, housing benefit, council tax benefit, direct payment monitoring, ILF monitoring, COP monitoring etc. Appeal to Health Trust for joint funding. Ridiculous amount of responsibility and paperwork. Need one payment and one body to account to.</p> <p>*21. Your response:</p> <p>*22. Please keep in mind the individual you are dealing with. Whatever decision is made, it is the families who love and care for the individual who will carry on caring come what may. It is distressing, in the media, to see examples of families who have come to the end of their tether with terrible results, often</p>

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		because they did not receive the appropriate support at an earlier time. There really is a terrible strain placed on some families with children and adults with a learning disability, (this is the area I know). One payment, by one body, please.
EM620	15/02/2011	<p>Dear Sir/Madam I am emailing you in regards to the concerns I have about reforming the DLA. I have looked at the questions within the consultation document but feel these are quite generic so have highlighted my main issues below:</p> <p>*I am a 30 year old male who has suffered from hemiplegia affecting my left side since birth. I also developed a separate condition called Multi-Focal-Motor-Neuropathy (MMN) affecting my right forearm and hand at the age of 15. I am currently receiving ongoing treatment for this as the condition has deteriorated and the original diagnosis may have been incorrect. Therefore I suffer from long-terms conditions affecting my everyday life.</p> <p>*If the reforms that are being proposed are implemented this will cause me major concerns and stresses as I currently use the DLA allowance to fund and support me when carrying out every tasks abled people take for granted, such as the following:</p> <p>*Taxis to and from the supermarket when I undertake my weekly shopping. *Purchasing aids aand equipment to help me around my home, such as a special knife for when I eat, a devise to help me open jars and bottles easier, a tin opener (This is not an exhaustive list).</p> <p>*Help with getting money out of cash machines.</p> <p>*Purchasing pre-cut vegetables and meat products.</p> <p>*Help with someone coming over once a week to assist with changing my bedding and changing my bin. *Paying for my doors to be adapted so I can open them.</p> <p>*I am also taking refresher driving lessons and will use the allowance to assist me in purchasing adaptations I require to drive safely when I buy a car. If this allowance is reduced or taken away it will have a detrimental affect on me carrying out my daily tasks and indicate to me that I am being disadvantaged for being born disabled. I hope my views are taken into consideration. Yours faithfully</p>
EM621	15/02/2011	<p>1.Disabled people are unable to live full and active lives without support from outside agencies to assist them in personal care, getting up and ready for the day can be a huge task. Likewise preparing meals, shopping, cleaning and laundry. Having any sort of work/social life is much more difficult if you need to involve other people to help. Some illnesses mean that one day you can do things and the next you are unable to do the same level of activity.</p> <p>*2.It should enable people to live their lives as their peers do and not be disadvantaged by their illness</p> <p>*3.Personal care, cleaning and laundry, shopping and cooking all need to be paid for. Transport is a major expense for people.</p>

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		<p>*4.It may make it easier to administer but this should not be the main consideration. Fair and just support to all should be a higher priority. Two rates will mean some feel they are not getting the appropriate level of support</p> <p>*5.It would be reasonable to say that some conditions should have automatic entitlement</p> <p>*6.Personal care, eating socialising and working are very basic needs</p> <p>*7.Listen to what people say in their assessments and act on it. Be aware that in many illnesses there are good days and bad days and allow for these in the assessment by using a time scale rather than a snapshot of one assessment.</p> <p>*8.Use of aids and adaptations should not affect entitlement.</p> <p>*9.By listening to the claimant, their medical carer (GP or consultant) and making it less of an ordeal to claim</p> <p>*10.The medical carer who knows the claimant would be the best placed to provide this,</p> <p>*11.Ticking boxes with someone you have never met is not the best sort of assessment.</p> <p>*12.This depends on the medical condition, again Levels of activity and how much of a struggle it is to keep everything going should be considered. The review should cover the same criteria for all</p> <p>*13.Your response</p> <p>*14.Eligibility criteria should be clearly stated and a free helpline available</p> <p>*15.Better to make the advice and information readily available so people are encouraged to use it. A free helpline could be part of this</p> <p>*16.Many buy their own. No, there should be extra funding for this</p> <p>*17.Making sure they are reassessed before they grow out of basic equipment like wheelchairs etc</p> <p>*18.Good clear and comprehensive information for claimants and carers</p> <p>*19.It would reduce the options that claimants have</p> <p>*20.Why not concentrate on providing DLA to all who are entitled and let them choose their care etc</p> <p>*21.Those who are not well informed will be disadvantaged</p> <p>*22.I am concerned that the tone of this consultation conveys that in future DLA will become more difficult to claim and disabled people through no fault of their own will be more disadvantaged than at present Life is difficult enough for them already.</p>
EM622	15/02/2011	<p>1. As the mother of a Down's Syndrome daughter, my main problems relate to her lower-than-normal mental capacity. Although she has very good social skills, she is EXTREMELY vulnerable in terms of being exploited by manipulative adults. So she needs to be accompanied almost all the time when she leaves the house. She is also unable (at present) to use public</p>

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		<p>transport. Down's Syndrome also brings some physical limitations such as mobile joints and poor muscle tone, sensory difficulties like hearing loss and vision problems.</p> <p>*As Down's Syndrome children become young adults, the main barrier to being fully integrated into society is the lack of proper jobs for those with a mental disability.</p> <p>*2. I have been very happy with the way DLA has worked for me, and I would wish it to remain the same.</p> <p>*3. Extra costs range from transport to specialised equipment and educational materials. It is very difficult to economise under these circumstances.</p> <p>*4. I don't think the problem of understanding and administering the DLA benefit will be solved by having two rates. The problem has always been finding enough time to complete 2 or 3 documents of 28-40 pages each.</p> <p>*5. there are some disabilities such as blindness which should mean automatic entitlement. But Down's Syndrome gives a wide spectrum of difficulties so you will never be able to do 'blanket entitlement' according to disability labels - individual needs are paramount.</p> <p>*6. Social contact and family life are vital for any human being to thrive, and even more important for those least able to integrate for whatever reason.</p> <p>*7. not sure</p> <p>*8. This is a very odd question! It's a bit like saying a physically disabled child can get around in a wheelchair, so because they are mobile, let's take the wheelchair away!</p> <p>*9. the claim forms must be SHORTER!!! My general feeling about forms is they are too prescriptive and repetitive - my daughter and I never fit into the 'boxes'. Also, we had to keep re-applying for several years, and I had to keep emphasising that Down's Syndrome does NOT go away or 'get better'.</p> <p>*10. Start with GPs and teachers.</p> <p>*11. I am very much in favour of face-to-face discussions and assessments.</p> <p>*12.: See above - some disabilities do NOT get better so fewer reviews will be necessary for those families.</p> <p>*13. not sure. You will always have a number of people who try to exploit the system, and some of them are in government! How about setting a good example so that it considered socially and morally outrageous for anyone to exploit the benefits (or any other) system?</p> <p>*14.: not sure.</p> <p>*15.: information could be disseminated through charities, disability support groups and the new parent carer network of forums.</p> <p>*16.: not sure.</p> <p>*17.: not sure what you mean. Surely all children are individuals?</p> <p>*18.: I have no experience of this.</p>

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		<p>*19.: not sure.</p> <p>*20.: not sure.</p> <p>*21.: please develop a policy which helps FAMILIES as a whole.</p> <p>*22.: I do not have sufficient experience of some disabilities but based on my own experiences, my general comments are these:</p> <p>1) The more you put in at an early stage, the more you get out - and the lower the long-term financial commitment will be. In my own case, I had to fight very hard for my Down's Syndrome daughter to access mainstream education, and pay extra for one-to-one help with such activities as sports, music and Brownies. But she has achieved some remarkable goals - 2 GCSEs, grade 1 piano, and numerous medals for gymnastics.</p> <p>*2) Education and good family life are even more essential to disabled children than to normal ones. The main financial pressure on these families is the lack of opportunity for both parents to work - so they will always be at a financial disadvantage. The pressure too of caring 24/7 puts the parents under even more strain so I would urge you to make Short Breaks a priority, not just for the sake of the disabled child but also for the siblings and the parents. A few hours each week without the 'burden' of caring helps keep families together and the parents sane.</p>
EM623	15/02/2011	<p>1. Your response: ,</p> <p>*2. : the levels of the allowance</p> <p>*3. : fuel bills, extra wear tear bed linen extra transport costs,</p> <p>*4. all claimants should be considered it would be a disadvantage to remove any rate or care component</p> <p>*5. : yes some conditions should have an automatic entitlement I.e. certain mental health problems cancer epilepsy, main health problems</p> <p>*6. : meeting people, shopping, days out,</p> <p>*7. : by seeking advice from people with disabilities Of all types and understand there needs</p> <p>*8. : aids should not be included this would be unfair. To include them if you are disabled you are disabled Having aids does not make you less disabled</p> <p>*9. : don't make the forms difficult to understand it would be a good idea to have forms for different disabilities</p> <p>*10. : your own GP. Care worker , ect , not atos health care They don't know your history, like your G.P</p> <p>*11. : in my wife's case it would be a bad idea as this would cause more stress and anxiety, as she has epilepsy and depression,, I would be concerned for her health,,</p> <p>*12. : yes</p> <p>*13. : a simple form ,, every six months or depending on allowance award</p> <p>*14. : yes</p>

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		<p>*15. : all people should be informed if they should be entitled to an allowance</p> <p>*16. : with there dla benefit a one of payment would not work as circumstances can change and the claimant should be in charge of there needs they know better</p> <p>*17. : there disabilities and the extra help and support they require as they grow up</p> <p>*18. : dla is very important ,, if you can improve this area all the better letting people know of help or organisations that can help there needs</p> <p>*19. : not sure just keep dla would save this problem</p> <p>*20. : I think the system does not need to be changed</p> <p>*21. : time will tell but I know many will be disadvantaged</p> <p>*22. : I fell that the only real reason for this consultation is to disadvantage disabled people, my wife has an indefinite award she will not get any better so why retest her don't see this question in your consultation *This consultation is more about cuts to benefit than help Also I think you should have sent this questionnaire to all claimants</p> <p>*So to say you wanted the views of all disabled people in this consultation is flawed,</p>
EM624	15/02/2011	<p>(I am answering all these questions from the perspective of a parent whose daughter has autism, a significant learning disability, a language disorder which means that she appears to be significantly more able than she is and right sided hemiplegia)</p> <p>*1. Being totally reliant on other people for their every need, be it on carers or family Lack of flexible and adequate funding – our L.A. does not “pay for people to socialise” *Being unable to make plans for themselves (partly as their life experiences have been restricted to what their parents, often exhausted, have been able to find or provide) Who else has to go everywhere with their parent or not go at all? Many people’s ignorance with no real desire to learn – think they are just relieved it isn’t their problem</p> <p>*2. : The fact that it is an additional benefit although the L.A. already takes the care component as a contribution towards the care package.</p> <p>*3. : Paying for someone to accompany and assist with every part of life from personal care to something as simple as getting a pint of milk – it works out as a very expensive bottle! Paying to be taken anywhere at any time e.g. to visit doctor incurs staff support time expense and fuel charge. Paying repeatedly to replace items spoiled as a result of disability. *Staff costs are a major issue for someone who has complex needs – no staff means NOTHING happens</p> <p>*4. : Difficult to express view as to whether it will be easier without seeing paperwork. Currently 3 levels of care mean that a high level of need, without the night time element, can have middle rate. If only 2 levels exist then how will high levels of</p>

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		<p>daytime need be addressed or will there only be the 2 higher rates. *Currently mobility element discriminates in favour of people with physical disabilities. It takes little account of someone who is physically able to walk but cannot move outside the front door without support and supervision. In reality they can be more “disabled” by their condition.</p> <p>*5. : Other than for those who are terminally ill I think that all claims should be based on individual circumstances but assessing that will have a huge cost implication.</p> <p>*I also think that some people are awarded the benefit whilst needing it but continue to have the benefit for many years after they have recovered.</p> <p>*6. : As stated in the document I think assessment should consider things like how much support is needed to enable the person to get around, interact with others, manage *own care (all elements) and medical needs – basically to have a safe life - the things most*people take for granted.</p> <p>*7. : I think this is a difficult one. I think the problem is partly that people do not want to relinquish their benefit in times of better health as it is so difficult to get it back if/when needed.</p> <p>*8. : No personal experience but think that aids and adaptations can only be taken into account if they can be used independently. Am aware that many wheelchair users have infinitely more freedom, choice and independence than my daughter who currently has lower benefit entitlement.*</p> <p>9. Your response:</p> <p>*10. : Information from the people, be it paid carers, relatives who really know the person and can provide accurate evidence for people without health conditions. *The current system favours people who have a disability which can be “seen” – others are put in a position of having to “prove” that they have a disability and many of these, unless they have a strong parent/carer are overlooked. It has taken 34 years for my daughter to have a diagnosis of autism – a classic case the experts now say!!!! She is at the developmental level of a 2 - 4 year old.*Many people with learning difficulties can be physically very well so the suggestion that assessments are done by doctors fills me with dread – they are the people who told me that I was an overanxious mother and to go away.</p> <p>*11. : The current system favours people who have a disability which can be “seen” – others are put in a position of having to “prove” that they have a disability and many of these, unless they have a strong parent/carer are overlooked. It has taken 34 years for my daughter to have a diagnosis of autism – a classic case the experts now say!!!! She is at the developmental level of a 2 - 4 year old.*Many people with learning difficulties can be physically very well so the suggestion that assessments are done by doctors fills me with dread – they are the people who told me that I was an overanxious mother and to go away.</p> <p>*12. : There are some disabilities which will not change so I</p>

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		<p>don't see the point in wasting money carrying out reviews – a lifetime award should be awarded.</p> <p>*13. : I think the problem is partly that people do not want to relinquish their benefit in times of better health as it is so difficult to get it back if/when needed.</p> <p>*14. : Think this will vary according to the disability.</p> <p>*15. : It's a bit insulting to assume that many people don't try to follow this route! Have you ever tried to "access advice and information"? If you think this is a good idea then you MUST ensure that this is readily available. Many people have carers who act on their behalf and don't need even more hoops to jump through.</p> <p>*16. : Can't answer this.</p> <p>*17. : Don't know sorry</p> <p>*18. : Very useful. Ensure that people are aware of these "passporting" arrangements.</p> <p>*19. Your response:</p> <p>20. Your response:</p> <p>21. Your response:</p> <p>*22. : I hope that it will turn out to have been worth my time considering the questions. I think that the current system discriminates against those who have autism and learning disabilities. It is too heavily weighted towards physical disability *e.g. many people who have higher mobility are far more independent than my daughter who is unable to set foot outside the door without another person e.g. for care needs people are assessed as to whether they are physically able to complete tasks. To me that is not the whole issue as I am sure that I would be physically able to perform brain surgery but I don't have the necessary mental ability or capacity for this role.</p>
EM625	15/02/2011	<p>1. Historically DLA has mainly recognised the mobility difficulties faced by people with a physical disability. Those with a learning disability, where it is significant, have been ruled out of higher rate awards because they are physically able to get around. However, in many cases of learning disability and autism for example, the individual may be completely unable to get out and about without a high level of support to both plan and carry out the journey. If you are unable to travel independently it follows that you are unable to take part in and social activity that takes place outside you place of residence: i.e. a very high proportion of all social activity.</p> <p>*2. It should continue to recognise the significance and cost of the extra care that a disability requires. It should remain non-means tested and free from tax. Could it also be protected from being taken back as part of "fairer charging policies"?</p> <p>3. The cost of the personal support needed to complete daily tasks necessary to maintain health, welfare and social interaction and to remain a part of society.*4. Again I would stress that within the two rates there should be no bias towards those with physical disabilities – having a wheel chair may</p>

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		<p>make getting around more difficult but many people manage very well. Having a severe learning difficulty or significant autism means that getting about and playing a full part in society is impossible without the support of others and should be recognised within the higher rates. At present the higher rate takes into account night time needs. How can higher rate be protected for individuals who have a very high level of daytime need but not night time need?</p> <p>*5. No, but each case should be judges individually and the genuine needs recognised. For example, someone in the early stages of Parkinson's may need very little support but this may change over time so the health condition should be assessed on the impact it is having at the time of assessment not simply on the condition.</p> <p>*6. That is almost impossible to generalise – one individual may need support to be with their friends or go to the cinema, be helped to shop and cook meals another may need support to take part in much more complex social or physical activities. It depends on the individual, their capacity and needs. Individual without disabilities fulfil their lives in many different ways – it is the same for those with disabilities.</p> <p>*7. Put in place a review system that is able to assess need “at the time” and make meaningful predictions as to whether the disability is likely to be long or short term.</p> <p>*8. It is vital that adaptations are not seen as a substitute for support if the personal support is the most significant contribution to independence and ability to live a full life.</p> <p>*9. Write forms in clear, uncomplicated English, include detailed but clear criteria for qualification, make sure that any professionals involved in assessment are fully versed in the criteria and are experienced in dealing with people with disabilities and understanding their needs. Take full note of the contribution of parents and guardians – the people who know the claimants best.</p> <p>*10. Evidence from parents, guardians and carers: the people who know the claimant best. Medical evidence, assessments of recognised conditions such as autism etc.</p> <p>*11. Many children and adults with learning difficulties, autism, language disorders etc are not capable of discussing their needs with a healthcare professional and would need support to do this – parent, advocate.*It is vital that people who are unable to speak for themselves are not excluded from support.</p> <p>*12. Yes: some people with have a clear, lifelong need that is never going to change. Others may have needs longer than 6 months but that will diminish. Review should be set on the basis of the assessed need. Someone with autism will always have autism.</p> <p>*13. Reassure them that keeping the Department informed will not threaten their care and support. If reviews (question12) are carried out at regular intervals changing needs will be identified</p>

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		<p>and benefits will not be given to those who do not need them.</p> <p>*14. Yes, as much information as possible.</p> <p>*15. Your response:</p> <p>*16. No, the award should remain as it is now – to be spent in the most appropriate way each individual decides.</p> <p>*17. That they are unlikely to fully understand their own needs and that it is more likely to be their carers that have the ability to express these for them. Carers should be fully able to take part in the process.</p> <p>*18. Your response:</p> <p>*19. Very serious – it is often only through signposting and support from trained volunteers dealing with things like DLA applications that people even know about entitlements, let alone are able to access them.</p> <p>*20. Your response:</p> <p>21. Your response:</p> <p>*22. I am the parent of an adult with autism, a learning difficulty and a complex language disorder. Without considerable support she would be a prisoner in her own home. She cannot read, write, tell the time, deal with money, cook or organise her life without a high level of support. She is unable to leave her flat on her own as the outside world is a frightening and confusing place for her. However, as she is mild natured, kind and completely non-aggressive the current DLA system does not recognise that she is completely unable to travel on her own. At the same time, people with quite minor physical disabilities are in receipt of higher rate mobility with no regular re-assessment of their needs or “testing” of their ability to get around on their own. There are many more people in the same position and I feel very strongly that the needs of people with learning disabilities should be fully recognised in the new system learning disabilities are not easy to see but they are just as crippling and disabling as physical disabilities; in fact they can result in the individual being trapped in their own homes and unable take any part in society or access the outside world.</p>
EM626	15/02/2011	<p>1. Disabled people cannot be independent in society due to lack of funds. My brother receives £91 per week disability living allowance and after paying his accommodation at [REDACTED] house he is left with £79 per month for any activities, clothing, personal hygiene products and other things that he may need to buy. I think that this is unacceptable. My brother has cerebral palsy and needs 24 hour care and could not live independently.</p> <p>*2. Your response:</p> <p>*3. General cost of living, transport costs to attend appointments if no access to mobility car, clubs or social events, costs for holidays (which they should be entitled to enjoy like anyone else) including paying for a carer.</p> <p>*4. Unable to answer as I do not know what the two component rates will be. However I do think that every individual should be assessed separately as all needs are different and my brother</p>

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		<p>could not be pigeon-holed into the same category as another person with cerebral palsy.</p> <p>*5. Should be individual to the person applying for their individual needs.</p> <p>*6. You should take each individuals needs into consideration. I think the second part of this question is ridiculous! everybody has the right to live a full life and it depends on the individuals' needs.</p> <p>*7. By monitoring any change in circumstances and the condition of the person involved</p> <p>*8. Yes they should be taken in to consideration as some people rely on aids as an essential everyday need. The assessment should take in to account aids the person might be eligible for. Aids and adaptations that should be included are any mobility aids</p> <p>*9. My brother is not able to fill in his own forms as he is unable to read or write, he can vocalise to an extent and understands what is being said. I am his appointee but always make sure he is involved in any decisions regarding his care and welfare.</p> <p>*10. The person himself, his staff at where he resides and family to get an all-round view of what the person needs.</p> <p>*11. Problems could arise due to a person having communication difficulties, some people may have issues when faced with strangers asking questions which could upset them. A benefit could be the health care professional would be able to see for themselves the person they are deciding their future for.*12. Reviews frequency should be set at the initial consultation and be dependant on the individuals needs, no-one can accurately predict if a persons' particular condition will improve or deteriorate and therefore affect their needs.</p> <p>*13. As stated previously this will be impossible for some individuals who don't have the ability or the understanding to report any changes.</p> <p>*14. A lot more than is currently being provided for this matter!</p> <p>*15. Your response:</p> <p>*16. My brother has to pay for his own personal aids – wheelchair, rollator, commode etc... Which I think is a disgrace and these items should be provided free of charge as they are part of his essential everyday life.</p> <p>*17. Again individual needs should be considered.</p> <p>*18. Don't understand the question!</p> <p>*19. We had no idea any changes were being made to this allowance until this questionnaire was shown to us by another service users parent we therefore have no idea of any implications. I find it a travesty that as a family of a disabled person we have not been informed of anything in regards to this and have no idea of the benefits or detriments it may bring!</p> <p>*20. Your response:??</p> <p>*21. We have had no literature to refer to and make an informed decision!</p>

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		<p>*22. I would love to be able to contribute at this point but may I refer you back to my response in number 19. After receiving no information on this proposed change and believe me we are very close to our brother as a family and keep up to date with any changes as far his care and wellbeing is concerned. I feel let down that changes are coming in that after attending several meetings regarding changes, no information concerning P.I.P has reached ourselves until a scope leaflet was passed onto us by another parent. I just wonder how many other parents/carers that take the time to attend various meetings are as uninformed as we are!</p>
EM627	15/02/2011	<p>1. A lot of the problems depend on the Individual, IE their personal difficulties. There are also physical barriers like, access into buildings also Public transport in rural areas, if this is not available and is not access friendly this can cause big problems to those with disabilities who are unable to drive and do not have a driver.</p> <p>*2. I think DLA is a good and fair way of helping people with disabilities to allow extra funds to make life a bit easier. With the different components and the different levels*of payment, it addresses the needs of the individual for their individual needs. I think it should all stay the same.</p> <p>*3. In my opinion the main extra costs are extra care, and transport/vehicle costs. because we are unable to walk any distance, we cannot walk to the local shop, we have to drive, or get a Taxi, this all entails extra expense that if we were not disabled we would not have.</p> <p>*4. This will be ok if it is administered fairly and it is accessed by professionals who do not favour towards their paymasters!</p> <p>*5. Yes definitely, things like acute MS, acute Rheumatoid Arthritis and any other condition for which there is no cure and there is no hope of improvement only decline.</p> <p>*6. The most important is personal care. Then comes things like socialising.</p> <p>*7. As already mentioned it depends on the illness/condition of the individual. If it is a case where there is no hope of a cure or improvement there should be no re-assessment. If it is the case where there maybe a chance of a change in the individuals condition then this should be re-assessed both fairly and for the individual not generalising the condition. The most important thing is that the Doctors who do the assessments are both understanding, listen to the customers consultants and GP's, after all they know the customer better than anyone. They should not make a judgement off their own back as this may be grossly unfair and not in favour of the customer at all.</p> <p>*8. It should not be the case where adaptations and aids are taken into account, this should be based on the the way it has always been, on the individuals personal needs, ability, and requirements. Ok they may have adaptations to help their daily lives but life is still a struggle with those adaptations, the</p>

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		<p>customers disability is still there, they still have their own problems, whatever adaptation and aids you have it still only helps their daily lives, it doesn't take away the pain, frustration and heartache.</p> <p>*9. This could be made more straight forward by asking questions in plain English also by only asking the question once and not disguising it and asking it from another angle. Again take more notice of the customer's GP and Consultant, then it would be much easier for the individual, some people have trouble understanding the form let alone filling it in. It is very daunting when you are given a form with nearly 50 pages in it, listen to the GP's and Consultants,, please, they know better than anyone.</p> <p>*10. Most definitely the individual, the GP and their Consultant, not a doctor who is paid by the organisation who is charged with getting the claimant off the benefit and back into work, this has been proved time and time again by the amount of appeals which have gone in favour of the claimant.</p> <p>*11. This again may be a good day for the claimant not an off day, this will portray the wrong picture of their health and this may bring about the wrong conclusion/outcome for the claimant, as the Doctor will only see the individual on that day. How can they make an accurate assessment under these conditions. The individual will not be at ease as he/she will be interviewed by a Doctor who they don't know, they will be worried they will be trying to "catch " them out, it will bring a lot of undue stress and upset to the claimant. Again if the decision makers take more notice of GP's and Consultants, the professionals who have been dealing with the patient's needs, this would be much fairer for everyone, I feel.</p> <p>*12. I think the reviews obviously depend very much on the individual, the review letters/forms should be sent out depending on the illness/disability of the individual and this would then dictate the frequency that they would be sent out. For example someone who has recovered or has a chance of recovering from an illness should be re-assessed more regularly than someone who has an incurable and debilitating condition who will never improve. These should not receive a form as it makes you feel that people don't trust you, that you are receiving something that you may not be entitled to. If their condition worsens then they should be able to make this known by themselves.</p> <p>*13. People will report changes, if they feel that they are not going to be penalised and that the benefits people really are there to help the individual and not to penalise them, when they report a slight change.</p> <p>*14. It would be nice to know how the benefit will help the claimant, what the benefit is specifically for.</p> <p>*15. I think it would be good if there was some good independent advice available to the individual. This could be promoted through disabled support services.</p>

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		<p>*16. I currently use all of my DLA to help with my disability to make life easier, plus I also have to use some of my other benefits too.</p> <p>*17. I could not comment on this as I have no children</p> <p>*18. I find DLA is excellent because if you are entitled to it and you get the higher rate mobility it entitles you too free road tax, you don't have to pay the congestion charge and you can also apply for a Blue Badge which is so valuable to me as I have difficulty in walking distances.</p> <p>*19. It could be very awkward indeed as you will have to fill in more forms and probably meet other criteria before you are able to get what you are automatically entitled to now.</p> <p>*20. I think all the disability benefits should be linked, this would save a lot of time and money on filling out and checking and decision making when the forms are sent in. There could be a main benefit for disabled people, one that is only for disabled people, when they meet the criteria, ie information gained from the GP and Consultant, they can then be eligible for other linked benefits. Being disabled is hard enough without having to fill loads of forms, go for medical that are most likely being viewed on the side of the paymaster.</p> <p>*21. There should be some advice about if/when a claimant feels that he or she can do a few hours work a week, they should be able to keep their benefits.</p> <p>*22. I feel that if the new system is allowed in it will be unfair, it will cause undue hardship on vulnerable people who are already struggling. This will hurt the genuinely disabled people in our communities. We should be supporting them, not looking for ways to save money. If this is the case, they should pick on the work shy instead of us who are genuinely unable to work due to ill health, because this is what it all boils down to.</p>
EM628	15/02/2011	<p>Dear Sir or Madam, I'm currently in receipt of DLA, and was concerned to hear that the government are considering overhauling this benefit in 2013/14. Consequently, I've read the public consultation document and written my responses to its questions in the file attached to this email. Thanks for taking the trouble to read them.</p> <p>* 1. As a Type 1 Insulin Dependent Diabetic, for forty years now, my disability affects virtually every major daily choice I make. This is because I'm currently taking three or four Insulin injections per day, which have to be supplemented by a food intake too in order to prevent low blood sugar, which, if it occurs, can create all sorts of side-effects e.g. confusion, convulsions, double-vision, and ultimately, if I don't ingest sugar quickly enough to combat this hypoglycemia, unconsciousness. And hypoglycemia is always there on a diabetic's mind, so for example, a new job would be thought of in terms of 1) What time is lunch? 2) Am I allowed to eat whilst working? 3) Am I allowed to check my blood sugar during work? 4) If I'm feeling low are there drinks machines or a canteen where I could get</p>

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		<p>food or sugar quickly? 5) How would new work colleagues respond to a severe hypoglycemic attack if though I'd explained my condition to them? 6) Would my colleagues and bosses panic and be inclined to dismiss me at a suitable opportunity? etc., etc., etc. ad nauseum!</p> <p>* Oh, and it's not just all those issues you deal with either! I currently do around 7 or 8 blood tests per day as well, which also largely determine whether I eat or don't eat, and can feel particularly embarrassing when in the company of people who don't fully understand your disability.</p> <p>*2. I personally know many disabled people who are incredibly thankful that they receive DLA, as virtually all of them have struggled to a greater financial extent before receiving the award, because of their handicaps, and because of employers tacit reluctance to offer them jobs. So because of these issues, I think it'd be unbelievably damaging to change the current system. If anything, the current application process and forms associated with it, should be made more claimant friendly so that more disabled people benefit.</p> <p>*3. I face costs from being diabetic all the time. From the seemingly moderate costs of constantly having to dip into my pocket to buy chocolate bars or cans of coke, making sure my mobile phone is always in credit, and always having £10 in my pocket in case I need to get a taxi in an emergency, to the unknown, and potentially huge, lifelong cost of being overlooked for work vacancies in favour of more able-bodied candidates, utterly undermining my earning potential throughout my life.</p> <p>*4. Well, it's pointed out in the Consultation Document, in section 16, that there are currently 11 different combinations of payment which a claimant can be paid, which make the system far too complex to administer. Well surely, considering the current DLA benefits have been in place since 1992, if it was really that difficult to administer, the system would have fractured long before 2010? The major disadvantages of introducing only two specific payments for the "mobility" and "daily living components", is that these components are going to be assessed under the new "social model of disability" rather than the current "medical model of disability". This will not only mean that there's a less nuanced approach to the financial needs of each individual claimant, but also, more crucially, the "social model approach" emphasizes overlooking the financial costs of physical and mental impediments if, the claimant can still somehow find a means of completing an average daily task.</p> <p>* So, for example, if I eventually lost a leg to diabetes complications, limiting my ability to walk and work, the social model approach would see this as resolved through acquiring a prosthetic limb, generally overlooking the long-term financial disadvantages in employment terms.</p> <p>*5. Of course many long-term disabilities should result in an</p>

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		<p>automatic entitlement to DLA or PIP. Blindness doesn't "improve". Amputees don't suddenly, octopus-like, "grow a limb". Diabetics don't miraculously lose the fear of Hypoglycemic attacks. Considering the new proposals require that new applicants have already had their disability for at least six months, and expect their disability to continue for at least six months more subsequent to their claim, the new PIP benefit will be draconian enough without repeatedly assessing the long-term disabled.</p> <p>*6. Look, the whole issue of trying measure who's more disabled than someone else, is not only incredibly socially divisive and stressful to disabled people, it's already been questioned as to whether it's actually illegal!* The activities which are fundamentally essentially for everyday life, are activities which make able-bodied and disabled people feel unified and relatively equal, such as being able to access decent job, educational, health and social opportunities, which are frequently greatly facilitated by fair access to state benefits such as DLA or PIP.</p> <p>*7. Surely one of the easiest ways of assessing the stage of a claimants long-term disability would be simply to ask their long-term doctor, rather, than as is proposed now, consulting independent specialists from health, social care, and disability backgrounds, previously vetted by the benefits agency, who have no previous understanding of the claimants long-term problems!</p> <p>*8. In my own case, for example, you could look at my blood test monitor and potentially conclude, "Well, he's got a blood test monitor. Therefore, that "aid" can usually provide a degree of protection against Hypoglycemic attacks.", which, if that were a belief in my subsequent re-assessments, would completely overlook the effect that exercise, stress, common illnesses like coughs and colds, can exert upon my blood sugar levels hour by hour. Yet surely the "social model of disability" which PIP is about to adopt, would have to regard my blood test monitor as a massive aid, to the complete detriment of the other factors I've mentioned. As for "looking into the future" with a view potential future medical aids and developments the disabled claimant may be eligible for, does that mean the benefits agency will be employing psychics in future? It would be interesting to see Russell Grant and Mystic Meg back in work.</p> <p>*9. Considering the present DLA claim form currently has 62 questions to be answered, which would test the abilities of a London barrister, why can't the whole emphasis simply be changed, whereby the onus is placed upon the DWP to show that a claimant falls into one category or another through consulting with that person's medical consultants, rather than requiring the claimant to fill out tortuous forms, year after year, which, through the sheer size of them, are prone to error or mistake?* With regard to publicizing PIP, obviously clear, lucid</p>

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		<p>advertising is the means through which to do that. But as government cutbacks take effect, and the emphasis seems to withdraw from encouraging people to claim what they're entitled to, I have my reservations as to whether the new system will be clearly understood.</p> <p>*10. All my medical records are contained on my GP's computer database. Although there are strict guidelines limiting access to personal information, in the case of a DLA or PIP claim, I'd be perfectly willing to give my consent.</p> <p>*11. There are all sorts of problems surrounding this issue. In meetings with people suffering mental health problems, for example, how are their responses going to be assessed? There's also issues surrounding trust in these situations, which could grossly misrepresent information being divulged and considered. * The whole scenario also raises the key issue of "why would a vetted official from the DWP, potentially without any formal medical qualifications themselves, be tasked with assessing personal opinions from disabled people about the state of their health?" This is a terrible idea. If the DWP want to assess a claimants health accurately, then they should be interviewing that claimants doctor with a qualified medical practitioner of their own!</p> <p>*12. Surely the whole point of filling out the claim form in the first place, is to give the benefits agency a full picture of the current and future impact of a disability on a claimants life. Therefore, the whole notion of constantly reviewing and re-assessing the current condition of a claimant, seems bureaucratic, incredibly costly, and largely pointless when considered in the context of unchanging conditions like blindness.* Asking whether there should be different types of review, is a bit like asking whether you could use different types of umbrella in a hurricane.</p> <p>*13. This again is infuriatingly bureaucratic. There's a plethora of disabilities where the symptoms are sporadic, yet still devastating, in something like Epilepsy for example. If I experienced a six month period where the serious Hypoglycemic attacks I suffer had reduced from say 10 to 7, would that indicate I was a recovering Type 1 diabetic? The question here is why do the DWP believe that potentially miniscule changes in a person's disability, should warrant the cost and stress required to re-examine the person's claim?</p> <p>*14. I think that any information distributed with a PIP claim pack, should include fully transparent biographical summaries of the departments Independent Specialists in Health, Social Care and Disability, tasked with assessing your claim once it arrives.</p> <p>*15. With the current government budget cuts coming into effect over the next two years, any disabled claimant being denied benefits, and pushed in the direction of the voluntary service sector to provide for some of their needs, would face a very,</p>

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		<p>very long wait in a queue at the moment.</p> <p>*16. Is this a serious question? Erm.....disabled people usually fund any aids and adaptations they need through benefits like DLA which they currently claim! If PIP is also going to provide a means to acquire one-off payments towards these enhancements, then good, so long as those one-off payments aren't simply a cost-cutting substitute for regular PIP payments themselves.</p> <p>*17. The fact that adults have to articulate the difficulties their children face, with children often being unable to fully articulate their own health problems or, be able to assess the bigger, long-term picture.</p> <p>*18. DLA is crucial in allowing disabled people to access disability premiums for other benefits they may receive, thereby allowing better financial stability when normal working avenues can deny opportunities and create such frustration.</p> <p>*19. It would just further increase the stress and sense of alienation disabled people feel with society anyway. There's already a real danger that the PIP changes will do that in their own right anyway.</p> <p>*20. Look, you know as a way of resolving some of this torture the DWP is going through over "Who deserves what?", "How can we legitimately cut payments?", "How can our department shine when seeking treasury funding?", why not just create a form for disabled claimants, with an extensive list of disabilities stated there, simply requiring a tick, and a whole pack of other information listed as to how an individual assessment of a claim will be conducted through writing to your doctor and other medical consultants, the departments own medical specialists being consulted, etc., etc, until the DWP reach a conclusion on your claim. Then there'd also be literature about appeals procedure, and voila, a completely easier, less bureaucratic system?</p> <p>*21. I would hope that through extensive advertising in a variety of media outlets, every group in society would have a good understanding and, equal access, to the new benefit. This is particularly important in terms of ethnic groups who currently appear less likely to receive DLA than whites.</p> <p>*22. DLA has been a really liberating benefit for me. It's enabled me to afford necessities such as a mobile phone and the associated costs of running it, a wider variety of foodstuffs, necessary for effective, long-term diabetes management, and just generally a better quality of life. PIP, for all it's apparently laudably claims, seems to be just another exercise in saving money, and the devastating, stressful impact that could have on disabled claimants would be terrible.</p>
EM629	16/02/2011	<p>Hi All, This is my response to the consultation. I am a parent of two disabled children.</p> <p>* 1. The disability of the person, financial resources, lack of services to suit their needs, unsuitable building layout,</p>

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		<p>unsuitable aids, lack of understanding or emotional support. Impaired cognitive functioning or physical functioning.</p> <p>*2. I feel that DLA is neither confusing nor complex. There are two mobility rates as there will be with PIP and three care rates (one more than PIP). I feel that the 3 different care levels are a good reflection of how peoples abilities are impacted by disability or disease. Some need a little assistance, some need more and some need even more. 3 rates is good. Maybe there should be 3 rates for mobility too.</p> <p>*3. Laundry, heating the home, fuel for hospital appointments, fuel for the car due to unsuitable public transport, medication, fuel for unexpected trips to school or hospital. Frequent replacement of furnishings or clothing due to accidents, specialist equipment.</p> <p>*4. I can't see what's difficult about the current system The removal of one rate from one component does not necessarily simplify things. If people who administer the current system cannot cope with a choice of 3 levels in one component then we are in a sorry state! I feel however that many in the DWP are well able to cope with this.*Having two rates prevents the benefit becoming a yes or no situation. This is important as people are vastly different in how they are able to deal with any given situation.</p> <p>*5. Yes. Definitely. Because there are some diseases or conditions that make life very difficult for anyone who has those conditions. Why add to the stress for them and those around them by taking away automatic entitlement.</p> <p>*6. Start by giving automatic eligibility for some conditions. Then ensure a proper sliding scale of need and ability. *Eating, drinking, toileting, being clean, feeling as comfortable as possible, warmth, touch. *Company, stimulation, being a part of the world, access to shops and services, being safe in the community.</p> <p>*7. Assess carefully and review annually maybe. However even with a very variable and fluctuating situation there must be an average to work with.</p> <p>*8. That depends. If it takes it into account that for them to function as well as they do they need that aid to do so then it should. However, if it's seen as the person has that aid and therefore the problem is solved that would be very wrong. *Any aids or adaptations could be included. The assessment should be based on what's in use.</p> <p>*9. Tick boxes are wonderful. Pictures too. No repetition. Have a good tv and internet campaign. Be sure to involve as many disability groups as possible. Contact all current recipients with details. Consult them.</p> <p>*10. Person, GP, Specialists dealing with person, School, Social Worker, Support Worker, Paediatrician.</p> <p>*11. I can't see any benefits. Only costs. If the health professional involved has no knowledge of the persons</p>

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		<p>condition and how they can be affected then it could be dangerous. Vulnerable adults or children do not need to see any more health professionals than is necessary. Meeting a new person can be an ordeal for some. Besides there are many other ways to get enough information from other sources.</p> <p>*12. Look at developmental milestones, recovery rates for surgery/diseases, set them around that. Of course there should be different types of review. There should also be scope to decide whether a person will ever need a review again.</p> <p>*13. Some people may never be able to identify changes in their needs, never mind report them. To encourage people to report changes you could send them an e-mail to remind them of the changed circumstances that need to be reported.</p> <p>*14. How to fill in the form. Where to get help filling in the form. How long the answer needs to be. Additional space for people with big hand writing. Example answers. It would definitely be helpful. Remember many applicants may have numeracy and literacy difficulties as well as neuro-differences.</p> <p>*15. I feel this would be an appalling thing to do. For someone with mental health issues it could be the last straw. It would be yet another relationship thrust upon them.</p> <p>*16. Unable to comment on this, not enough knowledge.</p> <p>*17. The assessed child's age and development and a typical child of their developmental age. Compare and contrast to get some idea of just how they have been affected. Have they support at school, whether stated or not. Statementing is being cut back.</p> <p>*18. Despite having the lower rate mobility component of DLA, I had to fight tooth and nail for a blue badge with my local council as they lacked awareness of how autistic people find it difficult to get about. So I would like to see improvements at that. It was useful in getting help for adapting the fencing around my home, once the lady from the council got her head around the fact that different disabilities bring different needs and adaptations aren't always about hoists or bathroom conversions, some times it's about other needs.</p> <p>*19. More stress, more delays, more paperwork, more costs. More of everything you don't need as a carer or disabled person.</p> <p>*20. Unsure.</p> <p>*21. I'm sure the main group of people affected by this will be anyone with a disability, regardless of age, gender, sexuality, ethnic background or whatever. There may be a few fortunate enough to have enough financial resources not to be reliant on the state for services or benefits of any kind. Everyone else will be unfortunate.</p> <p>*Maybe you should scrap PIP before you start it and spend a small amount of money making the existing system of DLA work by investing in training the decision makers to be more consistent with the decisions they make.</p>

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		<p>*22. I feel it's an attack on the most vulnerable in our society and that if changes need to be made in administrating the existing scheme, fine, make them.</p> <p>*However it does not surprise me to find that the numbers claiming DLA have increased. We have better ways of detecting many diseases in earlier stages, therefore prolonging life. We are getting better at recognising complex disorders like autism. People with horrific injuries from accidents or wars are now being saved when even just a few years ago they might not have been so lucky. More and younger premature babies survive. People live longer, therefore we have more people getting things like dementia. It's inevitable that there will be an increase in the numbers claiming this type of benefit.*There may be a small minority of people who claim it fraudulently, but I think that by making a face to face assessment with a "health professional" a compulsory part of PIP is like using a sledge hammer to crack a nut. Not only that but it is more than a little insulting to the honest majority who genuinely need and are entitled to this benefit to be viewed from the outset as liars. It sets the incorrect tone. Disabled people are no more dishonest than able people. *In the coalitions race to cut the deficit I hope they remember the human cost of the cuts for if they do not, then we will indeed become broken Britain. Children are our future, disabled people are present and our future. A modern society is judged on how well it looks after its most vulnerable.</p>
EM630	16/02/2011	<p>1. Your response: This is a huge question and it covers a huge area. The problems may relate to physical ability to access activity, to the cognitive ability to process and recall information, to sensory difficulties, to difficulties with communication and social interaction, not to mention mood and mental state and degree of development. These can all affect the ability to have control over one's own life and level of independence.</p> <p>* 2. Your response: The present system tries to take account of the amount of assistance that the individual requires in order to be able to access daily activities, considering their need for practical help and support with safety and independence. It works to enable the individual not to deprive him or her of autonomy. For many it means the person can access a degree of employment or education, it means they are not dependent on residential care, and it supports them with rebuilding independence whilst they recover or develop new ways of coping.</p> <p>*3 Your response: The cost of care, the cost of specific equipment, clothing, travel, re housing or alterations to housing, heating, medication, specific diets, *loss of income, difficulty with saving for a pension or saving in general, accessing holidays.</p> <p>*4. Your response: This depends on how the categories for the rates are defined. There is the potential to miss the more discrete areas of need which are subtle and harder to define,</p>

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		<p>often to do with behavioural and cognitive aspects of function. Deficits in these areas can have significant impacts on the person's safety and independent functioning socially and can mean it is difficult to live independently and to be productive.</p> <p>*5. Your response: In some situations where the impact of the condition or disability is permanent or terminal there is a need for the benefit to be automatic.</p> <p>*6. Feeding, elimination, hygiene, warmth and shelter are essential basics, access to communication, contact, functional, social and productive activities, the opportunity to make friendships and relationships, to access education and training, and to access areas beyond the home, all these are basic human needs. Individuals value different things: allowances can provide the means to support basic needs and to access more individual choices.</p> <p>*7. Your response: The assessment could consider the duration of effects from the condition. Advice could also be sought from professionals involved but these professionals must have understanding of consequence of these effects for the person and a working knowledge of their significance.</p> <p>*8. Aids and adaptations do not mean that activities can be achieved with the same speed and ease as someone without any disability. They frequently take longer, produce more fatigue, require more organisation and support and are not necessarily available easily. There are local restrictions, (more variable following fair access to care act), and some aids and adaptations are expensive and require ongoing maintenance.</p> <p>*People should not be penalised further for something which already impedes their ability to live a fulfilling and meaningful life.</p> <p>*9. Your response: Specific clear and concise details of what the benefit is, who is entitled to claim and how to claim.*This information needs to be readily available in appropriate formats, and relevant agencies need to know where to find it and to be informed of any relevant changes. Individuals should be able to access appropriate support to complete the forms.</p> <p>*10. Knowledge of the present abilities of the applicant, from the applicant him or herself, or those who know him or her. This can include families and others such as involved professionals and those who are aware of the implications of the illness or condition.</p> <p>*11. Your response: A health professional who knows the person and whom the person trusts would be best placed for this process, if it has to be done in this way. It a huge assumption and very intrusive to assume that only a health professional is able to identify the abilities and needs of an individual. Many people know their own condition and can verbalise it better than anyone else.</p> <p>*12. Your response: It may be with some conditions, for example rapidly progressive conditions, that frequent reviews</p>

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		<p>are more appropriate. The length of time it takes to process the review and alter allowances also needs to be considered when deciding frequency</p> <p>*An annual or a biannual review could be planned. If there are significant changes in a person's needs, {and this could be identified on a scale, of points for example} the person could request a review more frequently..</p> <p>*13. Your response: Make it as easy as possible to do this. Have information about what other support or finances may be available if their level of need is diminishing but there is a financial cost to reducing benefits for example. Availability of advice on what alternative services may be accessed in order to return to employment or independent living, with access to appropriate personnel.</p> <p>*14. Your response :Advice and information about what needs entitle a person to claim for this payment. It would be useful to include this as part of the process.</p> <p>* 15. If there is a system of allowances for those who need advice and support it needs to be advertised and accessible and those working in relevant areas need to know and understand what is available and the process for accessing it. This could be people working across the public and health sector and information needs to be readily available in areas of general public access.</p> <p>*16. Your response: Currently there is some provision through health and social services which is variable from area to area, despite fair access to care!</p> <p>*Frequently people purchase equipment privately, having been advised about sources. Personal independent payments could be used but this should not be at the cost of services essential to daily living and safety.</p> <p>*17. The child's ongoing developmental needs, their level of risk and ability to access normal developmental opportunities, the additional support they require and their potential needs in the future.</p> <p>*18. Your response: In my experience D.L.A. has been an enabling allowance in that it has allowed the holder to pay for services and help, often meant that family members did not have to work full time but could support their relative, and given access to activities in the wider community that are fulfilling and improve the person's level of independence and achievement.</p> <p>*19. Your response: It would limit the scope of activities and opportunities people could access.</p> <p>*20. Your response: Perhaps the person could hold their own record of their problem and details of assessments in order that any new professional could review this and avoid the need to duplicate information or evaluation which has already been completed. This could have full contact details to improve communication.</p> <p>*21. Your response:</p>

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		<p>*22. Your response: I would like to think that they are aimed at achieving a fairer way to support people with achieving their potential and the optimum level of support they might require in order to become full members of society in every sense of the word, However common sense dictates that they are driven by financial prerogative as opposed to humanity and fairness.</p>
EM631	16/02/2011	<p>Dear Sir or Madam, Please find attached a completed consultation form for the possible changes to Disability Living Allowance (DLA). Yours sincerely</p> <p>* 1. Your response: Mental Health Sufferers such as myself, may be able to live full and active lives at times but we have “Good Days” and “Bad Days” and I know that on a bad day I am incapable of going in to work. I am capable of producing work of a high standard on many occasions, but this does not change the fact that when I am experiencing episodes of my Schizoaffective Disorder I am no use to anyone as far as an employer is concerned. I do not believe that I am incapable of any work. Indeed I work throughout the week as a Volunteer and sometimes even for several weeks at a time, but if I was forced to take a paid job I greatly fear that I would become dismissed and at a very high risk of homelessness. I consider myself to have a very strong work ethic and I take great pride in my work at the [REDACTED] in [REDACTED]. I also am very highly committed to learning (e.g. Fundraising for charities and Web Site Design) and take an extremely keen interest in the news and current affairs.</p> <p>*2. Your response: Everything. Make people do Voluntary work or lose benefits.</p> <p>*3. Your response: Resources for voluntary work e.g. Fundraising books to carry out my job to a high standard – these are not currently supplied by my employer. Money for days out when not well. Travel costs. Food costs. Many disabled people such as myself do not have very good cooking skills and consequently have to pay more for takeaways etc. Voices in my head tell me to pay for things that if I was in paid employment my employer would pay for e.g. stamps for work letters and correspondence.</p> <p>*4. Your response: The current system seems to to work well enough, so why change it?</p> <p>*5. Your response: All claims should be based on the needs and circumstances of the individual applying. Mental Health Sufferers should not have to undertake ATOS Medical Assessments which do not take into consideration of their symptoms as is going to be the case.</p> <p>*6. Your response: Days Out, Support buying resources required for Voluntary work, Money for food and soft drinks, money for hobbies and interests, bus pass to enable free travel within the county the person resides in and not nationally.</p> <p>*7. Your response: Ask Mental Health Suffers about their Mental Health and not their Physical Health.</p>

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		<p>*8. Your response: Not applicable.</p> <p>*9. Your response: Happy with DLA form as it is.</p> <p>*10. Your response: Community Mental Health Centres e.g. Waverley House in Torquay.</p> <p>*11. Your response: The medical assessments by ATOS are very stressful for mental health sufferers such as myself, and often even the thought of travelling to Exeter in the next few months makes me feel suicidal. Things are bad enough as they are at the moment without the added stress of ATOS Assessments.</p> <p>*12. Your response: Regular reviews would be good if individuals were assessed appropriately e.g. Mental Health Sufferers should have an assessment relevant to their symptoms. I don't believe picking up a coin from the floor or walking a few meters determines a mental health sufferer to be fit for work and in a position to lose all disability benefits in an instant.</p> <p>*13. Your response: Send out clear and easy to understand information.</p> <p>*14. Your response: Ensure information is passed to the patient by the CMHC (Community Mental Health Centre) in the case of mental illness.</p> <p>*15. Your response: Don't know.</p> <p>*16. Your response: Don't know.</p> <p>*17. Your response: Don't know.</p> <p>*18. Your response: Keep the system as it is.</p> <p>*19. Your response: Don't know.</p> <p>*20. Your response: Don't know.</p> <p>*21. Your response: Don't know.</p> <p>*22. Your response: Don't be so tough on the most vulnerable in society e.g. Mental Health Sufferers.</p>
EM632	16/02/2011	<p>To whom it may concern, Having worked as a care assistant for young people with neuro muscular diseases for two and a half years now, I feel the proposed reform to the mobility allowance would have a drastic effect on the lives of many young disabled people. This would especially be the case for poorer families where such an allowance is the only support they receive towards transport and mobility. It is essential that young disabled people are given the same opportunities as everyone else and such mobility cuts would indeed be a hindrance in achieving this. Such basic needs such as being able to engage in a social life could be compromised if this cut was to go ahead. Since achieving 'fairness' across society is proving to be a priority for the government, if such reform was to go ahead it would indeed widen the opportunity gap between disabled and able bodied people. I hope the reform will be considered. Many thanks</p>
EM633	16/02/2011	<p>Completed questionnaire attached. This is a joint response from myself as a recipient of DLA and my husband, who is also disabled and is my main carer.</p>

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		<p>*1. Problems faced are physical, psychological, financial, social and cultural. They are multiple and overlapping in their effects. Physical problems - for example access to transport, to buildings and to the normal range of activities taken for granted by the physically fit can lead to social isolation and to a variety of psychological problems. While many of these physical problems are capable of being partially addressed by adaptations and/or support in the form of personal and social care, the residual problems remain and can have a significant effect on the disabled person, their family and friends. Adequate financial support can play an important role in minimising these psychological pressures. Financial problems – cost of adaptations to housing such as widened doors, ramps etc can be significant. Disabled facilities grants are limited and inflexible. Where property is not owner occupied it is even more complex. Disabilities may also lead to hidden costs, e.g. additional mortgage costs because of insurance issues. Other costs e.g. adapting cars, for portable ramps, for mobility aids, incontinence and personal hygiene products, orthotics, clothing can all add up to a significant sum each year. Social and Cultural problems – the psychological impact that can come with a disability is often substantially worsened by the effects of social isolation and the inability to take part in the normal range of activities available to the able-bodied. Day centres and respite care do not help since these merely increase the separation of the disabled from the day to day life of their community.</p> <p>*2. The current system works well for me and I see no reason to make substantial changes.</p> <p>*Several alleged problems are highlighted in the consultation report, for example at para 1: People are unclear about who can qualify and decisions about qualification are inconsistent and subjective. For example, many people incorrectly believe that Disability Living Allowance (DLA) is an income-replacement benefit for people who are unable to work due to disability.</p> <p>*At para 16: People are unclear about whether or not they are likely to qualify and there is evidence that people awarded DLA do not fully understand what the benefit is for. For example, some view the benefit as a form of compensation for being disabled, some don't view themselves as disabled and others incorrectly believe that their DLA payments will stop if they return to work.</p> <p>*And at Para 17: A significant proportion of DLA recipients believe that DLA is an out-of-work benefit. Applying for DLA is widely linked with the process of leaving or being out of work due to disability. A common assumption among people receiving DLA is that entering or returning to work will lead to a review of their circumstances and a loss of the benefit.</p> <p>*Most of these issues do not stem from the design of the DLA</p>

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		<p>system proper but from failures of advisors and administrators in central and local government.</p> <p>*The fact that people are unclear if they qualify is an inevitable consequence of any complex system. If such clarity was possible, and it isn't, the proposed face to face interview with a health practitioner would be unnecessary and it could all be automated.</p> <p>*The fact that some see the payments as a compensation for being disabled is in fact quite sensible. The payments are recognition of increased costs arising from the fact of disability and from the perspective of the recipient it is quite reasonable to see that as a compensatory payment</p> <p>*Quite frankly I do not believe any finding that says applicants for DLA do not think of themselves as being disabled, but even if true it is an irrelevance. The payment is for increased costs arising from certain conditions. How government views those conditions and what the individual calls them are separate matters. The individuals' perception of themselves is a critical factor in their mental and physical well-being. Even in the present system it has no direct bearing on the cost. The implied suggestion that payments should require the imposition of a self-image of disability on claimants is appalling and manipulative in the extreme.</p> <p>*The fact that some people think that their DLA will stop if they take up work is not a factor of the system but again a failure of advisors and others to communicate properly. No evidence is offered to suggest that such failures will not persist in any new system. Indeed, until all the advisors are fully aware of the new system the opportunities for error will increase. Change always has a cost.</p> <p>*3. Physical adaptations to the house to allow access and adequate circulation such as access ramps, widened doors, accessible bathrooms or kitchens, special flooring systems to cope with wheelchairs or visual impairment etc.</p> <p>*Health costs such as orthotics, physiotherapy etc where NHS does not or will not provide.</p> <p>*Equipment to help in day to day living such as hoists, wheelchairs, alterations to motor vehicles, special chairs, cutlery, large button phones, adapted PCs, Lifeline systems etc. Maintenance costs of same.</p> <p>*Additional costs or special terms for life insurance (arising from medical conditions) motor insurance (e.g. to allow carers to drive), mortgages etc</p> <p>*Costs of personal care such as incontinence and hygiene products, extra washing and cleaning, gardening, running repairs and cleaning/maintenance.</p> <p>*Costs of personal assistants/carers where social care not provided by the local authority or NHS or is not adequate, especially to cover problems of isolation and personal safety.</p> <p>*Increased costs of holidays etc e.g. some airlines impose extra</p>

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		<p>costs for wheelchairs</p> <p>*4. The so-called 11 rates offered as a critique are nonsense. There are currently three rates for care and two rates for mobility. These are independently assessed and are not aggregated when a decision on DLA is made. There is no confusion and no lack of clarity.</p> <p>*If only two rates are available for each component, this will result in a lack of flexibility of response. Other things being equal some people will get more or, more likely, some will get less than they would under the present system.</p> <p>*There is a case for more levels not fewer. In the case of those most severely ill, even the highest level of payment is likely to be inadequate, but in any event the adequacy of DLA is affected by the level of local authority or NHS support available and this varies across the country.</p> <p>*5. Allowing an automatic entitlement in appropriate circumstances will reduce costs, reduce bureaucracy and improve access.</p> <p>*6. This is not a question that can ever be answered when posed in such an ambiguous and open ended way. Priority however implies a degree of selection that appears at odds with the claim to support for an extra cost, non means-tested benefit.</p> <p>*DLA is based on additional costs, while the new system purports to be based on additional needs. Unless the cost of meeting those needs is made clear and is fully transparent the new system will be a retrograde step. The context in which the review is being undertaken, with constant use of terms like 'an affordable and sustainable system' and the references throughout the document to the high numbers of present claimants makes it clear that a significant driver is the need to cut costs.</p> <p>*If the present system is being applied inconsistently and subjectively, claimants do not cause that. This is a failure of government and of government alone. If the numbers of claimants are higher than forecast that means government forecasts were wrong, not that claimants are fraudulent or undeserving.</p> <p>*Returning to the question, what does 'prioritise support' actually mean? What is meant by a 'full and active life'? What special powers are available to government to decide for others what they feel to be an essential part of their life?</p> <p>*Any support system that is based on externally determined criteria of what constitutes a 'full life' is going to be intrusive and arbitrary.</p> <p>*7. If a variable condition exists it must be assessed at its worst. If at times the condition improves below the threshold, whatever that is, then the overall level of payment should be based on ensuring that sufficient means are available on meeting additional costs in the worst state. Many of these costs will in</p>

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		<p>any case be fixed and will not vary with the condition. Widened doors and access ramps cannot be removed in the case of someone with relapsing and remitting MS for example. A Motability contract cannot be suspended.</p> <p>*Can a condition be variable but not fluctuating? Or vice versa?</p> <p>*8. The assessment should be based on additional needs compared to an able bodied person. The fact that aids are available does not mean they are available to be used. Financial considerations may prevent them being taken up.</p> <p>*9. Someone is in chronic pain, can't afford to pay for the support they need and is applying for extra financial support and you talk about making it a more positive experience? That is the stupidest statement I have seen in a long time.</p> <p>*As for the detailed points:*</p> <ul style="list-style-type: none"> * Write in plain English not the language of this questionnaire * Ask relevant questions and don't put something in because it seemed like a good idea at the time. * Keep the system simple * Test the form on real people with a range of disabilities. * Test it again... * Write the information leaflets in plain English * Make them self contained – don't send people off for extra leaflets or forms <p>*10. Not a sensible question. The range of circumstances that will apply to people potentially eligible for DLA or its proposed replacement is enormous. Only the most generic of answers can be given. However not all disabled people have access to the sort of professional support and back up they need. It is important that any evidence comes from someone who knows and understands the condition or conditions that the applicant has and understands the personal and practical pressures that being disabled creates. They should also be familiar with the applicant.</p> <p>*Applicants should be able to submit their own evidence alongside anything gathered through the formal process. This should include statements from social workers, friends, neighbours, employers etc who will all have specific knowledge of how the disability affects the applicants life.</p> <p>*11. Regardless of intentions or what actually happens, the people carrying out the interview will be seen as representing government and not as neutral. In the present conditions they will be seen as being employed to reduce costs and reduce the number of claimants. If this is introduced it is essential therefore that applicants should be able to bring someone to help and advise them.</p> <p>*As in the answer to q10, applicants should be able, indeed encouraged, to offer their own evidence in support of their case and not be restricted to answering predefined generic questions. *Increased numbers of reviews by healthcare professionals will create an additional level of bureaucracy and</p>

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		<p>costs on the system and potentially on the NHS and other services.</p> <p>*12. Reviews should be brief and simple. Applicants whose condition is relatively stable should not require frequent reviews. Conditions that lead to a deterioration in the physical or mental state of the applicant may require more frequent assessment, but support workers such as health care professionals –or social workers should be empowered to support claims for supplementary payments if required.</p> <p>*13. No evidence is offered that any new system will be easier to understand. The new assessment procedure has still not been devised. However, reporting of changes in need will depend on applicants having some expectation that their needs will be recognised when they worsen. Since the context of the review and the underlying premise of more frequent reviews is likely to be seen as punitive – ‘there are too many claimants so someone is making false statements’ it is unrealistic to expect much support. *The consultation paper places great stress on fraud, but offers no evidence that such fraud is a significant factor in the increasing level of claims for DLA. This again reinforces the impression that the review is driven by a desire to cut the number of claimants and reduce costs, regardless of actual needs.</p> <p>*14. Entry to the system should be automatically triggered in a range of ways – for example grant of a Blue Badge, diagnosis with a range of conditions. At present access appears haphazard and dependent on the availability of professional and informed support. If support is ever asked for, potential applicants are often unaware of the existence of DLA.</p> <p>*15. The suggestion of compulsory support is bizarre. The final sentence of para 36 in this section is unclear. What does “We could potentially explore making elements of this part of the requirements of the benefit, where appropriate.” Actually mean?</p> <p>*16. If the payment is to be genuinely about securing Personal Independence, it should allow applicants to use the money in the way they believe will best suit them and this must include aids and adaptations. The present system of Disabled Facilities Grants is inflexible and complex, particularly where they do not cover the whole cost. Moreover, as stressed in the answer to Q4, the adequacy or otherwise of DLA depends on the level of support available from other sources, which is highly variable.</p> <p>*17. The key question is the need to ensure that any payment is used for the benefit of the child. This will not be an issue for almost all parents.</p> <p>*18. If the aim is to make a clearer and simpler to understand system this is vital. Sharing of data should be limited to the minimum required however, with no sharing of personal financial information and no transfer of such data to third parties, including private contractors..</p> <p>*19. It would mean the new system had failed. If you can’t do it</p>

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		<p>then don't make the changes.</p> <p>*20. Assessments for adult social care, for DLA etc should be combined in a single document to be held by the individual. At the moment care agencies, district nurses, OT, etc all make separate assessments and these are often held by the individual in their own home. A combined care format, held by the individual would ensure that this information was available to all workers and for all assessments.</p> <p>*21. DLA or its replacement should be available at any age. The present system of Attendance allowance for claimants over 65 and DLA for those under 65 has no relationship to actual needs. If this distinction is nevertheless retained, it should be adjusted with retirement age.</p> <p>*22. The consultation document is badly written, unintelligible in places and offers no evidence of any real problems with the present system. The only detailed figures relate to the increase in the number of claimants. It is difficult to avoid the conclusion that the driver for the review is not a problem with the system of DLA but a desire to cut the number of recipients and reduce costs.</p> <p>*The assumption is made that the increase in number of claimants represents an increase in fraud or of payments made to those not deserving of support.</p> <p>*The claim that the new system will be clearer and simpler to understand cannot be substantiated since it has not been designed yet. In the context of the review that claim is at best no more than pious expectation and in practice an attempt to justify a reduced level of support to the most needy.</p>
EM634	16/02/2011	<p>1. : For those disabled people who cannot take care of their personal needs such as getting out of bed, going to the toilet, washing, dressing, preparing meals, doing laundry, washing up, doing housework, there is obviously a need for help with these basic living tasks. There is an equal need for individuals to be able to go out wherever they live, whether they live with other people, alone or in residential care. If they live independently with other people in the house, it is likely that there will be someone who can assist with the transportation of the disabled person. If the disabled person lives alone they will require a much greater level of assistance so they can afford for example to hire a taxi. Those living in residential homes are often the most in need of financial assistance to ensure they can, for example, maintain a motorised wheelchair to enable them to go from one room to another, get to the toilet in time, move when they want to and maintain some sanity as a young person having to live in a residential care home as there is no-one else who can look after them. If they do not have the financial ability to maintain the motorised wheelchair they would be entirely at the mercy of the assistance of the staff whenever they wish to move which would make living an independent life impossible.</p> <p>*2. : I believe that the current DLA with its 2 components,</p>

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		<p>further divided into 3 levels of need, meets the needs of the disabled as far as I am aware. There is obviously a crossover of the 2 components where mobility within the home is inseparable from meeting personal needs, such as getting to the toilet and wash basin and shower, getting to the kettle, microwave, washing machine, front door, telephone etc., where the need for mobility is tied in to the meeting of personal needs. In such cases there is often a need for a motorised wheelchair which is often funded under the Motorability Scheme under the mobility component of DLA.</p> <p>*3. : For the disabled who require help with aspects of daily living there may be a need to pay for help with the preparation of meals, washing up, house cleaning, laundry, personal care, correspondence, lifts possibly by taxi to appointments. For those who need to adapt their environment, eg widening doorways so that wheelchairs can get through, building downstairs toilet and bathroom facilities or a bedroom, installing a stairlift, installing ramps outside so they can get in and out of the home in a wheelchair, replacing unsuitable flooring, buying a specially adapted car which can take a person in a wheelchair, buying a motorised wheelchair if there is insufficient strength in their arms to wheel themselves manually, buying grab rails so they can get on and off the toilet, insalling a hoist so they can get on and off the bed or buying a specially adapted bed where other aids are inappropriate, there will be major costs involved. Each person's case is individual and the corresponding costs will all be different.</p> <p>*4. : The current DLA is not difficult to understand. The greater flexibility provided by having 3 rates allows for greater accuracy and the most appropriate level of benefit to be assessed. In the entire spectrum of disability the greater the number of levels to ensure the most appropriate benefit the better.</p> <p>*Having only 2 levels of benefit would reduce the fairness of the benefit as people would end up being categorised under very broad categories which would not be capable of taking their individual requirements into account. I can't see such a system being capable of being fair.</p> <p>*5. : All health conditions induce a wide spectrum of symptoms in their victims so I do not believe there should be automatic entitlement to benefit.</p> <p>*6. : Being mobile within your home environment is a priority. In order to ensure disabled people can be independent requires a combination of assistance with personal care and mobility eg financial assistance with maintaining a motorised wheelchair so the individual can get to the toilet when required.</p> <p>*7. : The system of GPs providing certificates on a regular basis while the medical condition is fluctuating appears to be a fair way of monitoring the individual's disability. If/when the disability becomes permanent this would obviously no longer be required.</p>

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		<p>*8. : In assessing a person's ability any aids they use, such as walking sticks or a wheelchair, should be taken into account. It should not be part of the assessment to consider any aids or adaptations that the assessor believes could be used as this is not a decision the assessor is entitled to make. It would only be capable of being made by suitably qualified professionals in conjunction with the disabled person in a separate appointment.</p> <p>*9. Your response:</p> <p>*10. : Health professionals dealing with the claimant, headed by the GP, would provide the most appropriate data.</p> <p>*11. Your response: It is important that the healthcare professional is an expert in the medical condition which the claimant has. Obviously if the claimant is unable to travel to or access the location then offering to visit them at their home must be an option made available to them.</p> <p>*12. Your response:</p> <p>13. Your response:</p> <p>14. Your response:</p> <p>15. Your response:</p> <p>*16. : I have an NHS manual wheelchair but all other (very expensive) adaptations have been privately funded. The Personal Independence Payment should be as flexible as possible to ensure it meets peoples' needs.</p> <p>*17. Your response:</p> <p>18. Your response:</p> <p>19. Your response:</p> <p>20. Your response:</p> <p>*21. Your response:</p> <p>*22. : The priority is to protect the most vulnerable in the disabled community, one obvious group being those living in residential care homes. They are likely to have no family supporting them physically through providing transport or financially so they need help to meet their need for independence and dignity. I believe that making DLA a means-tested benefit would ensure that it is only paid to those who really need it, in the same way as Incapacity Benefit is adjusted for other income. Benefits should be paid to those who need them and the replacement for DLA should not be a general 'compensation' payment for being disabled.</p>
EM635	16/02/2011	<p>1. Cost; accessibility of buildings including own home; lack of carers; travel; running cars or other suitable vehicle.</p> <p>*2. Eligibility to both elements – care and mobility for 16-64 year olds; continuation over State Pension Age for those already receiving DLA</p> <p>*3. Travel - inability to use public transport; petrol; paying carers;</p> <p>*4. It might do – but which rate of care will you drop; how will people transfer if on the “dropped rate”? Some people receiving care component will no longer be eligible for this component;</p> <p>*5. Generally no – contradicts the idea of personal assessment</p>

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		<p>(but in the New Blue Badge scheme, automatic eligibility for some people contradicts the premise of based on needs!)</p> <p>Terminally ill should get automatically – regardless of whether cancer or other condition. However if there are to be automatic entitlements the list of conditions will be very long – and not as the very few conditions now. Who will make the decision?</p> <p>*6. Help to be able to get out of bed in the morning/back to bed in the evening and activities during the day at times the claimant wants – not when carers arrive/leave; eg help with toileting, washing and dressing; help with shopping and cooking; washing up; keeping home environment hygienic; help to go out (though this often depends on accessibility of one’s home, and the intransigence of local authorities and Disabled Facilities Grants resulting in folk becoming prisoners in their own home); overcoming actual/potential isolation; ability to get out of home to socialise as those without a disability can; travel – often too far away from local bus even if it is meant to be accessible. Ability to transfer DLA mobility component into Motability vehicle; access to a suitable car/vehicle .For those of working age suitable jobs and being able to get to them/home again.</p> <p>*7. Stop having preconceived ideas as to how the individual is affected; listen to the individual; acknowledge apart from a few who (like MPs and their expenses) claim fraudulently, claimants are genuine and deserve to be treated as so. (We don’t want to have a health condition or disability which stops us being as the non-disabled.) Ensuring the assessor is familiar with the condition, or each when there is more than one illness/condition; no assessor can be an expert in every illness/disability so selecting who will assess is very important. Ensuring those assessing are properly trained, and totally independent.</p> <p>*8. Common sense needs to be applied here; some aids and adaptations may help an individual – but what happens when there is breakdown eg a wheelchair, or a prosthesis cannot be used when eg infection or change in the limb stump; the assistance dog is unable to “work” or a person is no longer able to use crutches or walking stick because of change/deterioration in upper limb is detrimental.</p> <p>*Should you go along the road of taking into account eg prosthetic limbs then everyone should be able to have the highly sophisticated ones the armed forces have. Similarly wheelchairs should be better than the basic heavy models many are restricted to.</p> <p>*Are you really going to insist assistance dogs must be used by all visually impaired, hearing impaired, mobility impaired? Even if the animals were available some will not want one. This analogy can be applied across the board – so again the decision should be based on individual needs, and their concerns etc.</p>

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		<p>*Using stick(s) or crutch(es) can be detrimental to some – as medics or physiotherapists have advised some not to use them – yet this is poorly understood. This can apply across the board.</p> <p>*9. Get rid of the idea everyone is out to swindle the government. Once an application has been successful, for whichever component and/or rate, future applications should start from the point “what has changed” rather than each renewal being treated as a new application. Avoid duplication in questions and answers. After a number of years when an award has been made, accept the ward should be for life. Perhaps ask individuals to report changes both positive and negative, as and when the claimant considers appropriate – and stop this haranguing of individuals.</p> <p>*What the benefit is called doesn’t really matter; it is how it is explained/ marketed/ publicised that does. *10. Your response:*The individual. When someone has had a condition, illness or disability for many years, it is probable they do not see a consultant, therapist, or even their GP regularly – as the condition(s) is/are stable. Requesting evidence from professionals can be inappropriate; also professionals change jobs, retire – so an individual may not have anyone they are currently consulting. A partner or friend is often better placed to provide supporting evidence.</p> <p>*11. It takes time to build up a rapport in a face-to-face situation – and it is common when meeting new people for an individual to be suspicious, made to feel even more nervous than they are already. The “discussion” must be long enough for full understanding – and must not be based on a tick box form by the professional.</p> <p>*Circumstances eg physical and mental health problems can be inappropriate.</p> <p>*12. As stated above – must be individually determined. But of course the initial application must be dealt with properly and assessors realise some conditions will not change eg congenital and genetic conditions, so review is unnecessary. If someone is undergoing lengthy treatment it is reasonable to review at the end.</p> <p>*13. You could ask for a form/letter to be signed saying condition has not changed annually. But again for some conditions this is unnecessary. Again stop the threatening tone of letters etc to claimants. Most are extremely genuine.</p> <p>*14. Examples of what will qualify for an award; easy to read information and accessibility in other formats. Emphasise it is a benefit based on an individual’s need – and not a particular condition.</p> <p>*15. No comment as unclear what’s being asked!</p> <p>*16. Some use DLA; some rely on charities; some rely on benefactors or fundraising. No-one should be prevented from meeting a one-off cost and so if they wish to use PIP for that</p>

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		<p>then they should be allowed to.</p> <p>*17. Children's conditions affect them differently in different environments; as they grow and develop their condition can change either way. Almost without exception children who will have DLA/PIP will be under the care of a paediatrician who, along with other professionals is excellent at directing parents towards sources of help.</p> <p>*Sadly some parents, as adult claimants, are out for all they can get, or hear of someone else getting DLA so they apply. Some charities "help" with applications – so these are relatively standard and not really individualised; software should be used to audit this.</p> <p>*18. Not very. Don't know how such passporting would work – other than with Motability.</p> <p>*19. Increases in costs; isolation</p> <p>*20. Unsure other than it would make sense to link with out-of-work benefits, hence cutting beaurocracy..</p> <p>*21. Obsession with reducing costs could impact on the Disabled both negatively and disproportionately.</p> <p>*22. The report is based on the premise the number claiming is increasing and so the cost increases. It implies all claimants are fraudsters. People are living longer because of better medical care. Infants who in the past would have died are living; treatment of conditions is increasing longevity and hence number of claimants is increasing. Life is hard with a long term condition, disability or illness; DLA plays a small part in alleviating restrictions claimants have; PIP should do likewise.</p> <p>*The concept of removing mobility component from people in residential care will almost without exception keep them there, rather than being able to get out and socialise.</p> <p>*The question of children in residential care is more difficult; to qualify for such care there is already stated needs and these are paid for by local authorities, and usually at vast cost. Residential facilities need to have the ability to take their residents out – could the fees not cover this? Where children are away from home for short periods, eg term-time and/or respite care, they and their families should be able to be paid PIP for the time they are at home. Some will need specially adapted vehicles, and how these are paid for without giving up the mobility component to Motability will depend on the wealth of the family – quite wrong. Yet again are the majority about to be penalised because some parents/carers keep DLA and use it not for the person for whom the award is made, but themselves (I have come across this particularly re adults away from home.) This idea (ie no PIP for those in residential care) needs properly considered and should remain unchanged until a workable scheme is agreed, if ever.</p> <p>*Office based beaurocrats have no perception of how hard life is for those eligible for DLA – tick box forms merely strengthens this view. Claimants should be able to live an independent life</p>

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		<p>without worrying every two or three years at DLA/PIP review times if their benefit will continue or stop, when their condition is stable. The Equality Act 2010 must be taken notice of. *Please stop hitting the less fortunate and provide PIP to all who need it – and not based on a fixed cost to the government. This is just an arbitrary figure anyway.</p>
EM636	16/02/2011	<p>1. Mainly cost and attitude. False newspaper reporting on doctored statistics creates a negative attitude in society. Unrealistic expectations of politicians towards business accepting disability in the workplace. Politicians not understanding living with a disability and trying to decide what happens to them and how their lives should be without actually stopping to ask. Employers and educators not making adjustments as required and legal action too long and expensive and risky to do anything about it. *2. Everything. I do not believe that anything should change about DLA. *3. Living costs, heating & electricity costs, travel costs. Costs for help with everyday things like cooking, shopping, cleaning. Medication costs add up. *4. Depends on the number of components. The standard system of Care and Mobility works well and there is nothing confusing about the low, middle and high rates already in place. Adding more to this could become confusing and taking rates away could mean less suitable support. *5. I think lifelong incurable and disabling conditions should mean automatic entitlement. Why for example put someone who suffers schizophrenia or aspergers/autism through the added stress of a medical when they already have to attend doctors appointments to gather the same information regularly. These people need support and understanding not tick box situations designed to intimidate and bring on fear. *6. Nothing I say here will make any difference to the outcome. Support should of course be prioritised on a needs basis but I don't believe the current system designed to assess needs or priority is fit for purpose. *7. Listen to the regular medical practitioners who work with the client, understand the conditions and listen to the people themselves. It seems current assessment systems do none of the above. It needs to be a more personalised approach and more professional respect given to the people who work with clients on a daily basis rather than a one off interview with a person behind a computer. *8. This question only accounts for physical disability. *9. Less beaurocracy. Lets two-ing and fro-ing for information. Ask for it all at first application and base judgements on that. Also don't lose applications and don't put emphasis on the already sick and disabled to have to gather information that they have already provided in alternative formats. *10. The disabled person and the medical teams dealing with</p>

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		<p>the disabled person are the best placed to provide assessment and development of ability. They understand the conditions and the personal effect it has on each individual. You cannot put people neatly into computer defined boxes.</p> <p>*11. This doesn't take into account many of the difficulties faced by disabled people. For example someone having agoraphobia or severe social anxiety or worse someone with a communication development disorder like autism may not feel comfortable with a face to face with a complete stranger. Probing peoples most intimate thoughts and feelings, especially where mental ill health is concerned can be more damaging than helpful if not done by a professional in a caring environment.</p> <p>*In home meetings should be a last resort and only with the consent of the client. Intrusion into someones private living space by a team such as Atos would be like a violation of their private life. If someone is too ill too attend a medical then perhaps listening to their GP or consultant is a better idea.</p> <p>*12. In cases of short term conditions, a review should be relative to the longevity of the condition. There is plenty of medical evidence and academic research to point to the longevity of a condition. In terms of incurable and lifelong conditions, reviews should remain much the same as they are now.</p> <p>*13. Many current DLA claimants do not have notable changes in circumstances and for those with terminal conditions or lifelong incurable conditions there is unlikely to be a change. It is both patronising and unnecessary to demand reports in change where there is unlikely to be a change. A proper understanding of conditions can point to a likliehood of change over time and the individual circumstances of each person taken into account for example through contact with GPs but only with the agreement of the claimant and never behind their back.</p> <p>*14. Your response:</p> <p>*15. There should be no requirement of access – it should be a choice available but not enforced. This is a patronising suggestion.</p> <p>*16. Many do so through DLA and other local authority / government schemes. There are rarely one off costs as things often need maintenance, upgrading, repair and replacement. Enabling someone to access PIP for large cost items is a good idea as long as it does not disadvantage them in other areas and doesn't remove funding from other sources to do so.</p> <p>*17. Your response:</p> <p>*18. DLA makes a huge difference to accessing services and entitlements and I do not believe this should change, however given the lack of access to DLA for some claimants and the liklihood of many more being taken off DLA due to imminent changes, I feel that it could become detrimental to those who</p>

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		<p>need to access services and entitlements the most.</p> <p>*I also do not believe there should be a passporting arrangement as this sounds like it could lead to misuse of personal information in a similar way to ID cards etc.</p> <p>*19. I do not understand why the current system of providing proof of receipt of benefit to access provisions is not enough. I do not believe that there needs to be a passport system that could too easily be abused. *20. If assessments were left to the medical practitioners who dealt with the client on a day to day basis, there would be no need to combine assessments for benefits. They provide the necessary information and the DWP make use of the information. The ATOS system clearly does not work efficiently and drives fear into disabled people.</p> <p>*21. a hierarchy of disability. Inability to take into account personal circumstances. Not considering wider effects of disability in life. Not considering the reality of disability in life.</p> <p>*22. I fear they are dangerous, designed to remove the most vulnerable from a supportive system and purely about money saving rather than offering suitable support to those who need it most. It intimidates, discriminates and doesn't listen to the disabled voice as regardless of what is said in this consultation, it appears as if the government have already made their minds up about how this is going to work and who is deemed worthy enough to qualify. If this were more than a PR exercise the questions to the public would have been worded in such a way that all people involved in DLA from claimants to workers of support agencies would have been able to understand it. As it stands a graduate found it difficult to see what the questions were really asking and the expected answers to guided to say what the government want to hear.</p> <p>*As disability encompasses a wide intellectual span, the consultation allegedly open to the public, should have aimed for the lowest common denominator and it did not do this. It was too complex and aimed at professionals rather than laypeople.</p> <p>*It was exclusionary and if I'm honest I don't see why the government even bothered to spend money asking the public when their minds are already made up.</p> <p>*DLA is a lifeline to many. It has allowed people to stay in their own homes, it has supported people who otherwise would have found themselves living on the streets or in poverty. Some claim it's a small difference to make their life worth while.</p> <p>*The fear that runs through the disability community, the most vulnerable in society, about these changes does not reflect a fair system designed to involve everyone. I am schizophrenic. My intellect isn't impaired but my ability to live a normal life is. DLA ensures that I have kept a roof over my head, been able to pay the ever rising fuel costs and in all reality it has stopped me claiming many other things I probably would have been entitled to or forced to had I not been able to keep a roof over my head. I use DLA to pay for my housing therefore I do not claim</p>

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		<p>housing benefit. It saves the DWP around £200 a month. Should my DLA be taken away or reduced I would have no choice but to claim more benefits to support me as no employer will realistically employ me. I may look normal but things like the stresses of an official government assessment could really send me over the edge and pander to my delusions of being spied upon. This wont be taken into account at an assessment. The weeks of worrying, the potential relapses. It may be worrying for nothing according to a normal person but to me it's the thin line between sanity and not. The stress of an impending assessment is more than I could bare. My quality of life would suffer, my symptoms worsen. I may be considered then fit for work because I appear normal but what of the employers who don't want me?</p> <p>*This is not the story of some benefit scrounger, this is my and thousands of others reality. Don't belittle their lives and experiences with a small questionnaire that has no real use and wont be take into account for something that has already been decided upon.</p>
EM637	16/02/2011	<p>Not being very knowledgeable with the computer I am unable to open the questions. So for what it is worth here are</p> <p>*my feelings.</p> <p>*As far as I am concerned so long as the powers that be do not make it too complicated and do not cut the money</p> <p>*on this allowance I won't have any objections.</p> <p>*I am a disabled pensioner (79) with a 51 year old mentally handicapped son for whom I am the sole carer - the people</p> <p>*who make these changes do not live in the real world and have no idea how expensive it is to care for and to provide*a reasonable quality of life for the handicapped.</p> <p>*Unless you live with someone in my son's situation you do not realise the extra expenses caused, He spends three quarters</p> <p>*of an hour under the shower which uses lots of electricity and water. How many people in a two person household can</p> <p>*go through four toilet rolls during the course of a day. To help me he makes tea, warms the teapot with half a kettle of water and then realises that he will have to boil another kettle full to make the tea drinkable. I put fruit in a bowl, clementines, bananas, apples and pears and he eats them like sweets. I am not able to watch his every move when he is at home and is not attending the Day Centre - it is just not possible. I think the DLA allowance should be increased considerably, all parents and carers save the government enormous amounts of money by caring for their unfortunate offspring all their lives.</p> <p>*Mr Cameron had a disabled child who sadly died - Mr Cameron and his wife had sufficient money to employ a number</p> <p>*of people to take the pressure off them and could give the child a decent quality of life.</p> <p>*Those are my feelings - at times very angry with the world - but I wouldn't give up on my son EVER!!!!</p>

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EM638	16/02/2011	<p>1. Attitude and misunderstanding of general public and employers. People get judged unfairly based on prejudice, misinformation and fear. Employers being money driven and finding sneaky ways around the DDA.</p> <p>*2. Prospective test, special rules.</p> <p>*3. Travel, home adaptations, having to reduce hours at work to remain in employment, prescription charges.</p> <p>*4. Better idea, the 'main meal test' was rather archaic.</p> <p>*5. People are all so different and very few conditions produce 'text book' signs and symptoms. Everyone should be assessed as an individual. Special consideration should be allowed for fluctuating conditions, such as multiple sclerosis.</p> <p>*6. Promote and support independence. Mobility – indoors, especially bathroom (shower / bath / toilet), outdoors physically and need for a companion. Hygiene, washing and dressing, eating and drinking. Very important to try to help people gain or maintain employment, and to have social life, holiday breaks. Not popular with the masses I guess, but vital.</p> <p>* 7. Improved flexibility of descriptors to take fluctuations into account. Focused training.</p> <p>*8. Any aid or adaptation that can improve function should be taken into account. If people could use aids and adaptations but choose not to the fact that they could should be taken into account. Maybe if aid / adaptation is not available on NHS a one off payment / interest free loan could be available if the person not eligible for benefit.</p> <p>* 9. Maybe have telephone / internet / face to face support should people require help filling form in. If higher proportion of people are to be examined, the form could be reduced. Maybe make the form simpler, and have secondary focused forms specific to the condition / functional loss.</p> <p>* 10. Physio, OT, CPN, psychologist, speech therapist, MacMillan Nurse, District nurses – all spend more time with patient than GP or specialist doctors so probably could give more valuable information.</p> <p>* 11.: Much better way of assessing people as individuals. Some people should be exempted from face to face assessment; terminally ill, inpatients, anyone having 24 hour professional care, severe mental, physical and learning disabilities, recent major surgery.</p> <p>*12.: Common sense with review times. Fractures may heal, an amputated leg will not regrow! CVA / brain injuries review after 2 years, if functional loss still there statistically likely to remain.</p> <p>*13.: Maybe a simple form / online report every 6 months that those in receipt have to complete about changes to need so that they continue getting payments. Annoying for genuine folk (but if very simple should be OK), and hopefully cut down people not reporting significant improvements.</p> <p>*14.: I would be happy to get and provide my own supporting</p>

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		<p>medical evidence as I know sometimes HCPs don't have time to reply to your requests. Putting the onus on claimant to provide supporting evidence shouldn't be difficult to most people as they have the documentation already, and may save the DWP time and money.</p> <p>*15.: More available support would be wonderful, but should be a recommendation rather than mandatory. It would be distressing to some if it was seen as punitive.</p> <p>*16.: It seems to be a bit hit and miss as to what you can have done free and what you self fund. A one off payment would be really useful for aids and adaptations, or getting the aid / adaptation free or at low cost rather than getting the money.</p> <p>*17.: I think the examining HCP should be experienced in assessing adults first then undergo further specialist training before they assess children. Best in the child's home, nursery or school environment rather than clinic.</p> <p>* 18.: A better, more cohesive and seamless system between DWP, local authorities, schools etc could cut down form filling and help every get help regardless of where they live.</p> <p>*19.: More time and stress for people, and more potential for people to miss out on vital help.</p> <p>*20.: Someone who is entitled to ESA, DLA, industrial injuries / war benefits, blue badge etc often end up having to fill in multiple forms and attend up to three separate examinations. Waste of time and energy, very stressful. Also, massive waste of tax payers money. A streamlined central system would save time, money and complaints. Reduce stress massively.</p> <p>* 21. Your response:</p> <p>*22. Your response:</p>
EM639	16/02/2011	<p>1. 1. Attitudes to disability , lack of motivation to make reasonable adjustments. Most people do not know what it is like to be disabled – they may understand what it is like to sit in a wheelchair but do not and cannot understand the emotional pressure on a young child growing up knowing that he will never walk but yet hoping that some day it may happen.</p> <p>*2. Transport remains a constant problem – we have to adapt what we are planning to do because I cannot carry a 12 year old and his wheelchair up the stairs at my nearest tube station or at central London stations. Visiting the theatre, is possible due to staff and ticket concessions but often we cannot get there because of the tube station lack of access.</p> <p>*3. People do not understand and make allowances for the extra time that everything takes</p> <p>*– transport – if we take the bus it takes so much longer than getting the tube. Only 1 wheelchair user is allowed on the bus, so if the space is taken we cannot get on. If there are buggies in the space, there is no obligation for them to be moved for a wheelchair user. I have been told by bus drivers that they cannot ask people to move buggies so I had to talk to the buggy owners. If my son wanted to go out on the bus with a</p>

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		<p>friend who was a wheelchair user , they would have to travel on separate buses – not much of a trip with friend! - Getting ready to go out, going to the lavatory, eating, drinking everything takes longer and puts stress and strain on family life</p> <p>*2 Your response: My son has cerebral palsy – he cannot walk or stand but is an articulate 12 year old. He has some learning difficulties but can read and attends a mainstream school . It is highly unlikely that he will be able to live independently as he has difficulties understanding money and has anxiety difficulties about his vulnerability as a wheelchair user, especially with regard to fire/ burglars at night. He knows a great deal about London Transport and his idea of a great day out is to plan a trip using as many different types of public transport as he can. He loves going out, seeing people and doing things. Many of the places we visit would not be possible without our car. I would like to see him settled in a residential setting before I die so that he is not, at that time, faced with losing me and having to move (both recognised as traumatic episodes in one's life). I am faced with the option of either seeing him safely in a home where he would be left with no means to go out (either to work or for leisure purposes) or waiting for others to arrange his residential placement after I die. The removal of DLA mobility allowance for those in residential settings, condemns the residents to a life sitting in front of the television , takes away the option of spontaneously making a decision to go out and takes away any independence which we and the school have been nurturing since he was born. There are not vehicles for residents to use as and when they wish. My son's life is as valuable as a non-disabled person and he should be allowed to go out as and when he wishes, with or without 2 weeks planning and having to save money for a month to pay a taxi fare.</p> <p>*3. 1. All equipment costs 2. Travel 3. Paying for the help to do every day tasks</p> <p>*4. Making the rates and the components easy to understand and fairly and equitably administered is important</p> <p>*5. Yes there should be some automatic entitlement or an easier way of ascertaining whether someone's condition has improved/ deteriorated. Every so often I have to fill in forms – each time saying what my son cannot do – the forms are lengthy, time consuming and take some of my time away from my son. It is also emotionally draining. He cannot walk and stand and will never be able to do so.</p> <p>*6. Having a life is important – for each individual this will differ but if we are a caring society we must allow disabled adults and children to have fun and enjoy their lives – whether that means working, having a family life or being part of the wider society.</p> <p>*7. The long term effects need to be considered. There will be days when we all feel more motivated, fitter, energised than others but it is the average of how we feel that determines what</p>

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		<p>activities we engage in. Claimants must not feel afraid that if they admit to having "better days" then allowances will be taken off them which mean that the "bad days" are intolerable.</p> <p>*8. :If my son has his mobility allowance taken away from him because he has a wheelchair, it will mean that his world shrinks to the area within which he can be pushed or push himself. See above (question 4) for comments about transport</p> <p>*9. :Involve disabled people and parents of disabled children in designing the form</p> <p>*10. : See above There are several possibilities but I am running out of time to answer this consultation as my son will return form school soon and I do not have time to answer in full.</p> <p>*11. It would depend on the training and attitude of the professional – some are empathetic, others consider all claimants as "trying to get more than they are entitled to".</p> <p>*12. Yes different types of review for different claimants e.g, children, those with deteriorating conditions.</p> <p>*13. Your response:</p> <p>14 Your response:</p> <p>15. Your response:</p> <p>*16. We spend a lot of time trying to get equipment e.g. wheelchairs. We have been waiting since November (it's now February) to get a cushion for a wheelchair which offers no support because it is worn out. Meanwhile my son has to sit in this all day and is expected to learn!</p> <p>*It's often left to us to fund equipment ourselves.</p> <p>*17 : Parents of disabled children are tired – often working, trying to do all the programmes and have some kind of family life. I wouldn't have believed how difficult this all is before we had our son. 12 years on, I am so exhausted that I may have to stop working in order to prolong the length of time I can lift, carry and support him. Make it easy for them- often schools can tell you in 1 sentence whether a child had made significant improvement – most children don't make that sort of improvement.</p> <p>*Schools already hold Annual Reviews for pupils who have a Statement</p> <p>*18. Yes by making it automatic and not having to apply for everything separately – e.g. blue badge, taxi card etc</p> <p>*19. Your response: More time/ effort needed by those who already support/ are giving of their time and energy.</p> <p>*20. Your response: For children Annual reviews in schools should be sufficient.</p> <p>*21. Your response:</p> <p>*22. Your response: Please consider carefully the life of disabled people and the future lives of those disabled children who are growing up. What would we like them to be able to look forward to? I am constantly having to tell my son what he will not be able to do – it would be great to be able to tell him what he will be able to do and for him to be able look forward</p>

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		positively and with excitement
EM640	16/02/2011	<p>Hope this isn't too late! I think you said the dead-line was extended to 18th Feb due to problems with your web-site.</p> <p>*1. Many problems and barriers, but poverty is one of them!</p> <p>*2. The overall amount my son receives should stay the same but increase with inflation.</p> <p>*3. My son lives in a house of his own with 24/7 support. He has a severe learning disability and is unable to work. He is reliant on benefits. The following makes up his expenditure:</p> <ul style="list-style-type: none"> *• Contribution to his Care Package - £88 per week • House contents insurance • Gas • Electric *• Water • Phone • Petrol • Food, toiletries, household & cleaning items • Activities – he cannot attend day services – he has an individualised programme of weekly activities, e.g. swimming, horse-riding. • Clothes • Shoes • Holidays – if he goes on holiday he does not only have to pay for the accommodation – he has to pay for the extra staff hours needed as well. *• Contingencies <p>*At the moment his income is only slightly higher than his expenditure meaning he has a little surplus to pay for contingencies. If his income goes down and his expenditure remains the same or increases he will go into debt.</p> <p>*4. : It would not make any difference to our son unless he was re-assessed and moved from the Higher to the Lower rate of either Care or Mobility. His Mobility all goes on a Motability car which is absolutely vital for him. He is unable to use public transport (due to his challenging behaviour) and taxis are too expensive.</p> <p>*5. : People like my son (who is never going to get better, and sadly gets worse as the years go by) who have been granted DLA for life, should automatically be granted the new benefit.</p> <p>*6. : To have a full and active life my son all the items listed in his expenditure list above are essential.</p> <p>*7. : Not applicable to my son therefore will not comment.</p> <p>*8. : Not applicable to my son therefore will not comment.</p> <p>*9. : It is a long time since I filled in a form for my son, but I do remember it was very lengthy, so it would be better if it was shorter. Simple, well-written information can easily be put in places where people can access it, both in paper form and on the internet.</p> <p>*10. : Supporting evidence (if needed) should come from someone who knows the applicant well, so in my son's case that would be, for example, his Senior Support Worker or his service manager</p> <p>*11. An important part of the new process is likely to be a face-to-face discussion with a healthcare Your response: None. My son is unable to communicate.</p> <p>*12. : See answer to 5 above. My son should not need a review</p>

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		<p>– he should be entitled to the benefit for life.</p> <p>*13. : I don't think my son will have any change in his circumstances. However, you should make it clear on the documentation</p> <p>*14. : People like David who are unable to apply for benefits themselves need an advocate who knows them well to assist them. This could be a family member, friend or a paid advocate.</p> <p>*15. : You should make sure information gets to people – for example to parents/carers groups, ethnic minority groups, voluntary and statutory providers of services to gypsies, homeless people etc.</p> <p>*16. Your response: Does not apply to my son. However, he does have to buy anything that helps with his care and support. So, for example, he needs pictures for his communication system. He needs a decent camera and video camera. He needs a mobile phone etc.</p> <p>*17. : I don't think there are many differences. My son had all the same needs when he was younger. He got to 9 years of age before I found out that we could apply for the Mobility component of DLA and get a Motability car!! Nobody told us!</p> <p>*18. : More information could be given out with the claim pack – see above example. Also, there should be no need to duplicate information when applying for benefit. My son has had the same name and NI number and disabilities all his life, but goodness knows how many forms I've put them on!!!!</p> <p>*19. : They probably would not get them!</p> <p>*20. : See answer to 18 above.*21. : Don't know and not sure where page 28 is! I've been working on this for about 30 minutes and I need to go and make tea!!!</p> <p>*22. : Yes. There are many vulnerable people like my son who must not be forgotten by the new Government! David Cameron's personal experience should tell him that Health and Social Care benefits and services are essential and should not be cut!!</p>
EM641	16/02/2011	<p>1. Access, having the right information, having the right help at the right time, lack of money, extra expenses caused by nature of disability.</p> <p>*2. It should not be made any more difficult to apply for this benefit than it is now.</p> <p>*3. Heating, power, costs of everyday items if the disabled person has no choice where to purchase from, transport costs, whether own car or taxi etc. Medical items, specialised equipment, i.e. braille for a visually impaired person. Extra things to keep someone occupied if they are unable to go out much.</p> <p>*4. Having the two rates for care will probably mean that some people will end up worse off. Is two rates enough to differentiate between people and their disabilities when the types of disabilities people have are so varied, even someone with a similar disability to another person could need different</p>

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		<p>help. It could be that one disabled person with less needs will end up getting the same amount of money as someone who is more disabled and has more needs.</p> <p>*5. Yes, if someone has a specific condition/impairment then they should be able to just tick a box on the form and not have to go through loads of questions, especially when their claim is renewed. However, just because someone might have one specific condition that would allow the 'ticking of a box' it must also be allowed for that this person could also have other conditions which also need to be taken into consideration.</p> <p>*6. Being able to have help with personal care, being able to feel part of a community, being able to have some sort of social activity. It is also better if disabled people who need carers to go into their homes, if they can have the same person as much as possible.</p> <p>*7. By listening to what disabled people have to say and what they want/need. Disabled people know best what they need.</p> <p>*8. Aids could be included as long as it is practical for them to be used re ability, and whether the person wants to use the aids.</p> <p>*9. The claim form could have less questions, especially if a tick box option is allowed for certain conditions as per question 5.</p> <p>*10. A doctor who deals with the person concerned. Also, if someone has a document to prove a condition, such as a registration document re say visual impairment.</p> <p>*11. It might be easier for the person conducting the face to face discussion to see and understand the claimant's disabilities if they actually meet them, as long as they are properly trained up and have empathy for such matters. They must be able to understand that disabled people have good and bad days, and as such can manage more maybe on a good day.</p> <p>*12. If someone has a condition that will not change then an indefinite award should be made if possible. Otherwise, three yearly reviews are ok, unless there are expected to be changes sooner than that in the person's disability.</p> <p>*13. Your response: Maybe you could send a reminder about this every year or two years. Some disabled people would not be able to think for themselves about this sort of thing and would not report any changes off their own back, and so maybe a Carer or such could be given this responsibility.</p> <p>*14. Yes it would be helpful, and it would be helpful for as much information to be given in a plain English way as possible.</p> <p>*15. Your response:</p> <p>*16. I would think that it would be up to each claimant to decide how they wanted to spend the money, and some of that decision would depend on what they felt themselves to be most important and of the most need. For example, they might need an aid which they could buy but they might feel it more important to maybe use the money for transport so they could</p>

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		<p>get out and about as opposed to being left isolated in their home. Many aids and adaptations are very expensive and are out of reach of a lot of disabled people unless they can get help with the costs.</p> <p>*17. Children obviously need someone to speak up for them as they won't understand the system, and parents views should be taken into consideration.</p> <p>*18. DLA has been quite useful to gain access to other entitlements, but sometimes only those on the higher rates can access other entitlements even though some of those on the lower rates would also benefit.</p> <p>*19. Disabled people would lose out yet again and have even more of a struggle to get on in life.</p> <p>*20. A one stop shop would be good, if someone had the DLA assessment and was then signposted to the necessary other departments without having to fill out yet another lot of forms.</p> <p>*21. Your response: 22. Your response:</p>
EM642	16/02/2011	<p>Myalgic Encephalomyelitis – Recovery Programme</p> <p>*1. The DWP and a national lack of education in respect of M.E. and its fluctuating symptoms which can be agonisingly and totally debilitating. Fear and poverty. Read on because this is very, very 'helpful' and 'constructive'. Some very good ideas here.</p> <p>*2. Direct payments are ESSENTIAL. We have the right to life.</p> <p>*3. Car < essential, car tax, insurance, 'petrol'!! Without a car, the patient with M.E. will be 'unable' to get around. It is difficult enough to make medical appointments even with a car. Alternative therapies like massage helps A LOT as the toxins drain off into the lymph glands and increases well-being DRAMATICALLY. Or provide on the NHS! Heating re muscle tension, air con. re collapse due to heat exhaustion, tumble dryer, home help would free up energy for more work but that's up to you – we can't do BOTH. Proper food (natural and toxin free). Can't run around lots of shops looking for cheap prices so have to pay more for food and possibly Internet shopping, or someone will have to do it for us. We can't work full time, accept it and work 'with it'. We have to get taxis sometimes. Chiropractor. Extra drugs we have to pay for. Travelling to meet medical appointments. These are no longer nowhere near covered and I am no longer attending the renal unit because of this.</p> <p>*Support at home should be provided – housework, shopping, washing, ironing and good meals. The patients home is their intensive care unit and the patient MUST learn to self administer high levels of tlc.</p> <p>*4. All of the money that is wasted in administration is desperately needed by the sick with resulting disabilities. If someone has a chronic illness with resulting disabilities, that is all that the DWP needs to know. Hand over the cash, stop wasting money and stop stressing the entire country. It is quite</p>

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		<p>irrelevant who needs what for what. Everyone who is debilitated is debilitated and needs to live and to survive with additional health costs. Not even a two tier system is required because 'either' someone is bed bound and in need of extra attendance, OR they are needing to get themselves out and about which may include for some, the joy of being able to work. The same money is needed by both categories. It is simply used differently, according to need. The gvmnt does not need to trouble itself with exact use and the hell that people are currently having to go through to communicate those intricate needs across. Someone is either well, or sick. End of story. The financial needs are the same, as long as they sufficiently cover needs and it is up to the gvmnt to ensure that they do. Please stop wasting money. We need it!</p> <p>*5. Automatic, if you want people to achieve full, long term recovery, they must stop everything immediately and give in to the illness completely; resting, resting, resting initially, possibly for 2 years. Then they must continue to be protected from 'all' stress as they enter a program of very slow and very gentle recovery. Pacing is everything.</p> <p>**"Countries with smaller and means-tested welfare systems tend to be higher on corruption, have lower levels of social trust, and lower levels of social well-being." European Journal of Criminology http://euc.sagepub.com/*Happiness and the welfare state</p> <p>http://www.thefreelibrary.com/Happiness+and+the+welfare+state.-a0233710897</p> <p>*All of the money that is wasted in administration is desperately needed by the sick with resulting disabilities. If someone has a chronic illness with resulting disabilities, that is all that the DWP needs to know. Hand over the cash, stop wasting money and stop stressing the entire country. It is quite irrelevant who needs what for what. Everyone who is debilitated is debilitated and needs to live and to survive with additional health costs. Not even a two tier system is required because 'either' someone is bed bound and needing extra attendance, OR they are needing to get themselves out and about which may include for some, the joy of being able to work. The same money is needed by both categories. It is simply used differently, according to need. The gvmnt does not need to trouble itself with exact use and the hell that people are currently having to go through to communicate those intricate needs across. Someone is either well, or sick. End of story. The financial needs are the same, as long as they sufficiently cover needs which is up to the gvmnt to ensure that they do. Please stop wasting money. We need it!</p> <p>*6. You invest in people who know what they are talking about and who are qualified to do this work, unlike the current crew who are crucifying the sick and disabled. Food, water, REST – everyone go away! Here is the Recovery Program which</p>

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		<p>should be introduced as soon as is possible and only when the patient says they are ready and able, one afternoon at a time, very slowly. The patient may not be able to participate in all activities and they are listed in order of priority.</p> <p>*1) One afternoon of alternative therapies with massage (preferably with reiki) meditation is also good. Yoga is good too, but it may not be possible to hold positions for long and holding positions for too long should not be encouraged.</p> <p>*2) One afternoon of exercise, which should be either swimming or cardiovascular – no pumping of weights as this increases pain.</p> <p>*3) One afternoon of study (to exercise the brain). If the patient wishes for two afternoons of study – i.e. one full day split into two halves, this should be allowed. It is essential that the subject interests the patient, or the effort it takes for the patient will be too great. The study must be sufficiently challenging to interest the patient and hold their interest but not too taxing for the individual. Nothing manual.</p> <p>*4) One afternoon of voluntary work to provide social interaction and raise self esteem/contribute.</p> <p>*NOTHING MORE THAN THIS FOR ABOUT FIVE YEARS and the patient must be encouraged to rest ‘completely’ between activities. Support at home should be given – housework, shopping, washing, ironing and good meals. The patient may then, possibly, at the patients discretion start to introduce two afternoons of suitable (i.e. no physically demanding) paid work, rather than vol. work and study. The afternoon of therapies and the afternoon of exercise should remain. If the patient relapses along the way, they will clearly need to ‘start again’ from square one i.e. return to total rest, though I would advise the massage and alternative therapies remain in place. The patient must be encouraged and never made to feel guilty about having to return to square one. The patient wishes to get, be and remain well.</p> <p>*7. Be educated and listen to experts. I am one.</p> <p>*8. Bedside cabinet, t.v. in bedroom if and when this can be tolerated. Rest is the greatest aid, balanced with a little exercise, as and when the patient feels they are able. Removal of all stress is another essential aid in recovery. Showers take less energy than baths. Baths are totally draining of energy for someone with M.E., though to have one now is ‘such’ a treat with essential oils and candles mmmm (I’ve converted to shower you see).</p> <p>*9. A form even remotely related to M.E. would be good. Here’s an example question for you: *Can you get yourself up, get showered, brush your teeth, get dressed, brush your hair, eat your breakfast, wash up, make your bed, put on your washing machine, go outside to the shops, shop, get yourself home and the shopping into your home, put it away, cook a meal, eat that meal and wash up all in one day? [If they laugh, no way can</p>

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		<p>they].*It is absolutely essential for someone with M.E. to take IMMEDIATE and total rest, protected from all of life's stresses for 2 years. This is the greatest investment the British tax payer can make. Even if the patient then feels well, they must still pace their recovery, or they will relapse again and they may NEVER then get the M.E. out of their system.</p> <p>*10. You should be experts in M.E. and there should be specialist, educated doctors to help you but there aren't which isn't our fault., so you should know if someone has it or not. If they have it, they need a 'good' income. Give it to them. If they are mostly IN BED, then their needs are greater, but not that much greater because everyone's life with M.E. is extremely limited and a great deal of it HAS TO be spent at rest/in bed. Stop punishing us! Be understanding. We do not like being ill! Some people with M.E. are abandoned by family and friends, unable to keep up with their expectations or they may be living in a new area, so they may not have witnesses. These people are in greater need of help, not less. Someone with M.E. needs immediate medical intervention. The G.P. should be on the ball and a support worker who is FULLY educated in M.E. should be provided immediately, to visit the patient once per week, putting into place everything that is needed to support recovery, aiming for the introduction of the recovery programme when this is possible, likely in 2 years time, but most definitely not before one year. In the meantime the patient must be encouraged to rest to a depth and intensity not known by most people. The patient may be unable to tolerate light or noise of any kind. If they can tolerate alternative therapies, in particular massage, these should be introduced as soon as is possible. Massage and relaxation are crucial in aiding recovery. M.E. pain is deep and the massage needs to be powerful and deep also. The pain of M.E. patients is not usually sensitive to touch. Therapeutic touch is well known to be exactly that.</p> <p>*11. A patient with M.E. is in great need of an advocate. The only person visiting a patient with M.E. should be an advocate. People with M.E. are unable to tolerate negativity and stress will cause health complications and relapse. Each relapse does more damage to the body and the goal of achieving full, long term recovery is kicked out of reach by every passing relapse. Relapses are to be avoided and in this way the patient is able to remain in control of their illness, rather than their illness being in control of them (refer diabetes – the same advice is given by specialists). People who are not fully and especially trained in M.E. and the care required for recovery should not be allowed anywhere near a person with M.E. as their ignorance causes great and highly distressing damage. It de-motivates and alienates the patient.</p> <p>*12. There should be no reviews. They are terrifying for someone with M.E., negative and damaging to health. The patient is doing their best to get well already. Remember that</p>

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		<p>their life is likely to be 'hell' and every moment they are able to spend 'out' of that hell is to be applauded. The patient should have an advocate who is constantly in touch with the patient. Anyone else involved also needs to be especially trained in M.E. and M.E. recovery. Some patients may 'never' be able to return to full time work and it is helpful for this to be accepted. The patient least needs feelings of guilt. Not only is guilt unhelpful in recovery, it may cause a patient with M.E. to end their life, so the situation is very serious indeed. It is against the patient's human rights to apply pressure to them to return to work full time, when they are unable to do so, due to reasons beyond their control. A patient with M.E. must not be made to feel guilty for not being able to return to work full time and it must be accepted that they may never be able to do so. Bear in mind that most of the patient's time may be taken up with essential 'self-care' too numerous to mention here and that it will be taking them hours to relax sufficiently to gain any stage 4 sleep and again the next day, to bring their body out of a state of sleep and essential rest. To hurry a patient in a morning is to cause them damaging pain.</p> <p>*13. Stop being a threat to people's health and well being. It is terrifying for them and extremely de-motivating/harmful. People with M.E. need FULL support. They are trying to get well. Their illness is painful and highly and completely debilitating. The patient with M.E. lives with the risk of relapse 24/7. Do not punish them for avoiding relapses as it is essential that they do. Be thankful that you may see them 'appearing' to be well. Congratulate them on everything they are achieving as it takes tremendous effort and support them fully in their courage. Accept that it is by smiling and laughing in the face of illness that many of us cope. Someone with M.E. will simply return to work as soon as they are able.</p> <p>*Personally my hours of work are cut by the DWP every other year, from 40 per month to 10 per month, to punish me for being ill. This is destructive behaviour by the DWP and it knocks me back down below the poverty line, which is very distressing and de-motivating. In fact I could have lost my job entirely, which is easy and I can manage so I value it. As it is, I can only regain 20 hours per month every other year now, as my employer has had to take on staff to cover me in the year I am reduced by the DWP to 10 hours per month. However, as I am under so much stress, I shall now be sticking to 10 hours per month until the situation improves and this problem area, which I have requested to be sorted out, is sorted out.*When I am working more, I am able to contribute more to my rent, council tax and medicines. I am also making physical progress on my very slow road of recovery and indeed, my self esteem is maintained. I would like my gvmnt to be working with me, rather than against me. Your call.</p> <p>*If people to do not feel safe, they are unable to make progress.</p>

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		<p>It is very unlikely that someone living alone and independently with M.E. is ever going to be able to come off benefits altogether, this is simply not realistic for someone struggling with M.E. and to expect it simply makes that prospect even less likely.*It would be in the gvmnt's interests to apply policy across the board. It would be in the gvmnt's interests to make it 'attractive' for someone to marry/live with someone with M.E. The patient and let's not forget that at any stage of recovery a person with M.E. remains a (very brave) patient, may then work part-time, whilst the other partner hopefully is working full time. The patient with M.E. still needs to retain some financial help to compensate for their shortfall in contributing towards the domestic bills and to ensure that they remain independent. Not only do others not wish to take on the burdens of someone with M.E., but they also in the current climate are unlikely to be 'able' to do so, financially. Good relationships and love, improve well-being and the gvmnt has already accepted this, so I suggest the gvmnt makes it attractive for people to marry/live with people with M.E. The illness very rarely, simply goes away and it is essential for us to be accepting and working with reality.</p> <p>*A partner would then need to accept that someone with M.E. cannot even work part time AND then be responsible for everything in the house too, such as their additional washing. It may be a good idea to give to everyone with M.E. home help for free. This in itself would make a dramatic difference in all of the areas discussed above and this in itself may make it sufficiently attractive in a very 'realistic' way for a fit and well person to engage with someone who is bearing the additional load of life with M.E. Yes, I think this is a very good idea and I can feel the empowerment already, just discussing it. This frees people with M.E. up to work and also to engage in hopefully, a solid relationship. It gives us some much needed worth. *Assign a home help to every person with M.E. This is my strong advice. This support should include shopping, washing, cleaning, ironing and please bear in mind that if one is not personally shopping for bargains, shopping will cost more. Then see how many happy, smiley people with M.E. are out and about, engaging and yes, also working!</p> <p>*It is a question of reducing physical activity to a manageable level. This is the reality we have no choice but to work with. Pressure or interference that threatens this essential management fills us with terror, due to the consequences of overdoing it 'physically' and we will only grind to more of a halt, in that fear.*It is not acceptable to keep punishing people with M.E. because as yet, no conclusive diagnostic test is available. *Perhaps the gvmnt needs to work better with G.P.s. Again, any failings the gvmnt may find or experience with some G.P.s is not the fault of the patient with M.E. I know my own G.P.s had used to be awful in respect of my M.E., so they hadn't used</p>

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		<p>to help me at all really. Therefore I worry for people in this situation who must also be protected. At no time, is scientific knowledge completely up to date. I hasten to add that I have at least one good G.P. now in respect of some knowledge and acceptance of M.E. and the help I need, which is usually that I am now allowed Prednisolone medication in emergencies.</p> <p>*Any and every relationship requires 'trust' (i.e. faith), even a business relationship. This country lacks faith.*If you increase the £amount of jobseekers allowance and make it easy for people to move in and out of work, there will no longer be a problem with people pretending to be ill. You are causing the problem and the sick and disabled are suffering as a result. It is not acceptable to lower the £benefits of the sick and disabled, one third of whom in this country were already living below the poverty line (per the EU Convention).*If you stop taking tax payers' contributions which are intended for those in need, here in the UK as our first responsibility, and you stop sending these contributions made in good faith of them reaching their intended destination, there will be absolutely and undoubtedly plenty of money to support the sick and disabled and for health and rehabilitation. Please stop punishing 'the innocent' as we are too weak and we can't take it. It's killing us, literally.</p> <p>*14. I repeat that someone with M.E. should have an advocate who is highly and thoroughly trained in the challenges and serious fluctuations of M.E. Nice Guidelines state that everyone with M.E. should see a specialist but there aren't any.</p> <p>*Everyone new to M.E. needs a huge amount of advice 'from someone who knows what they are talking about'.</p> <p>*May I just add that it is not helping people with M.E. to recover, if they are scared to go outside and scared to move, for fear of some camera mis-interpreting their temporary mobility.</p> <p>*The last thing someone with M.E. needs is to be speaking to someone not educated in M.E., or indeed someone who may think they are which is even more annoying! At the moment 'the patient' is the expert.</p> <p>*Here's a good opening statement "How can we help?"</p> <p>*15. Not take which action?</p> <p>*16. I have explained what those are for people with M.E. You are still speaking that other language that is not relevant to us.</p> <p>*17. Children can fall into the arms of loving parents and everyone helps them. Is this why more of them fully recover from M.E.? Imagine coming down with M.E. whilst 'fighting' to keep going, to keep your career, to keep the roof over your head, to keep food in the fridge? This is what does the majority of long lasting damage. Early diagnosis and immediate action to prevent the illness from establishing itself is essential.</p> <p>*18. Income support was more recognised, which is removed now, since incapacity benefit was raised a few pence, but not the threshold for entitlement to income support, as you will</p>

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		<p>know. To my knowledge I may no longer study for free and I like to study. It's good for me, in lots of ways. I also have the bother of the HC2 now, which didn't used to be the case. Well on 10 hours work per month I do. The higher hours are an even more complicated affair.</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? Already explained and my brain is tiring now.</p> <p>*20. Sorry, my brain is tired now.</p> <p>*21. Sorry, my brain is tired and I can't work this out.</p> <p>*22. Possibly, alternatively to the above, people with M.E. may be allowed Prednisolone treatment 'all of the time' (low dose maintenance). In fact to be denied it is cruel. Yes, some good treatment would indeed be nice and also some effective painkillers that one may take without too many side effects. Muscle relaxants (night times)? Speed (day times)? Anything please! It's the year 2011! Help us please, we are 'suffering' terribly 'and' we persecuted'!!*Please stop robbing, terrorising and killing innocent people and treat us with the respect our great courage deserves. Your co-operation would be greatly appreciated before there are too many hundreds of thousands of deaths. Thank you.*Once again I have done my best for the sick, for my country and for my Lord Jesus Christ. Amen. All of this work is killing me, so I do hope you are listening as my life is in fact, not worthless.*Now I shall have to rest my brain for the rest of the day and then it's back to my own Appeal [REDACTED] which is seriously damaging my health. I may in fact die of kidney failure, if I am not able to reduce meds soon, which are increased at present to be able to manage the stress without 1) having another horrific M.E. relapse and 2) having another horrific breakdown, as I have damaged kidneys already which cannot be treated due to M.E. relapses on that medication. So when I say that I am dying in the midst of all of this, that is an accurate statement.*Disabled described as 'terrified' 1:02.39+ http://www.bbc.co.uk/iplayer/episode/b00ymw0c/The_Politics_Show_Scotland_13_02_2011/*Plans to end life as 'Life not worth living' for sick with resulting disabilities*http://www.guardian.co.uk/society/2011/feb/14/disabled-facing-benefit-cuts-despair?CMP=twg_gu</p>
EM643	16/02/2011	<p>1. : Lack of appropriate funding. Constantly being reviewed and re-measured with a covert aim of reducing resources made available.</p> <p>*2. : Individuals should not get less money as a result of a replacement system.</p> <p>*3. : In many cases, support staff are needed. Many disabled people cannot drive and have to try to use public services which can be costly. A number of disabled people incur higher medical costs for services that are rarely met appropriately by</p>

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		<p>NHS.</p> <p>*4. : A reduction in the number of bands invariably leads to people losing out. Experience has shown that where other services have used banding, there is a natural inclination by the service provider to force people into the lower band.</p> <p>*5. : For obvious impairments the benefit should be an automatic entitlement. If there is any doubt then it will need to be based on needs and circumstances.</p> <p>*6. : People with disabilities should be able to lead equivalent lives to those without disabilities.</p> <p>*7. :It should be pitched at the worst case scenario for people with fluctuating conditions.</p> <p>*8. : People should be assessed as if they did not have the aids.</p> <p>*9. : Highlight which key words need to be used in order to best describe the needs of the individual.</p> <p>*10. Your response: It depends on the disability, but whoever is used they should be fully qualified and experienced in their area of experience. Impartiality is essential and such individuals should not be employed by DWP.</p> <p>*11. : This could be abusive if the disability is obvious and well recorded. If a face-to-face meeting is required then it should be on neutral grounds. Visiting the home tends to provide a bias based on the surroundings.</p> <p>*12. : There should be different types of review depending on the impairment and condition. Reassessment should not be necessary if the impairment is lifelong unless there is a deterioration and the needs increase.</p> <p>*13. : One example could be an annual self declaration of change/non change in circumstances.</p> <p>*14. : Clear advice using simple language/easy read literature backed up by a telephone help line.</p> <p>*15. : Dedicated staff at job centres and trained personnel at citizens advice bureau. Information such as posters at doctors' surgeries, pharmacies and hospitals.</p> <p>*16. : Many use own savings or rely on family or apply for complicated local government grants, or use charities. As such there should be an option for a one off payment to meet such costs.</p> <p>*17. : They are almost certainly being supported in the family home, which should not be an excuse to reduce the level of support.</p> <p>*18. : Currently DLA is very helpful in obtaining other assistance such as rail and bus passes, and companion passes. Issuing a card as evidence would be very useful.</p> <p>*19. : It would be difficult if not impossible to prove a disability and people would lose essential services.</p> <p>*20. : Foresee problems with data protection and confidentiality as such a system could be easily abused and used against a disabled person.</p>

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		<p>*21. : Everybody should be consulted and treated in accordance with their vulnerability.</p> <p>*22. : The very weakest, poorest and most vulnerable in our society are feeling threatened. Mr Cameron promised to “look after people” who are vulnerable but there is little evidence of this. In fact people do not want to be “looked after” but to have what they are entitled to.</p>
EM644	16/02/2011	<p>I have only heard about this consultation today. As a blind person it is difficult for me to get such information. I do wonder why all DLA recipients were not notified of this. I would like to respond to your questionnaire:</p> <p>* 1. Lack of sight is the obvious barrier for me. Finding my around outside safely. Dealing with correspondence including bills, handling money, checking correct clothing – stains and matching. Cooking and shopping. Assistance with attending classes and other social activities. Many of the day to day activities that sighted people take for granted.</p> <p>*2. Blind people over 65 have been excluded from the High Rate Mobility Component. This is blatant age discrimination. Blindness has the same effect whether you are under 65 or over 65.</p> <p>* 3. As well paying for someone to help with the difficulties described in question one, there are also large extra costs in buying and maintaining accessible equipment. We are not on a level playing field. A member of the public can walk into a library and borrow books without cost: I have to pay a yearly subscription to access books. I have to pay for white stick whereas a wheelchair user is given a wheelchair, and a deaf person can get a hearing aid from the NHS. Also DIY and gardening, general house maintenance.</p> <p>*4. It is not possible to answer this as there is no indication of what the rates, or the components are likely to be.</p> <p>*5. It should be automatic for conditions that have an obvious recognised impairment, such as totally blind people and spinal cord injury.</p> <p>*6. The same activities are essential for everyday life for disabled people as they are for non-disabled people, only for disabled it is more difficult to undertake these activities.</p> <p>*8.</p> <p>*9. Any form has to be filled in by a sighted person. Just make it clear – no gobbledygook, and no hidden agenda.</p> <p>*10. You shouldn’t need supporting evidence for people with obvious medical conditions. The disabled person is best placed to provide information on their difficulties.</p> <p>*11. Health care professionals DO NOT understand what it is like to live with a visual impairment, or any other impairment for that matter. Disabled people have far too long suffered from the so called “expertise” of health care professionals. This would be a retrograde step.</p> <p>*12. There should be no reviews necessary for those with a</p>

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		<p>condition which cannot improve.</p> <p>*13. This question does not apply for blind people.</p> <p>*14. Answered in Question 9.</p> <p>*15. Disabled people need to be informed more widely of the benefits that are around. It should not be a requirement to access advice and support.</p> <p>*16. Usually equipment for blind people is not covered by a one off cost. The equipment has to be maintained and updated, as well as running costs.</p> <p>*18. The criterion for different benefits is not the same, therefore information cannot be shared.</p>
EM645	16/02/2011	<p>Dear Sir Please find our response to the DLA reform consultation. Yours faithfully</p> <p>*1. Clearly – the response to this will depend on the nature of the disability being suffered. However, a unifying feature is that there physical and institutional barriers that need to be overcome. Some of these require investment in specific equipment or facilities to allow a disabled person to lead full and active lives. Here, the need is for flexibility and the ability to change and adapt to the person’s changing needs. Thankfully attitudinal barriers to support the need to give disabled people more support are less now than they were, but these have the potential to re-emerge as budgets shrink and the pressure to support the (non-disabled) masses at the expense of the (disabled) few grows.</p> <p>*2. The DLA is literally a lifeline for disabled people. While there is clearly the capacity to make it simpler and cheaper to operate, we fully support the retention of the PIP and the continued focus on flexibility and providing ‘what disabled people need’. Within this must remain the capacity for disabled people to retain their mobility even when living in full time residential care. Just because disabled people are living together in groups does not mean that they should lose their independence. This means that they must continue to have their own access to transport as an when they need it in order to support this independence. While we agree that there may be some capacity to reduce the cost of the mobility element of the DLA for those people living in groups, the over-riding priority when assessing need is that the person can still access independent travel when they as an individual and not be dependent on the group. This is no different to groups of non-disabled people living together.</p> <p>*3. There can be no single or simple answer to this question. The range of costs spans the need for extra medical equipment, carer support, help with transport, communication aids, etc, etc. The other issue is that these needs will change with time, making flexibility of support essential. The most important thing for a disabled person is to have access to funding which can be spent to meet whatever additional costs they suffer in trying to lead a ‘normal’, independent, active life.</p>

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		<p>'Mobility' is a key element of this. In our experience failing to provide what is actually needed actually leads to higher long-term costs for government (national or local). A key example here is the tipping point where younger disabled people have to go into long term care for want of extra (and far lower cost) support in the home.</p> <p>*4. Anything to simplify the current system will be welcome. The main potential problem of having two separate elements of the scheme are that in many cases it is not possible to separate daily living and mobility as there are often intimately entwined (services to support daily living are often remote needing 'mobility' to access them).</p> <p>*The problem with any 'tiered' system is that people close to the notional interface between the two levels are either disadvantaged or over-rewarded, with neither situation ideal.*Why have either of these barriers? The current Self Directed Support system allows a disabled adult's exact needs to be identified and funded. That way the disabled person gets just what they need and government spends only the right amount of money to provide that support. It is also likely to lead to a simpler system to administer. This could be extended to all disabled people of all ages.</p> <p>*5. It is hard to see why all claims should not be based on needs and circumstances. This is because even if all health conditions and impairments within the same description are the same (which they very rarely are), the other circumstances that the person finds themselves in will never be the same. So – the best outcome for all concerns is to support what is needed and no more, with the capacity for this to change with changing future circumstances.</p> <p>*6. The idea of an outside person (in a government department) making life changing decisions about how to support a disabled person based on (usually) a rapid, process driven approach is abhorrent. Even the idea of judging what is meant by a 'full and active life' is subjective. For instance a young person born able bodied and then who go on to lose a limb is likely to have a different view on what is meant by a full and active life compared with someone who has been disabled since birth. The answer here must be to use the Self Directed Support type of assessment to look at the circumstances of the persons disability, what that means to them, their lives and those who care for them and to take into consideration the views of the disabled person themselves where possible. The job of government then is not one of prioritisation of who and what to support, but one of moderation of carefully considered 'support plans' to ensure 'fairness' and value for money.</p> <p>*7. This is easily achieved by allowing the disabled person to make new applications for support when their needs change and on the other side of the coin by requiring some kind of statement of need to be completed to ensure that the allocated</p>

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		<p>funds are achieving the desired outcomes. The key here must be to move towards a situation which is not 'them and us' between disabled people and government, but where there is a partnership of trust. Government will provide what is needed to support the disabled person and the disabled person therefore only asks for funding for what they need. But this may take some time to achieve!</p> <p>*8. Why would government not take aids and adaptations into account when assessing a disabled person's ability? The real issue here is that there are additional costs and other needs associated with using the aids and adaptations and these do need to be considered.</p> <p>*9. We suggest that the process of applying for Self Directed Support becomes a model. This involves support from a named individual, focuses on real needs, accentuates positive attributes, takes a forward look and the individual disabled person is physically part of the process.</p> <p>*This approach will combine the proposed PIP interview and medical and would support the idea of entirely flexible support provision based only on need, which must also offer cost savings compared to the proposed 'banding' of support.</p> <p>*10. This depends on the individual, their circumstances and their medical condition. Again, the need for flexibility is paramount and in our view fits well with the application of a modified Self Directed Care application approach.</p> <p>*11. We feel that face to face discussion is an essential part of this process. However, this should be at the end of the application process when the required supporting information has been gathered. We have experience of this process through a Self Directed Support application and found it to be useful. This meeting must occur in the disabled person's home and be of sufficient duration to make it meaningful.*This approach will support the ultimate goal of 'joining up' all of the benefits packages on offer.</p> <p>*12. For people with a life-long disability reviews every 3 years or so feels appropriate. For those with short term disabilities these need to be at shorter frequencies as dictated by the condition.</p> <p>*The nature of the review also will be dictated to a large extent by the disability. Those with learning disabilities need to have their needs assessed to make sure that they are fit for purpose and delivering value for money. For those with short term conditions the issues are the same but the duration of support needs to be considered in addition.</p> <p>*13. This is a difficult area and comes from an approach which in the past was almost adversarial. In addition a system based on 'banding' of benefits will always promote secrecy for fear of losing money. What needs to happen now is a process to deliver trust on both sides. The disabled person needs to trust the government to supply what they need in order to allow them</p>

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		<p>to take a full and active part in society. Government needs to trust the disabled person to only ask for what they need. The approach used in the Self Directed Support programme goes a long way to achieving this. By having a complete, inclusive and fair assessment process at the outset and a constructive programme of review based on need, the outcome is more likely to deliver what is needed and no more – saving money compared with the traditional approach.</p> <p>*14. Getting the assessment process right is essential for all parties. Again, the Self Directed Support model is helpful here as the process is based on a rich supply of information, input from a wide range of ‘stakeholders’ in the disabled person’s future and on focus around need. The cost of providing this will be more than offset by savings made in ‘over providing’ support from a flawed assessment/communication process.</p> <p>*15. The key here is to ensure that the disabled person is being supported by a trusted professional. A GP or Social Worker may fulfil that role, and potentially teachers in the case of children. By empowering these professionals to lead the application and take a key role in the assessment, there is more likelihood of uptake by those who need support but who are daunted by the process or even victims of past problems in undertaking complicated DLA assessment. What must be avoided at all costs is a ‘stranger’ becoming involved at key stages in this process, especially if they are seen as ‘an Official’. This is a particular problem for those people with learning difficulties or mental health issues.</p> <p>*16. Our experience is that disabled people have spent their own money getting better quality aids and adaptations to allow them to access work and ‘normal’ activities.</p> <p>*The availability of aids and adaptations make access to employment, mainstream services, etc more feasible and therefore investing in supplying high quality equipment represents good value for money. As such, this area must be included in the PIP, as must the notion of providing more than just a ‘one off’ cost as in many cases this equipment may depreciate necessitating future replacement.</p> <p>*17. Here the key is to assess the value of early intervention. It is our personal experience that investing heavily in early intervention can reap massive cost savings over the life of the individual. In our case, our son benefitted from a rich signing environment in a nursery environment at the age of 2. This was backed up with the supply of augmentative communication aids over the following years which led to him acquiring speech at the age of 12. His Uncle (who has the same genetic condition) did not have this early intervention, failed to acquire speech leading to communication related behavioural issues and ultimate sectioning, with massive residential care costs as a result.</p> <p>*The other issue with a child is the need for support to be</p>

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		<p>flexible and regularly reviewed for relevance, with a low threshold for providing what is needed when it is needed. A model is that applied by HEPAC in Oxford where multidisciplinary assessment is undertaken and a 'whole child' support package identified. Again, this leads to far lower whole life support costs, potentially even removing the need for life-long financial support.</p> <p>*18. Any notion that government has that the 'passporting' arrangements that are in place now under the DLA are working are sadly very wrong. It is quite simply ludicrous how many times the same information has to be supplied. To be effective, save money and prevent stress in applicants, the PIP simply has to implement effective passporting and make it work.</p> <p>*19. Non-disabled people think that disabled people automatically get the support that they need. When they find out how much work must go in to applying for the support that is needed, they are horrified – not least by the inefficiency. If the PIP cannot be the means of passporting to other services then it means continued stress for the disabled people who have to make multiple applications for the support that they need and continued erosion of budgets to pay for these inefficiencies. More importantly, by failing to 'link up' these benefits and services there is the continued worry of over and under payment and inappropriate use of services – which is simply unacceptable to everyone in society, not just disabled people.</p> <p>*20. Again, we are impressed by the approach used in the Self Directed Support assessment process, which attempts to be inclusive and to provide a 'whole person' assessment of the person, their needs, their personal situation and their aspirations. To our minds, minor modifications to this process could provide information to cover the entire spectrum of information need, especially as the outcome is to provide the flexible support package that the person needs. Indeed, by taking a needs led approach the onus can then fall on government to decide how to provide this support across the benefits and services on offer, removing the onus on the disabled person to do this, even though they are least able to make these judgements.</p> <p>*21. Any policy that tries to 'fit' equality groups to it must be wrong. We argue strongly for a policy that is based on the needs of the individual, irrespective of any of the false segregations that you list. A disabled person is a disabled person irrespective of age, gender, ethnicity, sexual orientation, etc. Their needs are also their needs. The key is to put in place a fair process to assess these needs and then to identify how they can be met. Any policy that puts this onus on the disabled person themselves must also be wrong. They are the victim of circumstance and would give anything not to be disabled. Our role as a caring society is to meet their needs as fairly as we can, without overcompensation.</p>

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		*22. No
EM646	16/02/2011	<p>1. : Places and work places not accessible for disabled people to access, whom are Wheelchair bound or are unable to walk far. Living accommodation is not always suitable for disabled people. There are not enough adult services and day care places for profound disabled adults to attend to meet their every day needs.</p> <p>*2. : It should stay the same. Except for people that are faking their disability.</p> <p>*3. : Equipment. Expensive toys to buy for disabled children. Meal time cover clothing i.e. bibs etc is expensive to buy. Holidays that are suitable to accommodate the disabled person.</p> <p>*4. : Two rates could make the benefit easier to understand so long as the rates don't go down. As long as the rates for the two components are appropriate to the person applying, are fair to their disability.</p> <p>*5. : That can depend on the severity of that's persons health and impairment. But it should not be an automatic entitlement to benefit also should be reviewed yearly. Not the three yearly assessment</p> <p>*6. : More day care centres and respite care</p> <p>*7. : Have yearly checks</p> <p>*8. : Yes aids and adaptations should be taken into account if that's the only way that person can live their lives comfortable. That can depend on that person income or savings. But saying that children easily outgrow their aids and adaptations quickly and these items are very expensive to purchase.</p> <p>*9. : By not repeating questions that have been asked on other forms and pages. People applying who are genuine disabled would be clear what it is for. To qualify should be done by a thorough assessment.</p> <p>*10. : G.P.'s Therapist whom are working with that person. Full reports issued to detect the full disability .One persons view may not be a true assessment as another so a third party should be involved</p> <p>*11. : There should be face-to-face discussion. What difficulties should this bring? I cannot see what the problem could be wherever the location.</p> <p>*12. : Depending on each individual's disability. It can depend whether the disability is from birth and for life or temporary.</p> <p>*13. : Have G.P's or Health professional's updates on their patience. Or through a work payment system. Or stop their benefits immediately</p> <p>*14. : All information is essential and explained simply in layman's language.</p> <p>*15. : Advertising would help the minority or leaflets handed out in G.P's and community centres</p> <p>*16. : Yes</p> <p>*17. : Whether the disability is from birth to life. Or only a</p>

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		<p>temporary disability.</p> <p>*18. : It has been very important.</p> <p>*19. : Devastating. As they would not be able to afford other services.</p> <p>*20. : Regular up dates</p> <p>*21. : Not sure</p> <p>*22. Your response:</p>
EM647	16/02/2011	<p>1. Mobility, needing carers or personal assistants and communication barriers. The bad attitude of many people and an inability/unwillingness to understand and accept people with disabilities as equal members of society.</p> <p>*2. The DLA fulfils the needs of my friends with disabilities just fine. The age range, non means testing, not taxable or dependant on employment status are things that should remain the same.</p> <p>*3. Hiring or maintaining accessible transport and employing a PA are two major financial factors in allowing a disabled person to integrate as a member of society. Other adaptations around the home assist a disabled person to live independently. Education is also a vital tool to gain qualifications and promote an understanding of society.</p> <p>*4. I fear the application process will be much more invasive for a disabled person and must be tackled sensitively.</p> <p>*5. I agree with the existing system that some circumstances should result in automatic benefit, perhaps with a review after a period of time. Individual applications will inevitably take too long and cause more stress, initially the benefit should be automatic for the existing conditions and impairments.</p> <p>*6. Communicating with others, essential shopping/having a say in what food/clothes are bought, getting out of the house to travel to tasks or activities that mean disabled people integrate in society. Living a full life is not cooped up in a crowded home because independent living benefits have been cut.</p> <p>*7. Liaising with the benefit recipient (and carer/PA) and medical personnel to take into account the social and medical model.</p> <p>*8. YES. Wheelchairs, hearing aids, communicators, accessible toilets and baths/showers... anything that incurs an additional cost that an able bodied person would not incur. All potential aids and adaptations should be considered to ensure dignity and a good quality of life.</p> <p>*9. The form should be available in different accessible formats and should be sensitive to invasive information. Eligibility information should be readily available from healthcare professionals, pamphlets and online.</p> <p>*10. The individual claiming benefits is central to the process, carers/Pas and healthcare professionals could also provide an insight with regards to supporting evidence. Although it is vital to remember that the disabled person is the one affected so should be consulted the most. If you need more that hospital</p>

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		<p>notes and a carers statement maybe you should follow them around for a day to see what barriers that individual comes across in day to day life. There is only so far individual assessment can be taken.</p> <p>*11. A healthcare professional should already know the aids and adaptations the individual requires. If a discussion is required, face-to-face is the best way to do it. If this discussion takes place outside the individual's home, expenses of travel, employing a PA should be reimbursed for that visit.</p> <p>*12. Yes, disability covers a large range of conditions and impairments. Without sufficient medical knowledge of a variety of disabilities I cannot recommend the frequency of reviews.</p> <p>*13. This should be encouraged through healthcare professionals. If a doctor states that a condition is improving and there is no need for aids the individual should be reminded to notify the department. With periodic reviews for some disabilities this will help to keep the department informed.</p> <p>*14. The new system should be clearly explained in simple English and a range of accessible formats.</p> <p>*15.</p> <p>*16. Through the DLA and NHS mainly. The term "disabled people" covers a wide range, some work, some do not for example. I agree with the payment for a one-off cost, however it should be noted that what appears to be a one-off cost could extend further than that depending on circumstance.</p> <p>*17. I do not know much in that area.</p> <p>*18. You must involve other departments and organisations that use the current passporting system in the changes made to make sure existing claimants do not lose those benefits.</p> <p>*19. Huge! Disabled people would spend most of their time filling out various forms and being asked invasive questions. One assessment should be sufficient to cover other benefits and services.</p> <p>*20. Shared information should be dependent on the particular service, enough information should be shared with the individual's consent to prevent having to fill out another application. However personal information should be treated in a confidential manner and should not be shared unnecessarily or without the individual's consent.</p> <p>*21. Not much data is gathered on different equality groups. I hope your policies result in equal opportunities for all.</p> <p>*22. Please remember that your proposals are there to benefit disabled people not just to try and catch fraudulent claims. Many people rely on these benefits to integrate into society; reduced funds would force many people into care homes and have a destructive impact on society. Disabled people are not second class citizens and should not be treated as such throughout the application process or review periods.</p>
EM648	16/02/2011	<p>1. Inc. Question 3 and 6</p> <p>*Your response: 1. Frequent health problems or admissions to</p>

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		<p>hospital which prevents people securing employment. It can be difficult for people who have mental health problems to restart their activities after recurring illness or breakdowns as there often residual problems that hinder a full recovery.</p> <p>*2.Lack of finances to enable people to improve their life and well-being ie: courses (some courses do not give concessions) also lack of money to travel to various activities (again in some Local Authorities a free bus pass is not available to anyone who does not receive the higher level of DLA) which is discrimination. Loss of driving licence due to illness.</p> <p>*3. Activities need to be motivational and give a sense of worth. It is important that everyone is given a chance to improve their situation and Local Authorities, CMHT's etc have a duty of care to prioritise this. Too many people are left to their own devices after hospitalisation or when recovering. There is a lack of signposting into services or entitlement, often carers have to seek them out.</p> <p>*4. Participation in daily life is complicated for people with Mental health problems and assessments should not be lumped together with people with physical illness or learning difficulties. High doses of psychiatric drugs which can impede on someone's ability to take part in everyday living.</p> <p>*2. Your response: 1. There is a need for some changes. Physical Disability and Mental Health Disability (which Learning Disability is a completely separate agenda) needs to be assessed in their three different health and impairment categories/symptoms/levels/prognosis etc. instead of the same questions asked for all. Severe Mental Health Illness ie. Schizophrenia Bi-polar Disorder should have automatic entitlement. A person with bi-polar 2 is classified as having a less form of Bi-polar but nevertheless it is still a severe mental illness and all professionals who interview for assessment should be qualified and trained to understand the complexities of this. A medical professional ie: a Psychiatrist should be on the panel or at least consulted for these conditions as they can give clear information as to how that person can function on a daily basis.</p> <p>*3. Your response: 1. This could be an area where some people who are assessed as `having the ability to carry out a range of activities key to everyday life, including some related to a broader definition of mobility` will fall out of the PIP offer. Physical disability can be seen where mental health problems often can't and these people could be discriminated against leading to them having to fund areas that contribute to their well-being.</p> <p>*4. Inc. Question 5 and 7*Your response:1 The two rates of benefit that is being introduced will be detrimental to those people who receive the middle rate (assuming that it is the middle rate that will be discontinued) It is not about simplifying and making it easier to understand (who for)? People on the</p>

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		<p>middle rate will presumably be shifted to the lower rate not the higher</p> <p>*5. Your response:6. Your response:7. Your response:</p> <p>*8. Your response: 1. All aids and adaptations that are needed by disabled people on a permanent basis should be included in the assessment of their abilities. If they need aids this means they are less able than the able bodied population. Disability can be expensive if people have to fund their own equipment when it is absolutely necessary to help them. *2. Health and social care need to be combined because this where problems arise with communication and information. I.e. Post code problems where health care is provided by one provider and social care by another in a different county.</p> <p>*9. Your response:1. There needs to be simplified forms and more information available possibly from a worker employed to help with this. One to one appointments with service users and carers to explain application procedures to reduce anxieties surrounding form filling.</p> <p>*10. Inc. Question 11 12 13 17*Your response: 1. Doctors and healthcare professionals who do not have knowledge Mental Health problems cannot possibly conduct a face to face interview with someone who is suffering from mental health problems. People who are already suffering from anxiety could find it very distressing to be questioned by someone who cannot really understand their problems. They need support from CMHT/family or advocates to help them through the assessment. Reporting of changes to could be done via GP/CMHT with persons agreement.</p> <p>*11. Your response:12. Your response:13. Your response:14. Your response:15. Your response:16. Your response:17. Your response:18. Your response:19. Your response:*20. Your response:21. Your response:22. Your response:</p>
EM649	16/02/2011	<p>1. Lack of money for equipment and maintenance of equipment. Lack of funds/resources, long waiting lists and too tight eligibility criteria for government funded equipment leading to people self funding equipment. Attitudes and lack of insight of press, public, MPs and others. Inaccessible transport, services, shops and recreational facilities. Lack of suitable housing.*Inadequately funded social service/care system/NHS.</p> <p>*2. Think it should all stay the same, the 3 care components, 2 mobility components, not taking into account wheelchairs/aids/adaptations and not withdrawing mobility allowance for those in hospital / care. With its low fraud rate it seems to be working well, but if this is still a concern make a medical assessment compulsory for new applicants.</p> <p>*3. Aids / adaptations / mobility equipment eg wheelchairs. The ongoing maintenance, repair, insurance and servicing of the above. Extra travel costs for appointments or having to travel further to find an accessible service, facility or shop.*Extra travel costs due to having to find alternatives when</p>

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		<p>the nearest or cheapest option is inaccessible such as a taxi instead of a bus. Care costs. Special diets or clothing costs. Call aid costs. Extra car costs as a bigger car maybe needed to transport a wheelchair/equipment or a car may need to be adapted.</p> <p>*4. Quite simply no. The 3 rates system recognises that the multitude of disabilities and the needs stemming from them vary greatly. Two rates will be too narrow and appropriate levels of support will not be met. The disadvantage is people with needs may not get the appropriate support and this could impinge on their independence and choice.</p> <p>*5. I don't feel I have enough medical knowledge to comment on the above properly however it seems obviously that those with terminal or severe needs should have automatic entitlement.</p> <p>*6. Make sure the support covers a wide range of activities and does not just consider one or two basic activities. Personal care. Toilet needs. Meal preparation. Feeding. Transport. Accessing medical facilities and appointments. Access to shops/services. Access to the community / socialising.</p> <p>*7. The new assessment should be based on how the applicant is when their needs are at their greatest eg their 'bad days'. A piece of equipment or support has to be available all the time even if a condition fluctuates as there is rarely notice of a 'bad day' or 'bad patch' so the extra-costs remain always present. *8. No. This is one of the most worrying parts of the proposal. Wheelchairs should NOT be included. Just because a person can mobilise in a wheelchair does not mean their mobility is then on par with an able bodied person. The wheelchair in itself is an extra cost and the ongoing maintenance, servicing, repairs and insurance incur extra costs. This is what the benefit is supposed to be there for. Plus using a wheelchair leads to extra costs for transport if the cheapest or nearest option is inaccessible. Our environment still has many inaccessible aspects to it and therefore a wheelchair user may have to travel further to access facilities, shops, jobs and services thus again incurring the extra – costs DLA is there to help with. Taking into account a wheelchair in an assessment will have a devastating affect and will negatively impact on the independence and choice of disabled people. Many other aids / adaptations also require maintenance, repairs etc such as toileting equipment, alarms. To clarify I do not think the new assessment should take into account any extra actual or possible aids or adaptations..</p> <p>*9. I do not think it can be made simpler. It needs to be thorough, if it is too basic it will not cover all the relevant needs or various disabilities. I think it is impossible to make it a positive experience, whilst focusing on the negative is hard it is ultimately the things that someone cannot do that lead to the need for DLA. A person maybe able to plan a journey, brush</p>

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		<p>their hair and clean their teeth but these are irrelevant if they can not independently have a shower or get dressed.</p> <p>*Second point – leave DLA as it is, changing it is going to cause the confusion.</p> <p>*10. The people most involved in the applicant’s care are best placed – GPs, Consultants, Physiotherapists and other relevant medical experts. Social services and carers. These people should provide the primary evidence.</p> <p>*I think an ‘independent healthcare professional’ should only be involved if they are TRULY independent eg not being target driven or rewarded by the DWP. Plus they must have experience of the disabilities and needs they are presented with such as physical needs or mental health needs not just ‘general knowledge’. I also think any independent healthcare providers should be monitored and thoroughly researched by the department and independent disability charities before being employed by the department to ensure fairness.</p> <p>*11. To clarify many current DLA recipients have already had face to face meetings/ medical assessments with a healthcare professional, this is not new. Difficulties – healthcare professional may not have sufficient knowledge of the disability and needs, a meeting is not representative of everyday life, time restraints may not cover everything and fluctuating conditions may be assessed wrongly if person has a ‘good day’ on day of meeting. Impartiality may be compromised if Healthcare professional has targets to meet or is rewarded for meeting these targets. Benefits – possibly reduce fraud HOWEVER I doubt this as the DWP statistics already show that fraud rates for DLA are very low so this is unlikely to be reduced any further. *Point two – when it is obvious from current medical notes that the disability and need is genuine (surely a waste of resources and funds having the meeting), when they have already had a medical assessment with DLA and deemed to have a long term ongoing non improving need, when someone is terminally ill or is unable to leave their home due to dialysis or severe needs etc.</p> <p>*12. Carry out reviews by checking medical notes. If someone has a long term condition that will deteriorate or not significantly improve then the reviews should be infrequent if at all. This can be easily checked by accessing someone’s medical notes...if they continue to have the same medication or treatment etc as when they applied it is unlikely anything has changed.*It seems pointless to regularly review someone whose needs and disability are not going to significantly improve. If someone has just a one off problem that could get better then review them. It could be a waste of public money to keep reviewing people with non-curable long- term health conditions.</p> <p>*13. Judging by the low fraud rate I am guessing that it is only a minority that do not keep the Department informed and changing DLA to PIP isn’t going to alter this. It is already clear</p>

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		<p>in DLA information and letters that changes need to be reported, if someone decides not to report something changing the benefit is unlikely to change the attitude. I do not feel there is a problem with understanding DLA.</p> <p>*14. I think advice and information should be available at all times regardless of whether it is DLA or PIP. It should be sent out automatically but not be a replacement for the benefit just an added extra.</p> <p>*15. If it is a minority of claimants who don't take action then making it a requirement for everyone seems unfair. Plus the advice and support needs to be adequately funded. Many people use their DLA to access the support.*Need to avoid people being 'palmed off' with 'advice' and unattainable support instead of getting the benefit they need to cover extra costs. Plus who decides what advice and support is appropriate to whom? Will the person making this decision be properly trained?</p> <p>*16. Many disabled people self fund their aids / adaptations due to long waiting list, too limiting eligibility criteria, lack of funds, resources and suitable choice for government funded aids / adaptations. This is not going to improve with current cut backs. Unfortunately a one off cost won't cover the ongoing maintenance, repairs, servicing and insurance of the aids and adaptations that many people rely on their DLA for. It also won't cover other extra costs mentioned earlier such as extra expense finding accessible transport, services etc. This will not work and leave people struggling to cover the cost of the upkeep of their aids and adaptations.</p> <p>*17. Consider needs of whole family, stress on parents / care givers.</p> <p>*18. DLA is VITAL in getting access to the entitlements. Blue Badge Scheme is imperative for independence and being able to get to services and facilities. Motability provides access to vehicles (ones big enough to transport wheelchairs or adapted to meet the users' needs) and wheelchairs / scooters that mean disabled people can be independent and lead active lives. If being able to access this is lost it will have a devastating impact and will affect people being able to get to work, accessing the community, shop, go to hospital appointments etc. Think maintaining these passports should be a priority...according to the above proposals a wheelchair user may lose their mobility allowance which in turn means they'd lose access to Motability and not have a car. This does not promote independence or allow the disabled person to live an active life!</p> <p>*19. 1. The impact would be extremely negative and devastating. It would decrease independence, mobility, choice and being able to lead an active life. People would miss out on benefits and services they're entitled to. Poverty amongst the disabled could increase and employment decrease. It would also be extremely stressful and confusing if disabled people</p>

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		<p>had to keep being assessed and applying for different benefits and services instead of DLA passporting to services like Motability, Blue Badge Scheme, benefits etc. DLA as it stands has a thorough assessment which is why it can be used as a passport to other services and benefits. This should be respected and maintained.</p> <p>*It would also contradict the claim of the proposals that PIP could make things simpler by combining assessments and "minimise bureaucracy and duplication" if disabled people had to have separate assessments for all the current passport benefits.</p> <p>*20. Could share care plans from Social Services and Care providers as long as permission is sought from service user. Although I think this should be alongside GP medical reports not instead of.</p> <p>*As DLA is not an out of work benefit and the proposed PIP won't be I do not think it is appropriate to include the ESA assessment as this is assessing different needs and is relevant to employment.</p> <p>*21. Think it will have a negative impact on people with disabilities. I think people with a current genuine need as identified by DLA will lose out despite still having the same need.</p> <p>*I think it will have a negative impact on people on working age and due to the proposed stricter criteria the inevitable withdrawal of the benefit from some people despite their continuing need will impact this age group and even decrease employment.</p> <p>*22. I think it is inappropriate to use the unstatistically proven suggestion that DLA is a 'barrier to work' as one of the justifications for overhauling the benefit as</p> <p>*a) There are no statistics for the number of DLA recipients in employment</p> <p>*b) DLA and the proposed PIP are NOT out of work benefits so not only is it irrelevant it is also extremely misleading to the general public.</p> <p>*c) Has anyone considered the negative impact removing this benefit may have on accessing employment *I do not think the authors of the proposals have a proper insight into the costs of aids and adaptations and the ongoing costs and how hard it is to get government funded aids/adaptations.</p> <p>*I think the reforms and public consultation have been poorly advertised in the public domain.</p> <p>*I do not think enough charities were involved in the development of the proposals and reforms.</p> <p>*I think reassessing people currently on DLA who have already had medical assessments and been deemed to have a long term health condition that will deteriorate or not significantly improve will be a waste of public money and contradicts the government's suggestion that DLA needs changing as it is</p>

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		<p>unsustainable.</p> <p>*I feel MPs do not have a good enough grasp on what DLA is, how it is structured and what it is used for as it stands now and there for will not make an informed decision when it comes to voting for change.</p>
EM650	16/02/2011	<p>Question 1. Speaking for myself: ! Mobility and affordable transport (including available parking close to the destination) ! Fatigue ! Lack of endurance ! Pain if I push myself too far ! Slower speed ! Social attitudes have improved over the years, but there are still difficult buildings, including those that are accessible but have huge internal distances. ! Suitable employment is never as easy to find as it is for the able-bodied, and in times of high unemployment things are even more difficult. ! Disabled toilets could do with a re-think, and possibly modification of the Building Regulations ! For some, access to carers at a time when needed can be a problem. ! Getting timely (or any) provision of equipment and housing modifications, (especially at times of financial stringency - not just in the current financial crisis, but because allocated budgets rarely seem to last the financial year). ! Health Service provision of things like wheelchairs, surgical footwear and orthotics is in the <input type="checkbox"/>Cinderella<input type="checkbox"/> category, and can be a constant source of irritation for those who need these items to keep themselves on the road. You need a quality, reliable device, and a working spare. ! For some, the need for frequent help with medications, regular procedures (eg ! catheters, chest clearance, oxygen etc is inhibiting.</p> <p>*Question 2. There are those of us who wonder if the provision of DLA should not stay the same for some groups. Alcoholism and drug addiction seem to be classified as mental disorders, thus being treated as other disabilities. However, our strong suspicion is that being on these disability benefits is just feeding the addiction by increasing the individual's ability to purchase the drug of choice. This is the nature of addiction. We very strongly suspect the benefits are not being used for care, support or treatment. Is this how our taxes should be spent? Possibly this requires a re-think. If payments are to be made to this group of people, maybe they should not get into the hands of the claimant, but go into a hypothecated fund to go towards paying the costs of treatment?</p> <p>*Question 3. This is very variable, depending on the type of disability, severity of disability, and the needs and priorities of the individual. They could include:- ! Heating ! Transport ! Domestic and DIY help for things the able-bodied would do for themselves ! Special diet ! Heavy wear of clothing and footwear ! Extra laundry (eg from incontinence) ! Escort/helper for outings. (You may take a friend, and pay their costs.) ! Suitable housing, if you purchase your own. Something that can be made level ! access, and has sufficient internal space for equipment is not at the cheaper end of ! the market.</p>

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		<p>*Question 4. People tend to learn whatever system is available. It is a very big jump from mildly impaired needing a degree of daytime assistance or supervision only (lower rate), to very severely disabled, needing a great deal of day and night attention with most functions. Mild, moderate and severe would give more discrimination between levels of disability.</p> <p>*Question 5. This might be an area requiring research to find out the facts. Certain severe and permanent disabilities may be found to consistently qualify after assessment. Keeping statistics on the outcomes of cases as they come through would build up an information database.</p> <p>*Question 6. People need more than just being kept clean, warm, washed, fed and toileted to lead any quality of life. They need exercise, a purpose in life, and social interaction with people other than just carers. This will mean the opportunity to participate in educational, social and recreational activities, outings and holidays. This is particularly so for younger severely disabled people, who are likely to have few financial resources of their own Disability Living Allowance Reform (because they have never been able to work), but may have many years of life ahead. All people, and older people in particular, will deteriorate mentally and physically if their life does not include sufficient physical and social activity. Deterioration will, in turn, increase the need for support. Support at the level of warehousing (alone at home, or in residential care) is harmful. Those with the greatest difficulty in participating in the community are likely to be those who have the greatest mobility problems:- those who cannot drive and lack a willing friend/relative able to act as chauffeur at the times required, cannot use/lack access to public transport, need specialist transport, need the help of an escort.</p> <p>*Question 7. The assessor needs better medical information. In my case, with over 60 years of a neuromuscular disorder, I cannot remember being assessed in relation to my disability by any GP. They do not have detailed knowledge of any but (possibly) the most common disabling conditions because they are not consultants in these various fields. They lack the training, time and resources to do an assessment in relation to any particular disability. I found that when they do have to look at, say, a painful knee, the tentative way they touch you (if they touch you at all) says it all - they are not confident. They are therefore unable to give good certification. (My GP of the time phoned me up to ask me how my condition affected me, in order to fill in the medical part of the assessment!) Orthopaedic surgeons and neurologists wish to examine you in relation to the referring letter, and then give a diagnosis and/or prescribe specific treatment/surgery. The people who can do a holistic examination, including functional assessment, are those consultants in rehabilitation medicine who have a specialist interest in orthopaedic/neurological/neuromuscular disorders (in</p>

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		<p>my case). They can also look at management of the condition in order to improve long-term well-being and function. Their assessment would provide good quality information. In my part of the country, this service does not seem to be available. I find the medical profession in general, are not good at assessing those things that do not have a lab test, scan or X-Ray to confirm diagnosis. These are the things that bother many of us a great deal - pain, fatigue and lack of endurance, and I think these are closely related to the fluctuations in many neurological conditions. We can identify some things that make these symptoms more likely - stress, viral infections, overdoing things, illness, accidents and surgery, but sometimes there seems to be no very obvious cause. There is presumably something going on. I certainly feel very different within myself on good and bad days. The current state of medical knowledge has not identified what is going on. I do not know how you can assess it objectively. Doctors' eyes tend to glaze over if you ask about these matters.</p> <p>*Question 8. Independence in your own domestic environment with all your equipment is one thing, although the time taken for tasks will be longer than for the able-bodied. Can you function out of the house? Small assistive items that can be put in a pocket are one thing, but away from your trolley, special chair, hoist, Clos-o-Mat, or whatever, you may need assistance from another. Are you completely incapacitated if your electrical or mechanical equipment (eg a hoist) breaks down? I have reached a time in my life when I am willing to use equipment if it reduces stress and strain on joints that are beginning to suffer from wear and tear, or if my life is made easier using the gadget, even if I could, if pushed to it, manage without. I may not be the norm, but I feel this may be an important approach to take to maintain function for as long as possible. Some professional crips are knowledgeable about aids and adaptations, but may not be aware of all that is currently available, myself included, and I used to work in the field! There are many considerations - the individual; the environment in which the equipment is to be used; can the equipment be used safely by this person, and does the individual know how to do so; the interaction with orthotic devices, mobility equipment and travel needs; availability of back-up and servicing in the locality? Good professional advice is needed for a great many purchases, except for minor things like long-handled shoehorns. Giving in to the sales patter at an exhibition, or buying from the small ads in the back of a magazine can be an expensive mistake, and, at best, the individual can end up with something that is not the ideal thing for them.</p> <p>*The newly disabled are often ignorant of the equipment and services available. With early hospital discharge they may be somewhat left to their own devices. As mentioned above, this is an area in which GPs are not trained, or the knowledge they</p>

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		<p>picked up as they went along may be so partial that it is unhelpful. Some people may need specific physiotherapy to improve function, and need to be taught alternative methods of doing some activities of daily living, before the provision of equipment etc is considered. These people certainly need assessment and advice in the first instance, and it would be useful if the DLA*assessment could trigger a referral for this to the appropriate rehabilitation facility. (A disabled friend of mine used to work on the Appeals Tribunals, and found some applicants for benefits appeared to be a failure of access to rehabilitation in the first instance. They were claiming never to have seen a therapist and inability to do things that we have done independently for decades, in spite of our having a more profound level of disability.)</p> <p>*Question 9. With a multiplicity of conditions, physical, mental and learning in any combination, it is difficult to design an application form to capture all the information needed in one simple form. In spite of this, the <input type="checkbox"/>bush lawyers<input type="checkbox"/> who are <input type="checkbox"/>at it<input type="checkbox"/> learn what to say to qualify themselves for the benefit, while those who are really struggling to be independent and are*possibly in a degree of denial about their difficulties will understate their problems. I have never been certain about self-certification because people may overstate or understate their situation (although a personal statement about how your disability affects your life would be mandatory), and note what I have said above about GP<input type="checkbox"/>s. I have been equally*uncertain about the current and past methods of assessment. A brief examination does not evaluate all the difficulties of functioning with my particular condition (and those like it), and can give a misleading picture to those without detailed specialist knowledge – and that is something the assessor will not have. Applicants should be strongly advised to seek advice and support in making a claim, and get help with filling in that form from someone who has some expertise, such as a welfare*rights worker (if there are any left in the community after all the cut-backs!). This will ensure the form is properly filled in and includes all the relevant information, and thus save it from ping-ponging backwards and forwards as the Department tries to clarify the information it needs. Information about the benefit needs to be widely disseminated through the media, disability charities and clubs, and all health and social service professionals who deal with disability. Carers need to be targeted and emphasis made on reaching those with recent disability who do not know the system.</p> <p>*Question 10. In an ideal world a person disabled enough to apply for this benefit should be known to services other than the GP. Disability is not merely something that just is. It should be properly assessed, medically and functionally, so that a management plan for living as healthy and productive a life as possible can be set up, and this re-assessed at intervals,*as</p>

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		<p>age, progression of the condition and intercurrent problems enter the picture. Unfortunately, this is frequently not the case, and I suspect most people do not have current assessment, if they have had one at all. (See Question 7) I do not know what to suggest.</p> <p>*Question 11. Being in a person's home can tell you a lot about their environment and how they cope in it. However, different professionals have different skill sets:- ! Medical assessment – doctor ! Mobility - physiotherapist! ! Functional assessment - O.T. with experience in physical medicine ! Mental health - C.P.N. & O.T.'s with mental health experience! ! Learning disability - ? Unless you are going to do more than talk to the person and listen to what they say they can do, the visit will take time, as the applicant demonstrates the various elements of their problems. Bringing the applicant into a multi-disciplinary unit would miss out on the domestic information, but make holistic assessment more practical, although it may be so taxing for some applicants that more than one day is required. This might identify those who are "at it" as it is difficult to act a disability while under observation for a lengthy period of time. A minority of households are not places for a worker to visit unaccompanied. Some persons have very unpleasant friends and relatives, people in the household may be unpredictable because of drugs or alcohol, and there are those aggressive dogs... Can such households be identified? On the other hand, the applicant is vulnerable, and should be strongly encouraged to have someone with them in the house to act as support and advocate. This is absolutely essential if there are communication problems, memory problems, learning disabilities,*and some mental health problems. An advocate, carer who knows the person well, welfare rights worker, relative or friend would do, but preferably be one of the first three.</p> <p>*Question 12. This would have to be set individually for each person. Some conditions may have a possibility of improvement with medical advances, surgery etc. Some people may deteriorate because of illness, surgery unrelated to the main condition, or injury. The loss of a caring parent/partner may alter the picture entirely - they have frequently been giving more assistance and support than was realised. The wear and tear of using the body abnormally over years will slowly result in greater disability, even in a condition that is relatively stable. People with the same diagnosis of a progressive condition will have a*different rate of deterioration, as happens with MS.</p> <p>*Question 13. People do not trust the assessment system currently in place, and have been somewhat afraid to approach it again, lest they end up worse off for it. I have spoken to people afraid for this reason to ask for an increase in their benefit because of deterioration in their condition. Many people cannot contact the Department because of the nature of their impairment. Some will forget or not be aware that they should</p>

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		<p>do so. It may be more realistic to set a shorter review period if a change for better or worse can be anticipated in the shorter term.</p> <p>*Question 14. They need to know, in plain language, what the benefit is, who qualifies, what the process of application and assessment is, what the duties and responsibilities of the claimant and Department are.</p> <p>*Question 15. Those who are reluctant to take action may have many reasons, eg:- ! Difficulty with communicating and interacting with □the system□ ! Uncertainty about what to do ! Fear of what will happen ! Denial of the extent of their difficulties ! Just not getting around to it because of fatigue or depression The key to such people is probably the encouragement and support of any community workers they have contact with, who should be urged to be pro-active, but this may not be a topic that readily comes to the top of their minds. Everyone should have contact with a GP surgery, but again, this will not be a priority matter for them.</p> <p>*Question 16. The cynic in me says that this is another ruse by the Coalition Government to reduce the benefits available to vulnerable people. Most disabled people I know depend on the Health Service/local authority. These bodies have the benefit of trained staff to assess what is required and teach how to use equipment properly. Some people can get help from disability charities (some acting on behalf of the local authority), but these are now struggling for funds as a result of the recession. In attracting funds from the public, charities vary in how appealing their cause is to the potential donors, ie the public, therefore their ability to fund the work of their cause varies. Preferably you should be very well-heeled if you wish to be disabled and acquire all you need, but in fact lower than average income is the norm. Apart from Motability, I am not happy about using DLA for equipment and adaptations. The application process seems to measure the need for care, supervision, and help with*mobility. If payments are used for purchasing equipment, does the person not need the level of assistance they were assessed as needing, or are they doing without the help they need in order to get the equipment? That would be equivalent to a cut in the benefit required. On the other hand, I would be distressed if we go back to the days of seeing articles in the evening paper reporting how the Lions (or whoever) did fundraising to provide essential equipment for some individual - often an attractive disabled child. The non-photogenic, and those with the less publicly attractive conditions would have more*difficulty accessing such charity funds. People with some disposable income do choose to purchase things for themselves. It is very important to get help, eg from an Disabled Living Centre, who will give objective, informed advice before a vulnerable person parts with what can be a lot of money. Without advice it is so easy to purchase</p>

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		<p>something that turns out to be unsatisfactory in use. If you live away from the main centres, it is more difficult to access assessment and advice. This sector of the population often uses the internet to shop, and the impulse would be to buy an item on spec. through the internet, and hope for the best. Purchasing the smaller assistive devices can be a problem, although these are the small gadgets than a majority will use. I am told that the bigger firms in the market are not really interested, as the profit margin is small, and to stock a good range (which is essential to meet differing needs) requires storage space and staff time. Lower costs and higher profits drive the market, and they really wish to sell you complicated beds, mobility scooters, bath hoists etc. The consequence is that access to the useful smaller items is often by mail order or the internet. You really need to handle equipment and try it out, to ensure that the version you purchase will suit your needs. How do you know if the gadget advertised in the insert in your magazine is any good at all? (I don't.)</p> <p>*Question 17. A faster rate of change, for better or worse, as the child grows older. Most disabled children will be well-monitored by the paediatric services. The parents and siblings are very much part of the picture. Adolescence can be a difficult period in terms of behaviour, and the child is getting very heavy to lift and handle, if this is required. Mobility may alter as the child gets heavier. When the child grows up it enters the adult medical services, which provide much less ongoing*support. When statutory educational provision ceases, the parents may find they get much less support in the form of the child going out of the home daily (often with special transport provided).</p> <p>*Question 18. The benefits system is too complicated, but as long as politicians have the urge to keep fiddling with it, it will always be thus. There is also passporting to other non-benefit services, eg. entitlement to Blue Badges, help with home insulation. Our local leisure centres give discounted charges, which encourages disabled people to use them.</p> <p>*Question 19. More people would probably miss out on benefits to which they are entitled, because of the complications of negotiating the benefits maze. The amount of welfare rights work would increase, and this has a cost. However, knowing that electronic information is not as secure as we would wish, there is concern about personal information going astray in transmission.</p> <p>*Question 20. This would need to be thought through in detail. The emphasis of assessments for different purposes will differ, and may well include involvement with other people, both within and without the family eg assessment for respite care, housing modifications, need for social contacts. The situation will differ for each of the devolved administrations in the U.K.</p> <p>*Question 21. I cannot see that there should be any impact in theory. There may be different cultural attitudes to disability,</p>

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		which would effect what is expected of disabled people within the culture concerned.
EM651	16/02/2011	<p>Please see my responses to your DLA consultation:*1. The biggest barrier that we have experienced has been a lack of support from the NHS, which resulted for an extremely long time, in a lack of benefits, and a lack of support from a multitude of other agencies. After nearly 15 years of pursuing the NHS/Social Security etc etc relentlessly for support for my disabled husband, he has now been diagnosed with an acquired brain injury and adult ADHD (among other secondary problems). He is now 35, out of work (no specialist provision available to help him back to work), and likely to cost the NHS and DSS/DWP a lot of money. He could have been a productive member of society with the right support (he still could actually, but we are still struggling to obtain appropriate treatment and support). The NHS may have some experts working within it, but people's ability to get support should not be dependent on such chronically underfunded, limited services, otherwise what is a gap in NHS services, results in people being completely marginalised, and completely explains why such individuals end up on the streets or in prison. *It would work much better if the DWP was able to request health assessments and/or treatment in order to maximise the patient's functioning.*As a senior health service manager, partly responsible for monitoring GP performance, I was extremely shocked and horrified to discover a GP who had been "retired" as a result of extremely poor performance, turning up to assess my husband for disability living allowance. Something needs to be done to ensure the standard of practice of the GP's doing these assessments. *The claiming process and procedure needs to be more accessible to people with mental health problems and intellectual or cognitive disabilities. At the moment, it is far too complex, and is only accessible to those patients who have had enough ability or informal support to convince mental health services that they deserve treatment.</p> <p>*2. The use of the benefit to allow the claimant to receive other forms of support and assistance should remain the same.*I agree that there should be an assessment of each claimant's abilities and disabilities, but I don't agree that it needs to be independent. It would be more helpful if the NHS was required to support the claiming procedures, and then if the DLA assessment board/tribunal felt there were specific things which could increase the individual's level of functioning they could make those recommendations to the coordinating healthcare professional and in turn, the amount of DLA payable could well decrease. I have heard many, many anecdotes of patient's who have been assessed by an "independent" practitioner, but who's level of functioning has been either over or under estimated.</p> <p>*I also don't agree that General Practitioner's are the best</p>

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		<p>people to assess patient's level of functioning. I have a background in Occupational Therapy, but as I explained, I work with GP's now. GP's are exactly that - general practitioners. They are not specialists in assessing and improving level of function in self care, work or leisure activities. A comprehensive assessment should involve a whole multidisciplinary team. Again, link the whole process to the NHS, and the infrastructure (allbeit underfunded), is already there.</p> <p>*I also agree that there should be periodic reviews of claimants awards, where there is a possibility of the condition or the individual's level of function improving. My husband, however, is still subject to periodic reviews, despite the fact that his acquired brain injury, and his adult ADHD will now be lifelong. There is no rehab, no support etc.</p> <p>*3. Transport costs. Health costs. Support costs. If there is no recognition, and no support for an individual's condition, then they will just have to foot the bill to pay for whatever it is that they can't do for themselves. I had to pay for full time childcare for nearly three years because it was not safe for me to leave my daughter with my husband... and because he was at home, we were not eligible for tax credits... until I proved how disabled he was. I became insolvent before I had managed that. Because of the lack of recognition, he was also not entitled to any other benefits... not even incapacity benefit, because he left it too long between his last job and putting in a claim... he was far too ill to do it during that period.</p> <p>*My husband now compulsively over eats as a result of his brain injury, and feels most aggrieved that alcoholics get extra payments for their addiction while he goes without other things which he needs.</p> <p>*4. I'm not sure how helpful this will be. What claimants need to understand, is how to claim, and how to provide the right evidence for their claim, and how to appeal. I don't think there is any actual disadvantage from having a payment structure which might have more than two rates, which might be more sensitive to the needs of the claimants.</p> <p>*5. All claims should be based on the needs and circumstances of the individual applying. See my comments about linking in with NHS.</p> <p>*6. In an Occupational Therapy setting, the tasks which we would focus on would be 1) making a cup of tea 2) preparing a meal 3) going to the toilet 4) getting in and out of bed or a chair 5) shopping 6) bathing 7) Getting dressed and undressed 8) Walking 9) Sleeping 10) Eating (not in that order). Beyond the hospital setting, we would look at whether the individual is able to participate in social, occupational, recreational and self care activities. An individual has to be able to achieve a balance of all of these activities in order to live a full and active life. If you need to be absolutely prescriptive about the stated activity, then perhaps you could look at whether the patient would be able to</p>

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		<p>go out for a meal, for a social activity.... and whether the patient is able to participate in their previous, or any occupation.</p> <p>*7. You could allow claimants to detail what they are like on a good day, and what they are like on a bad day, and what the split between good and bad would look like as a percentage or a score out of ten. Many claimants have said to me that they feel as though they are lying when they complete the form, because they would prefer to provide a balanced viewpoint.</p> <p>*8. I am not sure what you mean in your paragraph about aids and adaptations. Some aids and adaptations can be extremely enabling, and it would be extremely beneficial for claimants to be able to be assessed and prescribed such adaptations as a requirement of the claiming process. However, many people will not have been able to access such assessments or support. My husband has never been assessed, so he uses a baby's buggy to get about (fortunately he's married to a qualified Occupational Therapist).</p> <p>*It would be helpful if there was a focus on exactly what the individual is going to use the money for.... in some cases this may not be appropriate, but as with many other benefits, it would be much more helpful if the DLA was being paid in order to promote that claimants independence, and to enable them to contribute to society (most genuinely disabled people want to find some way to do that in my experience).</p> <p>*9. It would be much easier to claim, and much easier and more reliably assessed if it was all done in partnership with the NHS.</p> <p>*10. See my comments above. It needs to be a multi-disciplinary team, because General Practitioners do not have the necessary expertise to provide the whole assessment.</p> <p>*11. This is probably the best alternative for the reasons I have outlined above. It must still be recognised however, that the NHS doesn't always get it right, and they have been telling my husband to "pull his socks up" for most of his 35 years... we now have brain scans to prove they were wrong, which we had to pay for privately! There needs to be some sort of safety net for patients who lack the medical support to obtain a second opinion etc. The NHS complaints procedure is not robust enough to ensure the success of this for the most vulnerable members of our society.</p> <p>*12. You should have recommendations from a multi-disciplinary team about how often an individual's claim should be reviewed. Reasonable adjustments should be made, in line with DDA legislation, if necessary.</p> <p>*13. The system for Personal Independence Payment will be easier for individuals to understand, so we expect people to be able to identify and report changes in their needs. However, we know that some people do not currently keep the Department informed. How can we encourage people to report changes in circumstances?</p> <p>*Again, if it was all done in partnership with the NHS, then</p>

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		<p>individuals would know that information about changes in needs was held in their medical records. I think this in itself would encourage people to keep you better informed. At the moment, you seem a bit out there.</p> <p>* 14. As I said earlier, people may need all sorts of information and advice, and a multi disciplinary team would be well placed to provide some of this and signpost to other support.</p> <p>* 15. Your response: I'm not sure what you mean, but if you mean that it would be a condition of the payment of benefit for an individual to access advice and support... I think that might work for some claimants who might be quite passive. In my husband's case however, that would probably be more of a frustration, as we have done so much hoop-jumping with so little effect... and a lot of the advice and support which has been offered has been too generalised to be helpful to our situation. I imagine we are not alone.</p> <p>*16. The majority of disabled people fund their aids and adaptations privately, if they are not supplied by health or social care services. I think there should be an option to use PIP to meet a one off cost, as many claimants may not be able to access finance etc.</p> <p>* 17. I am not able to answer that.</p> <p>* 18. There is not enough information available about these passporting arrangements. It's very hit and miss whether you find out about them, and arrangements are often very local, so it would be great to have a central database that would encourage service providers etc to advertise their arrangements.*It would be helpful to have a credit card size passport as the DLA award letter tends to get a bit dog eared.</p> <p>*19. There would be no evidence of disability, other than perhaps a blue badge. It would cause some difficulties for service providers in terms of ensuring it was actually disabled people accessing their disabled services.</p> <p>*20. Under the data protection act, you could legitimately request permission from the claimant for access to specific parts of their medical record, according to individual requirements. The systems could be seamless in the same way that many health services are now able to share information and be seamless.</p> <p>* 21. There are variations in how different groups access healthcare and/or services. I think linking DLA to health and social care could have extremely beneficial effects for some in that they would be encouraged/signposted to appropriate services and support as part of the claiming process. Some groups who are currently not dealt with well in the health and social care sectors would be vulnerable however... including patients with mental health problems, learning difficulties, acquired brain injuries, pervasive development disorders etc... the invisible problems which often get swept under the carpet.</p> <p>* 22. It's about time... I just hope you're going to do the job</p>

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		properly and fairly. Kiersten
EM652	16/02/2011	<p>What things stop lives? Money or lack of it, society's attitudes</p> <ul style="list-style-type: none"> * What parts of keep? Both mobility and personal care * What extra things ...? The list is endless... Waterproof sheets for bed, replacements for torn and shredded clothing specialist "tough" furniture, more expensive travel insurance for pre-existing conditions. Transport if impossible to take on public transport due to challenging behaviour * The new benefit will have 2 amounts... The present middle rate seems sensible - probably should apply to mobility element as only 2 levels - some people only get lower - may need something more than this but not necessarily the higher rate. * Do you think some health conditions ...? I would have thought that many children with severe learning disabilities, severe physical disabilities and profound and multiple disabilities and terminally ill children, all of whom will clearly never be able to work might qualify. They are usually known to social services. *Adult amputees, stroke patients, spinally injured wheelchair users, brain damaged, Parkinsons. Motor Neurone disease - VERY difficult to compile definitve list and ensure that fairly administered *Or do you think that all claims should be based ...? People can have similar diagnoses but differing needs However I would have thought that, for example, that wheelchair users should automatically qualify for higher mobility (I know of one case where a child wheelchair user was turned down! * How can we make sure that ...? Disability registers of Local authorities, ensuring that parents of disabled children are told about the benefit by professionals - this is surprisingly common. * What activities or actions ...? Ability to go into community, shop, eat out, leisure activities go on holiday, get an education and a job, get around by suitable transport, affordable suitable housing - anything that non disabled peers do in fact. People have aspirations, hopes and dreams regardless of whether or not they have a disability see UN Convention on rights of disabled people The Convention establishes internationally recognised benchmarks for disabled people's rights in all areas of life, such as: the right to not be discriminated against the right to education the right to employment the right to health the right to equal justice the right to participate in culture. * How can we make sure that the new benefit ...? Where someone is caring for someone with a degenerative condition like MS or muscular dystrophy - there should be swift re-assessment. It should also be recognised that in some cases like severe autism or cerebral palsy or brain damage that has occurred at birth, there may be little or no improvement during that person's lifetime. They should perhaps have the claim looked at a couple of times up to age

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		<p>18* When a person ...? Should we only ...? The fact that they need aids and adaptations surely just underlines their disability - many adaptations don't remove the disability and require a carer to be on hand to assist eg hoists</p> <p>*How could we make the claim form easier to fill in? Make it a lot more concise - you seem to be asked to provide the same information several times possibly consider an additional version more geared to learning disability. Questions like how long does it take to get person dressed - very hard to answer - in case of autistic young man can take several hours if constantly removes clothes.....</p> <p>*How could we tell people ... likely to get the benefit? Massive publicity campaign would be needed - one that is learning disability friendly and accessible to all sections of community speakers of other languages. Outreach via carers centres, family information services NHS, social services, CABs Voluntary organisations, TV radio, press</p> <p>* Who are the best people ...? people who have seen person regularly and recently, carers, GPs Social workers etc</p> <p>* What information will we need ...? Ability to go into community, shop, eat out, leisure activities go on holiday, get an education and a job - anything that non disabled peers do in fact needs to be assessed along with support needed to attempt any of these</p> <p>* An important part of the new benefit.... What good things and bad things may this bring? Is there any time ...? Not a good idea or even possible in some cases e.g A non verbal autistic person with extreme challenging behaviour some one with profound and multiple disabilities terminally ill people</p>
EM653	16/02/2011	<p>I am a disabled lone parent and carer of a child with autism, receiving High Rate Care/Low Rate Mobility. I am currently trying to appeal for him to receive High Rate Mobility and I have no DLA myself although I am finally trying to claim. I have tried to work as well as care for my son as without tax credits we would be starving. We receive no other benefits, but with all the cuts and uncertainty I am now applying for Housing Benefit so I do not lose my house.</p> <p>*Question 1 There are various reasons why disabled people struggle to be involved in society; access is still extremely limited and takes only into account what people can 'see' as a disability, without taking into consideration that pain, mental illness, and complex chronic conditions are all just as disabling as having amputated limbs. However the biggest barrier is the most obvious one: no one asks disabled people what would help. Instead, assumptions are made – we just need to work, we just need to lose weight, we just need to stop “begging” for things and get tough about our illness. For all the studies and papers which are produced I find it rather telling that none of them are actually produced by disabled people themselves. Charities may be consulted, but it's merely taken “on board”</p>

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		<p>with the final decision coming from people who have no disabilities whatsoever.</p> <p>*The truth is that not all disabled people are slugging layabouts who pretend to have back pain in order to roll in benefits. That would be roughly equivalent to claiming that, due to what we read in the papers, all men are potential murderers and rapists and therefore all should be dealt with accordingly. I and my son would certainly love to live our lives to the full, but the constant obstructions to getting even the basic rudimentary care to do so is incredibly daunting. I am aware that perhaps the government was completely unaware how many vulnerable and disabled people there are in our society at the moment and were unprepared to support so many, but we are not an un-educated rabble, and are quite capable of speaking up and speaking out for ourselves.</p> <p>*Question 2 I have extreme reservations about DLA being solely for the “severely disabled” as there is no real indication as to what that means. Severe to whom, exactly? With my condition, it varies from day to day and I never know how bad it’s going to hit me, not to mention it is very likely I have several undiagnosed conditions which are not being treated at all. Only recently, the DLA forms have started to take into account that disability does not always equal having paralysis or amputations and I would be very distressed and angry if this now reverted to disability being solely about helping only those who are paralysed from the eyes down and everyone else has to fend for themselves. We have only just managed to get DLA to accept this sort of thing, and now it seems it’s going to be taken right back again.</p> <p>*I’m also appalled that there’s an assumption that people in care homes no longer need transportation, and that the home somehow will provide this. If the care home actually had the funds to do so, surely they’d be doing it already, but they aren’t, and no amount of forcing them to do so will help, especially if piling up requirements to cut their spending comes down the wire. Nor is it a sensible plan to assume local councils will pick up the slack and provide transport or mobility to people who have suddenly found their independence whisked out from under them. Believe it or not, but no one in these councils or care homes are going to voluntarily cut their own wages or bonuses to make sure that their patients and clients have taxi-fare. “We’re in this together” only goes so far – and therefore the mobility component needs to stay in place.</p> <p>*Question 3 I simply cannot do this question justice as there are so many factors and every disability is different. But if I were to choose two things I must say in this day and age I believe mobility aids are some of the most expensive items, and they are absolutely required for so many people. When I found my mobility getting worse, I honestly thought there would be provision for me through the NHS to get a wheelchair or a</p>

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		<p>scooter. But lo and behold, once again because I was actually able to stand for a grand total of two minutes, I am not considered in need, even though it takes me nearly a half hour and a considerable amount of pain to walk a mere 300 yards. Transportation isn't just a "get it if you can afford it" like a car, it is vitally necessary to a disabled person to be able to do the simplest of tasks, and yet this is woefully underfunded. Most scooters are more expensive even than the average car, and they are either funded by a mere handful of charities which are often overflowing as it is, or out of the pocket of a disabled person who happens to scrimp and save – many of these people who are still fighting the battle to get a higher rate of mobility funding, such as myself. This is vital, necessary equipment, and sadly, it's nigh on impossible to secure.*Another issue is food –my son and I (both of us disabled) eat very well, but this is due to me sacrificing many things so that we both eat a balanced diet (no television license as we don't watch telly, no flash mobile phones, I make my own clothes or buy second hand). I grow my own food, I shop for food I can cook from scratch (when I can cook, which is only about twice a week) and then freeze the rest. I do not buy "bargain meals" which are often full of fat, sodium and calories. This of course means that our food is more expensive and my food budget is much bigger than other families of a comparable size. However as my son is autistic and has major sensory issues when it comes to food, the little food he does eat has to be of the best quality. And, if I want to be able to care for him to the best of my ability, I have to eat healthily as well – sometimes I don't have the energy to do anything but sling a frozen meal in the oven, which I know isn't the best option, but it's better than eating toast. Again, you would think that local councils would provide hot meals for people who cannot cook, but they have not done that for years. Instead, you get a brochure featuring bland incredibly overpriced food which is delivered in frozen form. Again this is another example of a blatant assumption that services already exist for our needs, and yet they just do not. I sacrifice considerable energy in my day to provide my son with good meals and to grow a portion of our own food outside. I am well aware that others are considerably worse off and can't even begin to take such measures.</p> <p>*Question 4 I have to admit I don't understand how only having two rates for support makes anything easier to understand as I doubt the administrative process will be any easier or less of a nightmare to go through just to qualify. I do recall that the high rates consider that you need care at night (and of course, even if you DO need care at night, you have to be paralytic before anyone believes it) or that you either can walk a little or walk not at all. Honestly at the rather miniscule rate of payout that both rates tend to be I don't why we shouldn't just do one flat</p>

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		<p>rate for everyone at the high rate of scale, especially considering most of us (if not all of us) need that anyway. Again this always seems to fall into the “you’re disabled, but you don’t look that disabled to me” thinking which is such a slippery slope. If I have a diagnosis of a condition which will not go away (and most of them won’t) then that should be that. “Levels” of disability is ludicrous - most of us have to appeal these decisions as the low rate barely covers any of the most miniscule needs which just raises administrative costs even higher when we appeal.</p> <p>*Question 5 Again, this is a matter of what is actually considered a disability by people who aren’t disabled. DLA is completely independent of employability and to my mind should completely be treated as such, without taking into consideration what you can do if you’re yelled at in a Tribunal/forced into performing for an assessment/bullied into doing out of fear of losing even the mediocre low level benefits. The benefit is to help provide for needs, not to “prove” that one is disabled enough to have it, and therefore I feel that any and all diagnosed permanent conditions should be an automatic entitlement to benefit; let's face it, if someone didn't need the help and had a diagnosed condition, they wouldn't be claiming for DLA.</p> <p>*The only time I feel there should be a question of claims and payments is when the diagnosis is rather nebulous. Let's take the overused "just back pain" example. Yes, as a sufferer of fibromyalgia, my main symptom is supposed to be pain which in theory is easily dealt with by using analgesics. However, for the past year and a half I have been presenting a lot of other symptoms other than "just pain". I have a suspicion I have lupus but it has not been diagnosed. What I HAVE had however is two hospitalisations within a year and quite a few nasty symptoms which, even though they don't have a convenient name for them, do prove that I have definite issues with anaemia, pleurisy, extreme fatigue (even more than pain), swollen joints, lowered immune function, arthritic pain, rash sensitivity to light, incontinence and hypothyroidism, all of which I have discussed with my GPs and they are well aware of. Combined, those are some rather severe issues to cope with and when taken into account certainly aren't "just pain" of fibromyalgia, and I can make these notes available to the DLA and prove the issue. *</p> <p>Question 6 As far as “activities which are most essential”, I can say when I started putting together my list of things to ask my social services for, I was amazed at the suggestions from disabled people on the forum I’ve joined for advice. Things they’re receiving through social services: personal therapists for exercise and occupational therapy such as massage, trips to get hair done and to go to outings were “luxuries” to my mind. Surely, I’m just supposed to suffer stoically in a box room and</p>

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		<p>eat toast and not complain? Well at least that's what society tells me. The fact that I can actually have a proper life like anyone else almost baffled me. I am barely capable of washing my hair more than once a fortnight and have just managed to get used to it, but I was encouraged to realise that these things are this oh-so-nebulous 'quality of life' which I've gone without for so long. Socialisation and exercise are recognised as completely obvious for health and well-being and yet for many people who are disabled they are entirely out of reach. All very well to say "take a walk" if you can, but if you are like myself – an ex-bodybuilder who finds walking excruciating – trying to find alternatives is next to impossible. The pools at my local leisure centre are too cold (a recognised fact by OTs when it comes to fibro patients), if I exercise for even a half hour I am done for the day, and that means everything – cooking, cleaning, taking care of my son – has to be doled out piecemeal or just left out entirely. I am sure a lot of my symptoms would improve as well as my quality of life (and maybe even be able to hit the Oh So Important Goal of working) but right now, there's no way I can possibly do so. Making the ability to get out and about, and also creating access to more disabled friendly exercise programmes would certainly do a world of good for many of us, but this is another instance in which it seems the populace assumes these measures are there, but sadly aren't.</p> <p>*I also find it interesting that things like purchases for gardening or DIY are considered to be "luxuries" and potentially a red flag for fraudsters. Strange, considering that there are many occupational therapists which tell disabled people to garden, and indeed several charities are specifically created to get disabled people into garden for its therapeutic benefits. I just underwent a year's worth of work petitioning charities and getting assistance for a garden both accessible for me and safe for my son, and it's a delightful space, especially as we spent most of the year at home due to my deteriorating condition. Is this now considered completely pointless? Someone had best inform all the specialists and charities then!</p> <p>*Question 7 To me the answer is painfully obvious (and therefore might be why it's so utterly overlooked): either get people on the team who HAVE these conditions, or to consult with charities which deal with the conditions on a regular basis. Specialists are all well and good, but the thing about specialists is they are individuals, most of them retired; in short they are often several years out of date with their information, haven't been in a GP office in years, and at the same time already have established ideas on how a disability affects people which are completely outmoded. Individuals have individual opinions, and more often than not these opinions can be wrong (hence the 'seek a second opinion' we're all told when dealing with doctors or specialists in everyday life). When dealing with conditions such as CFS or lupus, always plan for the worst case scenario</p>

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		<p>and unless there has been a marked improvement through medical reports over the past year, do not assume people are suddenly “cured”. Lupus can go into remission (I'd be overjoyed if mine did!) but there is no warning when it does...and no warning when it comes back with a vengeance either. Again, working with a patient's own specialist will do a considerably more than getting in a privately paid stranger who has zero familiarity with a particular case painting the whole of an ailment with a broad brush. To be honest, most GPs aren't really capable of dealing with fluctuating conditions as they are able to deal with acute problems, but are less skilled or knowledgeable in dealing with the chronically ill - at that point a specialist is required, and unfortunately getting a specialist for oneself requires going through various "gatekeepers" as it is. This needs to be a much easier process.</p> <p>*Question 8 This is like saying a man with two prosthetic legs is no longer disabled. I think it's a ridiculous distinction to make, but I have come across this issue repeatedly, especially with my son: he is on the High Rate Care/Low Rate Mobility (and quite honestly the latter should be changed). He is very bright, but very tall, strong and hyperactive. He has classic autistic behaviours and can be quite aggressive, even violent, and is difficult to restrain due to his size and strength. However the big barrier I have always had to getting people to accept he has autism is he is verbal (due to a backbreaking amount of work by myself and specialists over four years) and he takes some Omega 3 supplements to help his concentration. He has therefore been shoved into mainstream school because they feel since he is verbal he isn't “that autistic”. This however is only due to the fact he is on supplements and also due to the “honeymoon period” of starting a new year of school. I ran out of his supplements one week and his behaviour at school was pretty much how his behaviour is at home before I give him his Omega 3's and the school was utterly shocked at the difference. Currently, the honeymoon period of being in Year 2 is now over and he's once again getting aggressive and disruptive in class – like any person with autism will get in that kind of environment. After two years of saying this myself, they are now making a move to get my son transferred to a special school as they are completely incapable of dealing with his behaviour and blow-ups. They perceived that, due to his ability to talk, his autism wasn't that severe. But that is like saying a person who is medicated against their mental psychoses, or a person who has a prosthetic or a mobility aid is no longer considered disabled and would be fine. They aren't cured or suddenly well – they're just as disabled as they were before, and it's ridiculous to try and assess people as suddenly being fine if they just had the right drugs/support/equipment – especially because in many cases the equipment isn't there. I was stunned to hear that the ESA is actually considering</p>

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		<p>assessing people who can walk a short degree as if they were using a wheelchair, and therefore would be assessed as capable of mobility with a wheelchair which they don't even own. How can I possibly be assessed as capable of working with a wheelchair when I don't actually own one in the first place? And who in the world is going to provide me with one?</p> <p>*As far as buying aids oneself: the reason that these aids are acquired, often before the DLA application is made is because this is vital equipment which people have to have, and they cannot wait the weeks or months for the DLA to clear. People often scrimp and save, beg and plead, appeal to charities or what have you in order to get that equipment whilst they wait for DLA, but it doesn't mean they are now completely unhindered and capable of coping. As I mentioned, mobility aids alone are frightfully expensive, and this isn't even counting the dizzying variety of equipment which people are often forced to get long before the DLA comes through. So no, I do not feel that an assessment should take into consideration what someone already has, but should acknowledge that if the person was completely able, they probably wouldn't have needed the equipment in the first place. Powerchairs are expensive – you don't buy it unless you need it.</p> <p>*Question 9: First, let's state the obvious: it would be a considerably more "positive" experience if the form did not automatically assume I was a liar and a criminal. It also asks some incredibly humiliating questions (toileting, etc) in MINUTES of the day which is demeaning and depressing. There is nothing pleasant for us about filling in these forms – the advice I was given was "If you don't feel like having a good cry after reading it, you've done it wrong." I also have to say if a form actually requires several recognised charities to help you fill it out in a way that you fit the criteria, the form is overcomplicated. *I honestly think the form needs to stop asking many of the questions it does and instead takes on board the diagnosis (if there is one), the GP and specialists notes, the advice of a charity which deals with such disabilities and base decisions on that. The trick questions on the form (designed to try and trap you in a lie) are ridiculous and only confuse the honest claimants – for example, I had no idea when it came to cooking and preparing meals that putting a frozen meal in the oven did not count as a home-cooked meal. I do try to take great care over my diet but no one explained to me there was a difference between cooking a meal on the stove from scratch and putting some frozen food from a meal I made earlier in the week into the microwave. Obviously I marked "yes I can" and this was considered proof that I didn't really have care needs, when in truth, I do.</p> <p>*Ultimately, the problem isn't that the form is "difficult to understand" - the problem is that the form is designed to not allow any but the most determined to be able to claim in the first</p>

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		<p>place. It would be a very easy process to discuss with a consultant/GP and/or Carer what someone needs in an 1:1 interview and then have done...but if it were easy, EVERYONE would claim. Can't have that!</p> <p>*Question 10 As above, the best people to provide the assessment of ability are the patient, the patient's GP, consultants, and friends and family members who deal with the claimant on a regular basis, NOT an anonymous body of experts whom have never met the claimant before. Most of us with legitimate issues have extensive case histories and it isn't difficult to do a bit of research into our backgrounds and note the same issues come up time and time again. There's no need for complicated forms when all systems these days are computerised, it should be an easy enough thing to see someone's files and note that there is a diagnosis.</p> <p>*The current DLA form asks so many questions (quite a few of which are humiliating and rather thorough), that I cannot understand why there would be a need to any further proofs from the claimant.</p> <p>*Question 11 Again, if I have a GP, two specialists, several friends who deal with me on a regular basis, and myself, all with several years of documentation, I do not understand why allowing a complete stranger who has never met me nor dealt with me at all on my case for longer than 30 minutes has the right to pass the final judgment on whether or not I am actually eligible for the benefits. I still have not seen a valid reason why this is even required as part of the process. Why is this considered important because it is "independent"? This implies somehow that my GP and specialists and friends and family members are somehow benefitting from me being declared disabled and on DLA – unless DWP is paying every GP who diagnoses someone as disabled, it's a ridiculous point and to my mind merely is adding a considerable cost to the whole process. Actually, the only reason I can think of as to why this is being introduced is to pare down the numbers of people who claim DLA whether they actually really need it or not in order to balance the books – but I can't see it working; we appeal, which costs even more money, and then win the appeal.</p> <p>*Question 12 See the above – I do not believe for a moment that reviews are even remotely necessary. *Question 13 It's not a matter of "failing to understand"; it's a matter of being constantly teetering on the edge of poverty. If you want people to report "changes in circumstance" (by which I am sure this question means 'when they won't need the help anymore') perhaps it would best serve to realise that if you have a disability, the chances are your circumstance doesn't change whatsoever, unless it gets worse. At the same time, if your condition worsens then with appropriate documentation, this should be taken into account and a higher rate agreed – NOT the usual practice of re-assessing the entire claim from the</p>

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		<p>beginning and (more often than not) bafflingly coming to the conclusion that instead of being worse, the claimant is miraculously cured, and therefore benefits cease. Such an error means that funds abruptly cease and for many people who are disabled, this catastrophic.</p> <p>*The reason people do not report changes in circumstances are, quite honestly, terrified. Terrified of losing their benefits or of human error in reports (due to erroneous information for example, my backpay for my son was paid to the wrong account and I lost it all; there was “nothing they could do” as over £600 of my son’s funds just disappeared as a result). People are not going to report changes to circumstances if it means that the carpet will be jerked out from under their already shaky footing.</p> <p>*Question 14 Personally, I feel if an entire independent body like Citizens Advice Bureau needs to exist just to help people get through the benefit claiming process, then the process is ridiculously overwrought. Having hidden criteria based in minutes of performing an activity which then determines whether or not you’re disabled enough to claim is absolutely ridiculous. I would imagine it costs more money to hire people or create organisations to help people travel through the minefield than it would take just to make the whole thing simpler full stop. Are you disabled? Right, done. How hard is it, honestly?</p> <p>*Question 15 You might be amazed at how many people there are who don’t take action and they’re not a minority. I didn’t bother claiming for myself or my son for years because the forms were so daunting and there are so many hidden criteria I had to get a friend in pensions to help me. Make the process less of a trial by fire and more something actually there designed to help people, and it will take care of itself. We were thoroughly entitled to receive the help, and still are - but the stigmatising was so horrific I just didn't do it and struggled along. That's a sad state of affairs.</p> <p>*Question 16 As mentioned above – and probably one of the most glaring examples – transportation very often has to be funded by disabled people or not at all. More often than not this comes under “not at all”. We scrimp, save, beg charities, or fight for years to get funds from DLA or local councils. Very few of us have suddenly won the lottery in order to care for our needs – and honestly, DLA was designed to be able to fund these aids and adaptations. So saying it funds a “one off cost” as if somehow this was special treatment is misleading – if the PIP payments aren’t doing that already, then it is not fit for purpose.</p> <p>*Question 17 Again it is important to note that children are not suddenly just going to be able to “grow out” of their disability: they are stuck with it for life. Of course they’re going to be claiming for more than five years, and probably be claiming for</p>

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		<p>at least fifty. That's what disability does – ruins your life for the rest of your life, end of. A bit more understanding that a child who is disabled is never going to just suddenly not be disabled anymore needs to be put into effect. The ACT NOW group has some very good points to make about how people with autism are going to be autistic forever, and can lose skills (called 'regress') if they are not used often. My son was talking well, did "good listening" and had stopped wetting the bed, but now he has backslid: he's incredibly violent in school, he refuses to use public transport and gets very agitated, he wets his bed regularly and even the floor and walls deliberately, and is very rude and vicious to everyone around him when he doesn't get his way. So now, he has regressed to where he was when he was four years old and I have to build it all up again with a older, stronger child.</p> <p>*Another point made is that autistic children are automatically given low mobility only - I do not understand that at all when it is well documented that autistic children have no sense of danger, have wildly unpredictable behaviour and find extreme difficulty with new situations. Take an autistic child onto a bus where they expect to sit in the same seat they sat in yesterday, but today someone else is sitting in it...and see what happens! If a doctor diagnoses a child with moderate-to-severe autism as my son was, then why am I just given the low mobility only? Why was his full case not taken into account for the need for High Rate? These sorts of automatic low-settings without actually looking at the full case is why it creates so much paperwork as now I have to appeal the decision.</p> <p>*In addition a lot more recognition of the stress this puts upon parents who try to care for their disabled child's needs as well as (more often than not) pressured to find work means that parents have very little, if any, support. Do not be fooled into thinking this is picked up somehow by local councils – it isn't. In my council there is no provision at all for autistic children between the ages of 5 and 10. For the past two years, and the future three, I struggle on in a vacuum with no care or help provided by my council whatsoever.</p> <p>*Having a child with special needs is shockingly expensive and draining, and any assessment which is given with regard to disabled children should also take the extra tolls of taking care of these children, and Carer's Allowances or other payments for carers (which are absolutely paltry) should be automatic if a child is assessed as being disabled and approved for benefit. There's no reason to have to take on extra paperwork and stress for applying for yet another benefit when it should all be linked under the same department.</p> <p>*Question 18 The fact I have no idea what this passage even means would probably point to this being "no". As a matter of fact, after wading through the process of DWP for the past year and a half it seems very clear that DLA and the office which</p>

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		<p>organises it has no idea what any other aspects of the department actually does. I have to apply for Working Tax Credit, Child Tax Credit, Disability Credit, Carer's Allowance and my own DLA in addition to DLA for my son – filling out a form each time and pointing the DWP office to my file over and over again. None of this information as to what I could apply for was easily accessible either – just pointing people to a website (assuming people have a computer) isn't even remotely helpful. I cannot perceive that when you enter all your details into the DWP system once that it requires individual departments to process the exact same information over and over again. And no one in any of these departments ever told me I'd be eligible for any other benefits – in most cases, they weren't even aware it was possible.*I have not felt at all the DLA was a passport to anything, as, once again, there is so little provision for an autistic child in my community. I don't get bus passes for free (that programme for carers passes have been stopped) I don't even get a blue badge (they don't give blue badges out for children unless in a wheelchair in my county). It may help me get the tax credits and that's well and good, but only if I am somehow able to fight exhaustion and illness and keep working. I have no desire at all to be on ESA or IB or anything else that would give me even more stress and scrutiny.</p> <p>*Question 19 Again, I'm not even remotely aware that DLA is a "passport" to anything as it stands. What I do know is it took me two years to even start getting DLA for my son, it took several months for me to realise I could also apply for Carer's Allowance, and then a further period of time to remember that this meant I could add the disabled component to children's tax credits (which may be moot considering most people will no longer be able to access these anyway now).</p> <p>*Question 20 As mentioned above, once information is put into the DWP database, it should be a simple matter of being able to tell immediately what you're eligible for. I don't however think there's going to be any chance of reducing duplication since having overfilled and redundant offices with staff seems to be a great way for councils to pad out their budgets and claim they are underfunded. The problem is not with assessments and needing to make these any more complicated, but in adequately training staff in the law and procedure of claims, making sure they don't make regular errors and cost even more funds to correct (losing £600 to human error cost me and the taxpayer a fair bit, and I'm pretty sure it wasn't an isolated incident). Having to bring a straightforward claim up for an entire review because staff overlooked information which was easily accessible is more expensive than the .01% completely fraudulent claims which supposedly are being made.</p>
EM654	16/02/2011	Please find attached my response to the questions in your consultation document for DLA reform.* 1. Inaccessibility and discrimination is still rife. My partner is a wheelchair user and

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		<p>only three days ago was denied access to a bar because he was told he was a fire hazard! This is by no means an isolated incident.</p> <p>*The DDA is not effective. It needs to be far stricter. There are too many defences for people who wish to discriminate. Old buildings are exempt from adaptations, and able bodied people don't need to know anything about disability – they can claim as a defence that they thought a wheelchair user would injure other people in a club. Yes – that has happened recently.</p> <p>*Employers don't want to employ us. They are obliged to give us an interview if we meet the criteria, but thereafter can say a disabled person interviewed badly as an excuse not to employ him. I have been told by Pluss that I do not score enough points on the employers' scale of previous experience because I find it impossible to get a job. It is a vicious circle, and, by the way, voluntary work or work experience counts for nothing.</p> <p>*2. The system of looking at what we CAN'T do. That is the point of DISability – we can't do things. If you base an assessment on what we can do, it defeats the point of a benefit to dispel extra costs.</p> <p>*3. Transport, alternative therapies that are unavailable on the NHS, extra heating, extra medication, wheelchair maintenance, extra footwear (my gait destroys a pair of shoes in 2 months), Specialised computer equipment, wheelchairs (I don't qualify for one on the NHS), car adaptations (e.g. hoists) and maintenance of same, extra petrol (we use our cars for journeys able bodied people can walk)</p> <p>*4. • Will having two rates ...? Possibly, but the benefit system in general is so badly administered I don't hold out much hope.</p> <p>*• What, if any, ...? If the middle rate care disappears, what will happen to all the linked benefits? And if you have back pain you are often put onto lower rate care automatically. It took an appeal and letters from Scope for DWP to accept my back pain comes entirely from my cerebral palsy and put me on the right rate. I fear that in your haste to eliminate fraud this will happen more and more, especially if there are only 2 care rates.</p> <p>*5. Unfortunately, I think that in order to prevent fraud all claimants need to be individually assessed.</p> <p>*6. That is subjective and needs to be assessed individually. Of course being able to dress and bathe is important, but so is being able to go out and socialise in order to prevent depression. Disability can often lead to clinical depression which needs to be taken seriously by DWP.</p> <p>*7. The present system of assessing someone using their worst days is correct and MUST be preserved. If you say, for fluctuating conditions, "they don't need so much help on 'good' days", that lack of help will lead to the person having more bad days, and to a worsening of their condition.</p>

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		<p>*8. • What aids ...? I only know what it is like to use a wheelchair so I am not going to talk about others. Wheel chair users must be assessed without their chairs. This country is not accessible enough for wheelchairs to be included. Only when EVERY building in the country is accessible can wheelchair users be assessed as mobile.</p> <p>*• Should the assessment? How are you going to decide what is 'easily obtainable'? Nothing is easy when dealing with a disability, the NHS and the benefit system.</p> <p>*9.</p> <p>*10. Charities who deal specifically with the claimants' individual disabilities are best placed. Doctors have a terrible habit of assuming that, since they have studied a disability for 20 years, they know all about it. Doctors pigeon-hole people and claim their word is law. They say "you won't be able to do this" or "that's what happens with cerebral palsy." I have a letter from my specialist saying a leg brace would solve everything, when it actually makes me worse.</p> <p>*11. • What benefits or difficulties ...? The above applies to healthcare professionals too. They don't know everything about every disability, and I would be very worried that they would dismiss what I say because it doesn't tally with their experience. I find many healthcare professionals bullying and arrogant. Disabled people will also worry that the interview is designed to determine that they are not entitled to the benefit to save money – especially people with conditions that are associated with 'skivers' or fraudulent claims – e.g. back pain or ME. The claimant must be allowed to have a representative from a charity, or of their choosing to support them in the interview.</p> <p>*• Are there any circumstances ...? Don't know.*12. Yes – if your condition is life long and never going to get better, you should have fewer reviews than if your condition is one which changes.</p> <p>*13. People are very scared of the DWP, Tax Credit etc helplines. You must make sure that the people manning the lines know EXACTLY what is required and what will happen next. Tax Credit is terrible for this – I ring up on 2 separate days and am told 2 different things, there are 5 call centres so you can never speak to the same person and spend valuable minutes re-explaining your situation again and again. Also, the phone number for reporting changes should be freephone – 0845 numbers can be extremely expensive and may put people off ringing.</p> <p>*14. Yes, you need an easy to read booklet accompanying the claim form. Use clear English, not DWP jargon. We need to know exactly what the claim form requires, how much money each rate gives us, what changes you need to know about, how to appeal against an unfair decision, and exactly how the process works – what will happen next.</p>

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		<p>*15. A requirement could get very Draconian. Claimants often do not claim because of the things I have outlined in the previous question. Sort them out and people will claim. Also, you must make sure people know about the benefit. No-one told me about DLA until I was 23.</p> <p>*16. People like me who are not entitled to a wheelchair under the NHS have to either apply to charities for help, take out a loan, or spend their savings. The trouble is, every benefit we apply for takes account of our savings. So yes, there should be an option to meet a one off cost.</p> <p>*17. Don't know, I wasn't informed about DLA until I was 23.</p> <p>*18. DLA gets you a railcard, concessionary bus travel, and a Cinema Exhibitors Association card. Middle rate care can apparently get you cheaper tuition at adult education college, so what will happen to this if there are only 2 care rates? To make it easier, you can make sure all the criteria are the same. I get mobility DLA because walking even short distances is extremely painful and tiring. The criterion for concessionary bus travel in Cornwall is receipt of higher rate mobility DLA, but the form says "unable to walk". This needs streamlining.</p> <p>*19. DLA is already expected to pay for every extra cost related to disability. If we also have to pay for full price train and bus travel (not everyone can drive, or can drive long distances) then PIP will have to stretch impossibly far.</p> <p>*20. PIP and ESA assessments should be shared.</p> <p>*21. I can't see that your proposals will have any impact on sex or race, but if people with "lesser barriers" receive less support, you have an obligation to ensure that the money they receive still covers their needs.</p> <p>*22. What is going to happen to Motability? The scheme must continue as at present.</p> <p>*There is a lot in the proposal about people recognising that they would be better off in work, both financially and healthwise. You need to encourage employers to take disabled people and to create jobs we can actually do. Even the agencies set up by the government to help disabled people into work cannot find employers who will accept us. I have been dropped by 3 agencies so far, and the present one, Pluss, has said they don't know what to do for me. The employers need targeting first.</p>
EM655	16/02/2011	<p>Dear Sir/Madam, I am a claimant of the DLA, I feel I must comment on the plans to change the system currently in place.</p> <p>* I will try to answer the questions as listed but they will be from my prospective as this is a subject that cannot be generalised, as you are trying to do. People are individuals and each one will have a completely different experience to me.</p> <p>*1. You ask what barriers there are for disabled people: Well from my own view, I would have had to given up my job if I did not get this benefit. I could no longer drive a manual car, and the one I had was getting dangerous, so the fact that I was able to receive the higher rate mobility meant that I could get a more</p>

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		<p>suitable vehicle for my needs. This has allowed me to continue working and to continue taking my daughter to school and to give me back a modicum of independence, that I was terrified was being lost. *The barriers are there whether real or imagined. But I have to battle every day, just to keep going. This consultation has completely taken the rug from under me. It is like being given a brief glimpse of what life could be like, only to have the prison doors slammed firmly shut again. It is cruel and completely unjustified. You speak of barriers, I suggest looking in a mirror. Under the new system I will more than likely not qualify, although I was visited by a doctor for the DLA who's professional appraisal, allowed me this much needed benefit to regain my semblance of independence. I cannot walk to the nearest bus stop without being in extreme pain and exhaustion and there is no bus to my daughter's school that is a good half a mile away. How would I be expected to continue my responsibilities? I would have to get taxi's, then I would not have money to do any food shopping. As it is my mother has to buy the school uniform, because I do not have enough money to do so.</p> <p>*If I cannot drive, I cannot take my daughter to school, and I will not be able to continue working. I will lose my home because I will not be able to keep up the payments and will more than likely end up on the dole as no one will employ someone with my health problems</p> <p>*2. Is there anything that should stay the same? Well I have to say that the mobility component is usually the most important part to people. I myself found that part the most beneficial. It allows people to actually get out and about, to pay for taxis or cars to get them places, or allows you to get a car that is adapted to your own needs which allows you the independence that most people take for granted. I was so pleased when I finally got my car. I didn't have to worry about the battery failing on me in the middle of roundabouts, or if my leg went numb whilst driving so I couldn't feel the clutch pedal to change gear. These have happened to me and you cannot underestimate how great a change this can give you to your self esteem, self confidence and just the feeling that life is worth living again.</p> <p>*3. What are the extra costs; That all depends on the individual. There are medications that cost the earth; I may need someone to come in and help with the house and garden. Also getting to hospital appointments. I could have several appointments over the course of a month and that is a minimum of £2.00 each time. Also in the winter months it has helped with my fuel bills. I have not had as many infections this year, because I have been able to heat the house for more than a couple of hours in the evening. Although I still don't put on past 16 degrees, as the cost would be too prohibitive.</p> <p>*That is something else that could be looked at. Disabled people tend to be at home more often and their health needs</p>

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		<p>mean that like me they feel the cold much more easily. Perhaps some arrangement could be sort out with the energy companies for people with this benefit to get reduced rates on their fuel bills? Its an idea, If disabled people were able to heat their homes better, there may well be less admissions to hospital, which saves money in the long run.</p> <p>*4. Two rates for the new benefit; The problem I can see with that is that many people will fall through the cracks. Mobility is only two rates anyway, but the care component has three, and I think that you can only qualify for certain care packages if you get the higher or middle rate. (I may be wrong!) So if like me you get the middle rate care component and that is taken away, what happens to us? I will more than likely end up on the lower rate or will not qualify at all, as I cannot see you bumping all the middle rate people up to the higher rate.</p> <p>*5. Should some health conditions be automatic; Yes there are some conditions that must remain automatically entitled to DLA. For example, those with a terminal illness, progressive illness for example MS or children with muscular dystrophy etc.</p> <p>*6. Prioritise support; That must be done on case by case, as stated before we are human beings, what one person can cope with another will not be able to. The most essential for me is maintaining my independence, that means being able to get out and go to work, pick my daughter up, go shopping etc, without hindrance, being able to have someone come in and clean the house for me when I need it or do the garden, these are things most people take for granted, I know I did before I became ill.</p> <p>*7. Take account of fluctuating conditions; simply reassess on a regular basis as is done now.</p> <p>*8. Take into account aids and adaptations; No you should never do this. Would you say that someone in a wheelchair can get around easily simply because of the chair? That person may still have problems getting out the house. I have to use sticks to help me walk, It doesn't stop my condition from getting worse, it just stops me falling. Never penalise someone who needs help in the house or outside because of their illness, that is inhuman!</p> <p>*9. The claim form is nearly 50 pages long, and a lot of the questions on it are repeated to catch people out! It is a trauma just filling the forms in, and most people need help from someone to understand what is being asked of you. Just set it out in plain English. Keep it short and to the point.</p> <p>*10. The best people to get supporting evidence from are the medical facility. Most people will be under consultants or specialist departments, having a report from this professional people should be enough to prove eligibility. In some cases a GP report would be proper as well.</p> <p>*11. Face to face contact; This would be ok in some cases, I didn't mind seeing the medical person who assessed me, she was very nice and very patient with me, but it depends on the</p>

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		<p>illness involved. You need to be very careful with people who have severe mental health issues, or children who have special needs such as autism or aspergers. These cases must be dealt with very carefully or you can make the illness much worse by simply being there. Especially children, as they do not handle strangers well, especially if those strangers wish to examine them! You could end up in a minefield!</p> <p>*12. How should reviews be carried out; Well the criteria should be fairly straight forward. If you have an illness that can be improved or you can recover from such as back problems etc, then a review might be carried out say every 18months to 2 years. If the person has a progressive illness like me or one that has a poor prognosis, then perhaps every 3 to 5 years. There should be different types of review based on the individual needs, and the disability they suffer from.</p> <p>*13. Reporting changes; Human nature as it is, I would suggest that it may be difficult in some cases to get the person to advise the department of changes to their condition. However, I would like to believe that it is mostly down to the fact that changes do not happen over night so many people will honestly not notice any improvement in their conditions. They should never be treated like criminals, as they probably genuinely believe that their condition has not improved at all. The best way I think would be the three strike rule, send out a review form and book them into a medical appointment, If not kept, again send review form with letter etc; If this is again not kept, then a final letter warning that they will have their benefits stopped and will have to reapply for the benefit. Carrot and Stick.</p> <p>*14. Advise and information; The best advise is simple instructions on how to fill the form in (and I mean simple!) How long the process will take, who is going to make the decision and permission to contact necessary medical personnel. It would be helpful as well if the department actually contacted the relevant doctors for medical reports and paid attention to them! I had to contact my own doctors asking for reports as on my first application the department did not do this and turned my application down without sight of them! That is extremely distressing when you feel so ill anyway, and it made me feel like a sponger! Even though I have worked since I was sixteen years old, and didn't ask for this disease.</p> <p>*15. Minority claimants; I have no idea as I am not a minority. But I would think it would help them the same as it would help all of us.</p> <p>*16. Funding adaptations: Many people fund them through having DLA, if you ask them. There are supposed to be funds from governing bodies to help, but most people cannot access them or there is a long waiting list to go on before being able to get the help you need, so I would imagine happens regularly any way. I would suggest a one off payment in addition to the</p>

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		<p>new benefit, to help those who need to adapt their homes. I need to have my bathroom adapted as I tend to fall getting in and out the bath, but have been unable to access help or even find out where I can get help to do this. My local Physiotherapy nurses have set me up with sticks to help with walking but that's about it. No one has the budget to help these days!</p> <p>*17. Key differences for assessing children; Children are not small adults. They get scared easily and have amazing stamina even when suffering from a disability. You cannot ask the same questions to a child as you would an adult, they simply won't understand. Their attention spans are short, (alright, so are some adults!) You need to be aware of every nuance with a child and you must have the parents participation at every level. If a parent says enough then take them at their word and make arrangement to return.</p> <p>*18. It is very important as a gateway benefit. I was working a 40 hour week before my disease took hold, I now manage to work 16 hours a week and that is a real struggle! By the end of the week I am exhausted, but it is important for me to do this not only to continue contributing to society but so that I don't feel embarrassed about having the benefit. The fact that I can get council tax relief, is a real benefit to me, as I was finding it extremely hard to pay that on top of my other bills and my mortgage. I am terrified that I will end up losing the house and the roof over our heads. But if I am deemed not to qualify for this new benefit, then that is what is going to happen.</p> <p>*19. It will make life almost to hard to maintain, keep going, to bare! Disabled people struggle everyday, in every way, and despite most peoples views that we are 'rolling in it', most people like me struggle from month to month having to juggle which bills should be paid and when, and worrying about how to pay for shopping each week, so those passport benefits are extremely important to people like me, even though I am only able to access the council tax relief, it has and will continue to be one less worry on their shoulders.</p> <p>*20. There should be one assessment. This should in an ideal world, be then submitted automatically to all the relevant departments that deal with the disabled either with help or benefits. They would then be able to write to that person to see if they require any further assistance. In this day of computers and emails that should be possible. There could be a section on the application form for the person to fill in requesting information on receipt of the new DLA, any further benefits that they are eligible for to be told and paperwork arranged to be sent out.</p> <p>*21. It may alienate some people, and may not encourage them to seek out the help they are entitled to and need. But like all things you cannot please everyone and there are bound to be problems if you throw the baby out with the bathwater!</p> <p>*22. I would like to say that it has been a life saver for me. I</p>

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		<p>never thought I would be disabled and struggling, but here I am. I think you cannot to set too narrow a criteria otherwise there will be many disabled people who would end up destitute, or dead. Most of the time I struggle to keep going emotionally and physically, each day is a tiring exercise of great proportions! But like most disabled people, I continue to do it day and day out. You MUST NOT underestimate the importance having the allowance makes to many peoples lives, and how much additional stress the news that this allowance is changing has put on people who are already struggling daily! Please do not be the distant bureaucrats on this one but actually acknowledge that we are human beings, who are generally on the edge of society, disenfranchised for the most part, and mainly tolerated by the general populace.</p> <p>*I used to be one of those general populace. So please be gentle and do not use a giant mallet to break the walnut, because if that happens you will not be the one to fall to pieces, we will. I hope this has been of some help. If you have any further question please do not hesitate to email me. Sincerely</p>
EM656	16/02/2011	<p>1. Pain & fatigue Society's attitude to disability - ignorance and prejudice, currently getting much worse due to the government and media's portrayal of disabled and chronically ill people as scroungers. E.g. if you are a part time wheelchair user and can sometimes walk people assume that you are faking it when you need to use it; if you are young and use a stick/park in a disabled space people assume you are putting it on. The awful comments people sometimes make in the street. Financial problems due to low income due to not being able to work/only able to work part time, the nightmare it is trying to get any disability benefits. Difficulties in getting a job when you tell employers you are disabled. Difficulties in finding jobs which will work around your limitations and cope with fluctuations in conditions, particularly when it comes to sick pay and time off (For instance one reason I can no longer work as a nurse is the NHS' draconian sickness policy as I would have had my contract terminated due to time off) Inaccessibility of buildings and services Poor attitude towards chronic pain sufferers by medical professionals, poor medical care generally Lack of recognition and support for the struggles of trying to live well while disabled/chronically ill Lack of respite for carers leading to stress on relationships/relationship breakdown*Mental health problems caused by all of the above.</p> <p>*2. Your response: Definitely the passporting to DLA & blue badge. The social model of disability being used. I am extremely concerned that you say you are working to this model but the only evidence you seem to take into account is that of medical doctors/consultants who often have very little idea of how a disability/chronic illness affects you day to day. It not being means tested.</p> <p>*3. Loss of income from not being able to work or only being</p>

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		<p>able to work part time/lower paid jobs Increased heat and lighting bills from having to be at home more than usual Increased cost of prescription medications Increased cost of transport from not being able to walk/cycle/use public transport (often a NIGHTMARE with a wheelchair, even if it claims to be accessible). Higher costs for parking if you don't have a blue badge Cost of assistive devices - wheelchairs (you now aren't eligible for a voucher if you don't or can't use one indoors e.g. your house is not accessible) are massively expensive Cost of sticks/crutches not provided by the NHS (my physio literally couldn't source appropriate ones, I had to buy them)</p> <p>*Cost of allied health professional care - Chiropractic/Osteopathy/Podiatry/Private Physio when NHS ones give up on you/your allocation runs out Cost of splints/adaptive kitchen/childcare equipment Higher cost of buying most things due to not being able to shop around e.g. for food when getting delivered from online. Higher cost of prepared meals Need for paying for care/home support or respite/childcare needed due to disability</p> <p>*4. Your response: Probably better than the current three and two rates, but worry it will make it less personalised and more likely to end up with people on the wrong rates of benefit.</p> <p>*5. Your response: All claims should be based on the needs and circumstances of the individual applying, IF they are assessed fairly</p> <p>*6. Your response: Difficult! Advocacy would really help for those struggling to fill in the form. Making it very transparent what the criteria are for PIP and how decisions are made so that people understand whether they are likely to qualify. Not getting rid of CAB and welfare rights workers. Activities most important: Food and eating, transport, social time & support with parental role, which is almost always overlooked, and mentioning it often gets benefit taken off you despite government legislation saying that disabled parents should be supported.</p> <p>*7. Your response: Extremely difficult! Provide examples of how it should be filled in for a fluctuating condition. Definitely make sure that people don't fill it in for their worst day. Don't penalise people for being honest, make it easier to change what level of benefit you're on if things change significantly over say, 6 months or so, rather than normally losing all benefit if you say anything has improved.</p> <p>*8. Your response: Yes it should take these into consideration, but it should also make sure you realise that most people applying are on very low budgets/useable income so even small adaptive devices can be very hard to afford and OTs no longer give anything out. Plus add in the cost of wear and tear on these. Most importantly please take into consideration how long it takes someone to do a normal task with an adaptive device and therefore is it reasonable to expect them to do it or</p>

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		<p>would it be more appropriate to have help. e.g. the slotted spoon thing is insane if for instance you are like me and are trying to provide food for a family of four, because it would take forever and there is so much other domestic stuff to be done with hugely limited time and energy. Provide signposting to more places that can tell you about adaptive devices as many people don't know what's available or how to get it.</p> <p>*9. Your response: Stop the repetitions in the different parts of the form. Stop trying to get people to estimate everything in terms of a certain number of days a week etc. if possible as fluctuating conditions make this almost impossible to estimate. Don't make CAB and welfare rights people redundant therefore reducing support and advocacy for people applying. Make it transparent how decisions are made and how much help you need to help to qualify so people know when to apply and don't do so and then get disappointed. Don't let ATOS keep the contract for medical examinations.</p> <p>*10. Your response: MASSIVELY difficult! Probably a social worker if there is one involved, sometimes a GP but I have had a hugely difficult problems with this as I was misdiagnosed for a long time and didn't have a good consultant, and when I did she passed all assessments on to an OT who said he couldn't assess someone in "flare" the flare had been going on for 7 months and was actually a new baseline. Using a social model of disability means that the current policy of only taking medical evidence most of the time is a bit odd. Provide medical staff with guidelines of what to write and information about doing it in conjunction with the claimant as it is so easy to give inaccurate information - most people cannot see their doctor on their worst days, and consultants see a snapshot every four months or so.</p> <p>*11. Your response: If it is done by ATOS it is likely to be punitive and unfair, a benefit could be your chance to fully explain your problems but if the government is looking to get as many people as possible off the benefit it would be very easy for this to turn into an opportunity to catch out someone saying something seen as inconsistent. Having to get to an assessment could be expensive and exhausting for a disabled person. Someone with very severe mental health problems or huge issues with dealing with change would probably not cope, some bed-bound people would need a visit.</p> <p>*12. Your response: Review by a simple form, every year if it is a new condition, going to longer if the condition has been around for a lot longer. Long term disabilities and injuries which will not improve should be exempt, except within the first few years from an injury where someone could be getting used to using adaptive equipment.</p> <p>*13. Your response: Not use punitive removal of benefits in these circumstances. Provide clear reminders that it is necessary.</p> <p>*14. Your response: Who is eligible - what care you need to</p>

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		<p>require/problems you need to have in order to be entitled. Information about what it is not for.</p> <p>*15. Your response: Very difficult, I think this would be extremely patronising for many and could add to already difficult lives. I think lots of information about where to access this advice and support would be massively helpful but am not for it being mandatory.</p> <p>*16. Your response: Loans, social services, savings, partner's earnings.</p> <p>*Am slightly unsure of what's being asked. What is a one-off cost? Like a wheelchair? I can't see anything stopping someone doing that now, and if there would be with PIP then those restrictions should be taken off.</p> <p>*17. Your response: Totally different types of needs, needs of the whole family, especially for transport and respite. Changes as they grow.</p> <p>*18. Your response: Very helpful, critical really, especially for Motability and blue badge. PLEASE return DLA to people in residential care so they can actually have some quality of life, especially those under 65.</p> <p>*19. Your response: Many of us would be stuck in the house, unable to see anyone, do errands, get to appointments without waiting in all day for transport, and there would probably be fast rising levels of depression as quality of life measures would go down so much.</p> <p>*20. Your response: Incapacity benefit and DLA could be combined but I am worried that it would just make it easier for people to be refused both!</p> <p>*21 Your response:</p> <p>*22. Your response: Please get some people involved who are actually disabled and know about living life with resources much more limited than the average person. Please take into consideration that some people could do certain tasks, but the cost physically is so high (pain and fatigue) that it is not reasonable to expect them to without help. This issue is stupidly misunderstood! Please get people on your tribunal panels who don't compare the tasks of cooking a meal to changing a nappy and consider them equal! Please please don't be so negative about people with disabilities, consider what you would want to happen if you or a close family member became disabled tomorrow and had to claim these benefits.</p>
EM657	16/02/2011	<p>Dear Maria Miller I am writing directly to you because the bureaucratic process for consultation is poor and the online process has not been working properly. You need to read first hand opinions so here goes....*There is no point in commenting question by question. Your consultation document is poor in content, detail and research basis that it is astonishing it has been sent out for consultation to the general public in this way. You ask about barriers. Well here we are. Right here is an example: an opaque and poorly considered document equals</p>

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		<p>barrier. Time is of the essence for a new government but this is a right dog's breakfast. Can you not deny it's a rush job?</p> <p>*I work in the field of disability having done so at a local and national level for over 20 years. I know disabled people with DLA and have been involved in research myself. The organisation I work for, is writing its own comments on the consultation.</p> <p>*I am submitting my personal comments because your questions, as usual, in consultations of this sort, are the wrong questions. The wrong sort of snow, leaves on the track, I'm sure you get the idea.</p> <p>*Public relations – real people's lives People are not stupid. Let's face it this is a shabby, rushed PR exercise to tick a box so you can cut the DLA benefits bill. Be honest. Reform takes time. Rush it and the whole system collapses: disabled people back in institutions, more hospital visits, fear, stress and social isolation. In short, disabled people's rights set back 30 years. Also it will cost more in the long run. Think again.</p> <p>* No information, no research – where is your evidence? Where is your evidence that DLA needs reforming? DLA system works – where is your evidence to the contrary? If you had real research evidence, please share it with the public who have a right to know. Yes you want to cut the money, but reform – think again. You provide no real or meaningful details of the PIP scheme which will replace DLA. It just looks like you haven't thought about it.*PIP SQUEAK Yes a new fancy name PIP - please add a squeak: PIP-SQUEAK. But seriously, Maria how can people comment on the impact of these reforms when you haven't given enough details to make a meaningful comment? Think about it.</p> <p>*DLA will continue to be a non-means tested benefit At least you propose to keep this – thank goodness for small mercies. The extra cost of living with a disability is what DLA is contributing towards. The Joseph Rowntree Trust, the social research expert , has researched this twice in detail http://www.jrf.org.uk/sites/files/jrf/054.pdf Why was this not in your consultation? Was it not convenient? It is an astonishing omission.</p> <p>*DLA is not linked to work. You, the Minister seem to think it is from your recent articles and what you signed in this consultation. Does this indicate you have little experience of the real lives of disabled people? Are you guided purely by a lightweight career politician's ambition? I sincerely hope not. Whilst climbing the greasy pole to power, please don't tread and crush DLA which helps so many people. Don't crush the pip until it squeaks. DLA is provided for people's disability, it is not about work. Please stop linking the two issues together. It shows you don't know very much about the subject. Politicians say things they think are true but often aren't. *What are the barriers to disabled people getting work? (Question 1)</p>

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		<p>*I suggest you ask disabled people in focus groups. Why have you not done this before? Shame on you for asking such an enormous question for question 1! I don't think this is a serious part of this consultation exercise. Get real. Many disabled people will fill in the questionnaire with heartfelt answers telling real life problems often real and raw. You won't even read the comments properly. Here we have a bureaucracy at its most disabling: the 'wrong kind of question' is a Disabling Bureaucracy. Ah yes – the social model of disability. Were experts consulted first? You do not list the well-known disability charities as having been properly consulted. Did you consult them? Probably not and, if not, why not? DLA has the lowest level of fraud. The DLA application form is difficult to complete and so it should be. It works. People have to show they have a real need. Many people are turned down. They then appeal and are booted off. The cheats are turned down – fraud 0.5%. (your figure for what its worth) The assessment questions probably need to be tightened up on certain areas. However, the DWP will know here are more people with disabilities around now, more children are surviving longer who have disabilities and thus inevitably the costs rise. Previous trawls for DLA fraud, showed people were underclaiming according to my colleague, a DSS Benefit advisor in the 1990s. Check it out.*My proposal for reforming DLA - Carry out more research on the specific areas identified as problems – certain applicants 'cheating' the system, the assessment process, certain questions on the form need clarifying or changing etc etc. Work with disability organisations to tackle these problem areas.</p> <p>*Cut benefit levels across the board - Consult with disability organisations to come to an agreement to cut across the board*Tell the truth. You just want to cut the budget. Fair enough. Be honest. People won't like it. However, it removes the stress of uncertainty that will hang over poor people's heads like the Sword of PIPSQUEAK Damocles while you mess around with reform. How much? Well you can know the figures: * £3/5/7 of every recipients benefit and freeze it for 3 years? *This is the Conservative way – direct non bureaucratic and understandable. People can cope if things are clear. *Review cases over say 3 years - Target the cases to review and work out a strategy with the help of disability organisations – to reduce overlap of provision. You can do pilot projects to see how it will affect some people. More research is needed before you wreck a fairly good system. You need to target those problem areas not re-write the whole bloody thing.</p> <p>*Your way = disastrous bureaucracy : surely not the Conservative way?</p> <p>*If you try to reform to quickly you will screw it up. Why? DLA has evolved over a long time. You say it's not fit for purpose but the real reason is that it is costing too much money. Don't introduce another stupidly named benefit with new complex</p>

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		<p>rules. Disability is complex, Yes Minister - don't let anyone tell you otherwise. REFORM RELLY CAN'T BE RUSHED. Too many pieces of disabled people's lives are linked together with DLA.</p> <p>*PIP (Squeak) won't work because: There are just not enough people to carry out assessments. Your PIP Squeak assumes more people to carry out assessments. Who are these? Where are they? Nurses are being used for DLA now and they do not know about disabled people's abilities, OTs – they are being cut back. There are just not enough people to do face to face assessments. Reform is time consuming and costly. It is impractical. You need to look in detail at the problem areas, not a wholesale reform. Trying to cut back when you say people get equipment from other services does not reflect reality. Equipment breaks down, needs maintenance - if a charity bought the equipment then that charities donation is then subsidising the State. How will the donors feel about that? The benefits now do not cover the extra costs of living with disability (Joseph Rowntree research again) National versus Local If you use the argument that the local council should be providing services in the time of cuts, then we will realise tough times lie ahead. You will be shirking your responsibility to support vulnerable people. I sincerely hope you honour your responsibility to disabled people, carers and their families.</p> <p>Yours</p>
EM658	16/02/2011	<p>I wish to express my concern about the new PIP. As a result of my MS I had to give up my part-time teaching post at a college where I was employed for 17 years. As a result, my financial situation worsened but the Disability Allowance and ESA helps but is not a substitute for my teacher's salary. The disease has effected my financial, physical and mental health. Please do not burden us with more red tape and medicals. We have already suffered enough.</p>
EM659	16/02/2011	<p>Responses Below Relate to People with complex Learning Disability.</p> <p>*1. : • Social isolation • Limited access to information and experiences • Personal safety in and outside home • Communication • Intolerance and prejudice due to unfamiliarity in dealing with disabled people *• Many people with LD have hidden disability because they look normal. Disability becomes apparent over time: attempting to communicate, deal with money and undertake normal daily routines / activities or travelling.</p> <p>*2. : • People with indefinite DLA awards for disability since birth / lifelong impairment awarded high rate care/mobility shouldn't have to repeatedly justify their disability – this only serves to humiliate and undermine them.*• Care (Daily Living) component should remain the same: low, moderate, high. • Mobility component for people in residential care should not be removed.</p>

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		<p>*3. : • Daily living: Care and carer/s, support worker/s, higher utility bills - need warmer environment. Specialist equipment / aids for communication or physical aids/barriers*• Mobility: Getting around indoors and outdoors, Personal support/s, Carer/s, Transport/ maintenance, Specialist equipment/aids/prosthetics.</p> <p>*4. : • No• Two categories: Low and high would fail to acknowledge disability in the moderate to high or moderate to low range. There must be a middle rate for this component. In order to adequately support the needs of individuals a broader range of levels should be maintained. Proposing only 2 levels is wholly inadequate for the complexity of peoples daily support needs.</p> <p>*5. : Yes, if present from birth and specialist provision for education / health with multiple agencies involved.</p> <p>*6. : Depends on disability: someone with cerebral palsy may need support for physical/personal care e.g. Professor Stephen Hawking though have a brilliant intellect. Opposed to someone with low intellectual cognition who can walk but doesn't have capacity to know what they are doing and needs support to enable them to undertake routine daily living activities or getting about.</p> <p>*7. Your response: Where health issues may change further assessment may be necessary. Where disability is lifelong due to physical impairment or low cognition IQ <70 or some mental health conditions they should not have to undergo regular assessments.</p> <p>*8. Your response: No*9. Your response: • Use of unambiguous language and questions. • Forms are too long and complex for people with LD and some carers. • Suggest people go to LD charities to help them• Educate GPs, Health visitors, Community Nurses, Special Schools, Social workers to ensure people are getting the correct benefits.</p> <p>*10. Your response: • What currently exists: Healthcare professionals in Special Educational schools, Community or GP.</p> <p>*11. Your response: • Currently children in special schools undergo regular health assessments by consultant paediatrician, Occupational / Physio and Speech therapists. These assessments contribute to current DLA applications – this is not a new concept. • Repeat reviews are an infringement and undermine former assessments which many will have previously undertaken two or three times prior to receiving a final award. Implementation of this will swell administrative costs, and is undignified for the claimant to have to constantly justify their disability – particularly if present since birth and lifelong.</p> <p>*12. : • If a young person/adult is awarded high rate for care/mobility they will have been for good reason. As stated previously, in the lead up to a final award – several</p>

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		<p>assessments will have been previously undertaken. Particularly for young people who have had the disability since birth and is lifelong.* Severity of an illness, impairment or condition should inform this. If high rate is awarded for both components – further reviews would be costly and wasteful. If within moderate or low range this may warrant further review.</p> <p>*13. : Clearly identify PIP grading criteria, and if changes occur there is a prescribed set of criteria to refer to.</p> <p>*14. : Access to other means of support/benefits not just for the claimant but for carers too. Other benefits, Transport/travel, Specific health groups, Wellbeing activities, Support networks, Special education options and much more....</p> <p>*15. Your response: • The Consultation has narrowed access for a minority group – people with learning disability who may not be able to read, or access the internet or use a computer. • Inclusivity and accessibility requires a broader approach by educating health professionals, voluntary / charity organisations who can help to inform minority groups. LD registered charities. Social workers, GPs, Mental Health organisations, Community health visitors, Schools, Citizens Advice.</p> <p>*16. : Unsure</p> <p>*17. : • Concern about how young people are assessed at 16 greatly affects post-school provision and access to other means of support, which enable those with disability to live more independent lives.* Children with lifelong disability are a worry and this puts immense strain, pressure and stress on parents/carers (as David Cameron will acknowledge) due to their additional care needs. This can lead to breakdown in family relations have severe impact on the health and wellbeing of all.</p> <p>*18. Your response: Helpful to be able to access other support and services to enable a disabled person and/or their parent/carer or family.</p> <p>*19. : Many will suffer and parent/carers too. Life may not be worth living particularly for those in most need.</p> <p>*20. : Fast track to other means of support for high rate awards.</p> <p>*21. : This will severely impact on people with varying mental health conditions and people with learning disability. They should not have to undertake a f2f interview if information is given by health professionals involved in managing their health or care needs.</p> <p>*22. : As a parent/carer I am exhausted at the prospect of having to repeatedly validate my child's disability (present since birth) to obtain basic financial help and support. It is a constant battle for people with disabilities and their carers - completing endless complex forms and dealing with bureaucracy necessary for different kinds of support – an arduous task on top of having to care for someone with high level complex needs. I urge you to be mindful of the most vulnerable in our</p>

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		society, along with the needs of their carers.
EM660	16/02/2011	<p>I am e-mailing you the attached response to consultation of behalf of my mother who is carer for my sister. Regards</p> <p>* 1. : need for 24 hour care and support for all daily living tasks and for social and leisure opportunities; physical access to transport, services and amenities; additional cost of accessing appropriate and suitable services (including support costs) and purchasing necessary aids and adaptations.</p> <p>*2. : an individual can be awarded the benefit for a lengthy period of time if it is known that there will be no improvement in their condition (my daughter has been awarded High rate care and high rate mobility component indefinitely)</p> <p>*3. : lifelong 24 hour care and support, heating, aids and adaptations, transport, laundry, cleaning, clothing, bedding, respite,</p> <p>*4. : I am only aware of 2 or 3 rates at present for DLA</p> <p>*5. : a combination of approaches would ensure the most flexible and easy access to the benefit and help to ensure it meets people's needs adequately, and promptly, if necessary</p> <p>*6. : give people access to full and comprehensive assessment involving them and the important people in their life to ensure that needs are clearly identified and recorded- individual's situation should be regularly reviewed to ensure that their needs continue to be met. The most basic needs for any person are personal care and daily living and household tasks. However it is also extremely important for people to have support that provides for their social and emotional needs, for them to feel a valued member of society, able to contribute and participate.</p> <p>*7. : clear information about what changes people need to pass on and clear information about what consequences will result from such changes. People who are known to have a variable and fluctuating condition should be 'flagged up' in the system and their situation regularly reviewed within agreed timescales. Processes for reapplying, appealing and tribunals must be subject to clearer, stricter and quicker timescales for individuals to be better informed and for those administering the system to be held more accountable</p> <p>*8. : aids and adaptations should be taken into account because they enable people to lead more independent lives, however the impact of their health condition, impairment or disability should be clearly understood</p> <p>*9. : less repetition in questions asked; clearer and quicker timescales; better access to welfare advice; information through employers, GP's, job centres</p> <p>*10. : any professionals in regular contact with the individual and specialists who can comment on the particular condition that an individual has- i.e. GP and any other appropriate medical and healthcare professionals; social work, education</p>

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		<p>and support services</p> <p>*11. : irrespective of the background of the professional they need to be sufficiently prepared for the meeting by having knowledge of the individual's condition, have an open approach to gaining a full and comprehensive understanding of the impact of the condition on the person's situation, and not be restricted by using a limited set of questions</p> <p>*12. : if an individual is in receipt of high rate benefit and has a condition that will not improve then this case need not be subject to review (as is currently the case for my daughter). If a person has a condition that is known to vary and fluctuate then more frequent reviews would be helpful.</p> <p>*13. : ensure that people are fully aware of consequences of reporting/ not reporting changes.</p> <p>*14. : information on which agencies can offer support in completing forms</p> <p>*15. : it would be helpful if all claimants did access advice and support but the concern would be a delay in applications because of limited access to advice and support</p> <p>*16. : some aids and adaptations are funded by the individual and others through social work and this should continue to be the case</p> <p>*17. : needs of children should be assessed on an individual basis and reviewed regularly if required.</p> <p>*18. : motability car scheme, blue badge scheme, free bus pass etc are helpful entitlements and options linked to DLA</p> <p>*19. : impact on quality of life due to decreased access to transport, additional responsibility on carer, more complicated and lengthy processes to access other benefits and services</p> <p>*20. : I don't have an up to date working knowledge of the range of benefits and services but it would be helpful for information on the individual's condition/ impairment to be shared.</p> <p>*21. : introducing a new benefit could exclude people who already find it difficult to engage with services and experience barriers in accessing services due to language or culture</p> <p>*22. : I am concerned about how the changes will affect my daughter, unsure whether I will have to complete new application process and assessment when my daughter was awarded DLA for life at age 10. I feel this would be an inappropriate use of resources.</p>
EM661	16/02/2011	<p>Dear Sir / Madam, These are my answers to the questions regarding the DLA consultation:</p> <p>*1. Accessibility – ie, there being ramped access for people with disabilities who can't use steps Lack of understanding from non-disabled people.</p> <p>*2. The qualifying periods</p> <p>*3. Extra clothing / constant replacement of clothing Adapted equipment, such as reading aids Having to take taxis everywhere*Extra heating, water, etc.</p>

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		<p>*4. Having two rates means people will miss out. Ideally, there needs to be 3 mobility rates and maybe 6 care rates.</p> <p>*5. All should be based on care and /or mobility needs – excluding those with terminal illness.</p> <p>*6. Social activities. People do need to go out and do things with other people</p> <p>*7.</p> <p>*8. Aids that the disabled person own should only be taken into consideration. The limitations of these aids should be considered too.</p> <p>*9. There shouldn't be as many questions. It would be easier to ask the claimant to list things like – walking difficulties, help needed outside, help needed during the day and help during the night.</p> <p>*10. GPs, consultants and social services.</p> <p>*11. Many disabled people already see health care professionals. It's a waste of their time to see others.</p> <p>*12. The frequency of reviews should be determined by the persons disability. IE, there are people out there whose disabilities will either only get worse or stay the same.</p> <p>*13. 14. 15.</p> <p>*16. Many disabled people are having to save up their DLA to fund things. PIP should reflect the true cost and not just the fraction of costs. It's wrong that a disabled person can be left worse-off because of the cost of their disabilities.</p> <p>*17. 18. 19. 20. 21.</p> <p>*22. It's wrong full stop that DLA is being messed around with. If they mess around with DLA, it's only fair that AA is looked at too. Yours faithfully,</p>
EM662	17/02/2011	<p>My wife and I spent 2 days putting together a considered response in time for the deadline on this consultation only to find a day later that the proposals on which you purport to be consulting are included in the Welfare Reform Bill published today. I can only conclude, that like so much government consultation you have no intention of actually taking any notice of what is said to you. Presumably the intention is to get us to the point where we realise that we can have no influence and then when we all give up responding you can claim no one objects. *ADDENDUM*Further to my previous email, copied below, and to my joint submission with my wife to the consultation document, (now attached for the benefit of Claire Perry), I have now looked in more detail at the Bill and it appears that there are some significant differences between the consultation document and the Bill.</p> <p>*In particular, Chapter 2, para 41 of the consultation document states:</p> <p>*People who become disabled after reaching 65 will remain eligible to claim Attendance Allowance, which provides support based on care needs. However, at present claimants who are already in receipt of the benefit when they turn 65 may continue</p>

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		<p>to receive it past the age of 65, for as long as they require support.</p> <p>*I realise on rereading that this actually promises nothing, but the phrasing used is clearly intended to give the impression that the present situation would continue. Note the implied 'as' in the second sentence after 'However'. It could I suppose be taken as implicit in this statement that the status quo on retirement age is not to be maintained, but if that is the case this is a very manipulative way of saying so.</p> <p>*Sec 81 of the Bill says:*(1) A person is not entitled to the daily living component or the mobility component for any period after the person reaches the relevant age.*(2) In subsection (1) "the relevant age" means— *(a) pensionable age (within the meaning given by the rules in paragraph 1 of Schedule 4 to the Pensions Act 1995); or*(b) if higher, 65.*(3) Subsection (1) is subject to such exceptions as may be provided by regulations.*This proposal is unacceptable and inconsistent with the concept of DLA and its proposed replacement "as a non-means-tested cash benefit contributing to the extra costs incurred by disabled people." (Ministerial Foreword) . These additional costs do not disappear in retirement. The need to get about doesn't evaporate when you pass some magic age on which you become apparently only fit to stay indoors and watch TV. Removing both mobility and care allowances on retirement at a time when local authority care services are severely hard pressed is not going to help "disabled people to exercise choice and control over their lives." (Ministerial Foreword)</p> <p>*The publication of detailed legislation before the consultation period has even expired, the detailed changes in the Bill when compared to the present position and the wide use of secondary legislation in the Bill giving great power to the Minister of the day all add up to convince me of the truth of the recent words of the Deputy Prime Minister –</p> <p>***"I need to say this – you shouldn't trust any government, actually including this one. You should not trust government – full stop. The natural inclination of government is to hoard power and information; to accrue power to itself in the name of the public good."</p> <p>*Text of previous e-mail</p> <p>*My wife and I spent 2 days putting together a considered response in time for the deadline on this consultation only to find a day later that the proposals on which you purport to be consulting are included in the Welfare Reform Bill published today. I can only conclude, that like so much government consultation you have no intention of actually taking any notice of what is said to you. Presumably the intention is to get us to the point where we realise that we can have no influence and then when we all give up responding you can claim no one objects.</p>

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EM663	17/02/2011	<p>One of the reasons I can't live an independent and active life is my hearing problem when out and about I need someone with me if people are trying to speak to me and I cant hear them. I can't go swimming on my own or even a simple stop at the post office as the screen in front of me stops me getting close enough to hear what that person is saying it's so frustrating I have also walked across the road when oncoming traffic is coming as I'm not aware their coming from behind</p> <p>*I think people with a disability that will never change. Should never have to go through filling out forms again and again what a complete waste of time for the government and the person who could be blind or not able to fill in forms without the help.</p> <p>*One of the main costs for me is living in my own home. I need special equipment smoke alarm doorbell, that's lights up when some one is at my front door. A special alarm clock that lights up to wake me up for work, telephone I could go on as the list is never ending and all this costs money I don't have.</p> <p>*I feel that only having two rates for assessing some one with a disability is not right because different people have different needs and you will only fit in top or bottom</p> <p>*I think if you have a health condition that is under control but will never get any better you should automatic be entitled to disability living allowance. With confirmation letter from a hospital or GP.</p> <p>*People with a disability that with treatment can get better, and lead a full life should be the ones that feel in the forms on a regular base.</p> <p>*We can ensure that new assessment of people that have been awarded disability allowance. Can be monitored by means of DWP sending a form to be filling out that must be accompanied by a doctor's letter every 12/18 weeks.</p> <p>*I also feel that a disabled person who needs lots of help and aids to live a normal life, the assessment given should reflect this</p> <p>*I think it would be helpful if at the hospital or council there are staff on hand to help with filling in forms I have a big problem filling in forms as I find it hard to express my self on paper If you are a person who cannot read or write help will be needed and this help should be made known to people.</p> <p>*A clear assessment of a disability is a doctors/Hospital letter*I don't feel that a one to one with a healthcare person will be enough to process a claim, as that person will have no knowledge of the needs of the person standing in front of them or how they cope living in their own home and this will mean more stress to the disabled person attending that session.</p> <p>*As I already have stated above, the Doctor or hospital staff that are aware of the person in front of them can carry out Reviews</p> <p>*13 N.A. 14 N.A.</p> <p>*I would like to see more advise and support for claimants' who</p>

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		<p>are unaware of what they can claim I never made a claim for living with a disability for 17 years because I didn't know I could claim as I was a working person</p> <p>*I would like to see more information or booklets re: help for the disable at doctor's surgery or hospital waiting areas these booklet will be read while waiting for appointments</p> <p>*I so far have brought all my aids that I use in my own home I like to go on line to find out what new equipment there is to help hard of hearing people at home and at work</p> <p>*17 N.A.*I have been more than happy the way the DLA has been run these last few years and I am aware that the must be changes made but please look to the fraud cases</p> <p>*19 N.A. 20 N.A. 21 N.A.</p> <p>*I think it's the governments fault that were in this mess today because half of claimants have not been asked for evidence to support their claim, having been given the benefit based entirely on their original application form. The problem is there is no system of review. People can be given the benefit and no checks are made if they still need it.</p>
EM664	17/02/2011	<p>████████ Council staff member - profoundly deaf:</p> <p>*1) This depends on the nature of the disability. Most fully abled people are NOT disabled aware, which impedes people like myself participating fully in society and makes a full and active life difficult. I am profoundly Deaf.</p> <p>* 2) All allowances are subject to review, but the DLA should stay the same when addressing special needs and equipment. For example,*I need a vibrating alarm clock and a pager to vibrate and alert me to certain situations. Also my door bell needs connecting to the lights in my home and I require a mini-com to communicate with the outside world. There are many other things required, above are just a few examples. Subtitles on presentations and interpreters to ensure full understanding</p> <p>*3) Please see answer to question 2.</p> <p>*4)I don't believe the two components will be easier to understand at all. Having two rates can become very confusing, especially for Deaf people where English is not the first language</p> <p>* 5) This is difficult to answer. All claims should be based on the individuals needs and circumstances, but I think there will be several impairments that should have an automatic allocation of DLA..... i.e BLIND, Deafblind, Deaf, Usher sufferers. Basically, those with a 'sensory disability'.</p> <p>* 6) The activities essential for daily life are simply the basic ones:- Communication ability for ALL, also assistance in mobility. E.g. Signers and hearing dogs for Deaf people, and guides (or guide dogs) for the blind.</p> <p>* 7) This could be done by arranging an annual review of the assessment for each person.</p> <p>*8) The answer to this question is :- "Of course !" Any aids and adaptations they use are there to ensure quality of life, many of</p>

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		<p>them being absolutely essential. The assessment should not be about whether the disabled person already had these aids, but to ensure that the aids are available if easily obtained.</p> <p>* 9) You could make the claim form easier for Deaf people by providing a 'Sign Interpreted' DVD. People who are not 'Deaf aware' do not understand the difficulty congenitally Deaf people have with English. Thiis questionnaire for example is full of so many big and difficult words, all in the same sentence. It is very difficult to understand. You can improve the information by making a 'Signed' DVD explaining the questions in FULL.</p> <p>* 10) I believe the medical life records from a GP for example would help provide thiws information.</p> <p>*11) This would bring many benefits to the assessment, because it would be a chance to explain all difficulties being experienced by the client. A face-toface meeting with a health professional would be good, but it is IMPERATIVE that a 'Sign Interpreter' is present if the health professional does not know BSL (British Sign Language).</p> <p>* 12) I am not a health professional, so I cannot answer this question. I think reviews should be annually. The second part of the question, I agree that different types of review should be incorporated depending on the needs of the individual.</p> <p>* 13) I'm not sure how you will encourage people to report changes. However, with an annual review, these can be questioned, also finding out when the changes actually took place.</p> <p>* 14) I think the best advice would be to explain that if changes are not reported, the PIP could be affected and possibly changed. The DWP perhaps could include video streaming on the website explaining this in Sign language.</p> <p>* 15) Please see answer to question 14. I can only really speak for the Deaf community, but I can say, try and avoid sending out letters with professionally structured sentences and large words such as 'amalgamate, consequently, remuneration etc. People born Deaf, or became Deaf as a baby find this very difficult to understand</p> <p>* 16) Aids and adaptations are normally claimed for, or are provided through several organisations, such as deafPLUS etc. I think an option should be arranged via the PIP to meet one-off costs.</p> <p>* 17) When assessing children, their Education and educational needs are paramount to be taken into account. This is the main difference that should never be ignored or taken lightly. More Deaf children are being educated in mainstream schools now and facilities for them are important. Refer to Thomas Tallis school in Kidbrook South London. Good example. Education is the main difference.</p> <p>*18) The DLA has been VERY important in assisting disabled people to access other services and entitlements. I think a big improvement would be to have a member of staff who can 'sign'</p>

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		<p>at every job centre. There is a lot of time wastage and delays when appointments have to be re-booked when an interpreter is available.</p> <p>*19) I think if the PIP was not allowed to link to other services, it would be a step backwards for the disabled community.</p> <p>* 20) All assessments for various benefits and services should be combined as per the needs of the person. They should then be referred to when having a review. Hopefully bureaucracy and duplication should then be at the minimum.</p> <p>* 21) Again, this is a very difficult question for me to answer. I really have no idea of what kind of impact this will have on 'equality groups' but I have no doubt some comments will be made.</p> <p>* 22) Yes, indeed, there is one thing I would like to say VERY passionately. This survey would have been sent out to many Deaf people. It should be understood in basic 'Deaf awareness' that these questions were almost impossible to understand. They should have been set up in a much simpler format. You use words like 'component', 'fluctuating' and 'administer' in the same sentence. People born Deaf would find this almost IMPOSSIBLE to understand. I needed to ask a hearing friend of mine to assist me in answering this survey. Please note this for future questionnaires.</p>
EM665	17/02/2011	<p>Dear Sirs, I've met someone recently who, through no choice of his own, has been forced to stop working as he suffers from progressive multiple sclerosis. He is now significantly disabled and relies solely on benefits including DLA.</p> <p>*David Cameron questions his commitment to working. There are undoubtedly a huge number of people who claim benefits when they could quite legitimately work. Nevertheless, I am stunned that you question cases such as his. He has become a vulnerable member of society through no choice of his own. I know for a fact that he would much rather be out working (as he was able to do - and did do - until only quite recently) than relying on benefits.</p> <p>*Our benefit system was designed to help people like him. He maintains a remarkably positive attitude but this review, and the possibility of having what little income you give him being taken away or reduced, is depressing him enormously.</p> <p>*I urge you to remember that there are people in our society that genuinely need our help and are not playing the system.*Yours faithfully,</p>
EM666	17/02/2011	<p>1. What are the problems? Difficulty gaining employment due to employer attitudes, lack of awareness of Access to Work, lack of flexible or part time opportunities, inaccessible buildings.</p> <p>*Public transport difficulties; buses and trains inaccessible or ignorant staff. 24 hour assistance booking for trains reduces spontaneity. Lack of accessible housing.</p> <p>* 3. What are the main extra costs that disabled people face?</p>

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		Equipment, travel, heating, carers.
EM667	17/02/2011	<p>This is my response to the DLA consultation, I have also attached it as a word document.</p> <p>*I currently receive higher rate mobility and higher rate care, this DLA award has very recently been increased from the original award of Lower Rate Care after I applied for a supersession due to decreasing mobility and ability to look after myself. I have a rare genetic Connective Tissue Disorder called Ehlers-Danlos Syndrome, Chronic Migraine with Vertigo, possible POTS (an Autonomic Instability Syndrome) and Chronic Pain Syndrome. EDS effects the connective tissue in the body making it too lax and loose. The type I have mostly affects my joints, but also some of my internal systems and organs and my skin. I suffer regular joint sprains, strains, subluxations and dislocations, along with the tissue damage that goes with them. My muscles ache and I get exhausted very quickly from the extra effort it takes to try and hold my body together. But my condition fluctuates, some days are better than others (I might only have my shoulder and thumbs out, instead of all of those plus a knee and a hip plus a migraine and vertigo with severe nausea). I've explained this so you have an idea of my responses are coming from. Everyone is different, I know a lot of people who have the same condition as me and none of us are affected in exactly the same way. Some of us have other conditions as well or were diagnosed early and responded really well to treatment, while others like me had to wait years to be diagnosed and suffered from inappropriate "treatment" which just made us worse.</p> <p>*1. This depends very much on the person in question and the type of disability or health condition they have. What if they suffer from agoraphobia? Or are deaf-blind - in which case it it a combination of societal limitations, limitations in care provision, accessibility - both of housing and public places, poverty. Other conditions such as mine can be looked in terms of both the medical and social models of disability. I use crutches and can only walk a short distance from my car, yet many city centres now are pedestrianised, so I can only go a very short distance before I need a substantial rest. I am limited in buildings I can use by stairs and lack of lifts, but am equally limited to activities I can do by the limitations of my body.</p> <p>*2. The name. Motability. The fact it is a cash payment that the claimant can spent on anything they need to. The use of evidence from our own doctors, specialists and carers to prove eligibility should be enough to negate the need for expensive, outside-sourced "medical professionals"</p> <p>*3. Transports costs - I can't walk to my nearest bus stop, it is too far and too steep, so I have to drive everywhere. I use DLA to help run my car. To help pay my heating costs, as I feel cold all the time, I have the heating on more. For care - either for</p>

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		<p>social services or private care. For prescriptions or other medical products - I use heating pads to help ease my pain, they cost from £2 each and only last 8-12 hours. Special foods - wheat free, gluten free, lactose free, etc. Continence products, feminine products, TENS pads. Splints, mobility aids, alternative therapies, private healthcare, glasses, dental care.*Personal Assistants/Carers.</p> <p>*4. • Will having two rates ...? No - it is not hard to understand now. Having two rates of care will just mean that you cut a lot of people off from support and make their lives much harder, probably ending up making them worse in the process. Most people applying do not try and work out every single possible rate they could end up with, they just hope they end up with something.</p> <p>*• What, if any, disadvantages ...? By removing eligibility from people with 'lower' needs, you will only be increasing their problems and increasing their needs, so creating a larger problem for yourself in the long term. You are also pushing them further into poverty and further increasing their chances of developing a poverty related health condition which could cause an even greater increase in their 'needs'.</p> <p>*5. Some conditions should receive automatic entitlement, such as those registered as blind, those that have received an electric wheelchair from the NHS (as eligibility is so tough for this).</p> <p>*6. How can you prioritise support? By saying one person is more worthy than another?</p> <p>*To enable people to live full and active lives they should have access to all the services and facilities to which everyone else has access. This should include social, work and family life. Currently grocery shopping is excluded from DLA as something you can say you have difficulties with, yet it is one of the most basic and essential activities carried out in everyday life. This activity should be allowed under any new reform legislation.</p> <p>*Carrying things, such as a shopping bag was excluded from my recent award as something I have difficulty with. They can't take things like that into account apparently?! I use crutches, it is really pretty impossible to carry a bag with crutches. I carry essentials in a small rucksack but because of my shoulder instabilities I can't carry heavy things in here. I think the means in which one transports objects about is fairly essential to everyday life.</p> <p>*For mobility - walking outside is limited to a level surface and the DWP won't take into account how you cope on ramps, inclines, etc. But that is just not realistic to an outside environment, even the shallow incline of a dropped curb can be enough to make my knee dislocate. Many companies think that putting a ramp in is all they have to do to make their building accessible, but these are often unacceptably steep even just to walk up or down. My hip and knee joints are more unstable on</p>

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		<p>inclines and more prone to dislocating. Just because the DWP says they can't take that into account doesn't mean it doesn't happen. Any reform should be more realistic and based on real life situations</p> <p>*7. Any assessments must be subjective, as objective assessments simply cannot take into account all the differences between different claimants or subjects. I have a fluctuating condition and wrote what a typical good day, average day and bad day was for me. Then I wrote on average how many of each I had experienced per month in the last 3 months. I think that would give a fairly good overview of the variability of a person's condition/s. Maybe there could be a question to fill in for people with fluctuating conditions with this approach.</p> <p>*8.No*What aids and adaptations should be included? None</p> <p>*Should the assessment only take into account aids and adaptations where the person already has them or should we consider those that the person might be eligible for and can easily obtain? *You cannot possible take into account aids that a person does not have, even if they are 'eligible' for them - I have been waiting for an appointment with wheelchair services since September 2010. I have been informed by them over the phone that due to my complex needs I will very probably get a voucher, which will not cover the cost of an appropriate wheelchair and so I will have to save up over several months (or years) to be able to get one. Even then my condition means I will have difficulties using a manual wheelchair, but I am ineligible for a power-chair. A wheelchair will increase my ability to get about slightly but it won't make me equal to an able-bodied person in terms of mobility. I will still need to park in a disabled space, cobbles and other 'trendy' paving will be very difficult for me. Steps will be completely out-of-bounds, as will escalators, so thats even more buildings and environments I'll be shut out of than I am currently using my crutches.</p> <p>*An example of an aid I actually have; I have an Sacro-iliac belt which helps to hold my pelvis and hips in place, so they don't slide around and dislocate when I walk. But I don't wear it all the time, for a start it would cause my lower core muscles to begin to atrophy (a bad idea!). But the second reason is, to check it is in the correct place (i.e. holding my hips in their sockets), I have to 'try' and dislocate my hip. If it pops out, the belt isn't in the right place, if it stays in joint then the belt is on fine. I have to check several times, each of which is acutely painful until it is on correctly. I have to wear this belt over my trousers as it tears my fragile EDS skin otherwise, that means I have to take it off every time I go to the loo and put it back on again, starting the whole rigmarole over again. So I only wear it when my hips are really bad!*For other aids - a white stick does not make a blind person see, e.g. it can't help them read road signs to tell them a pavement is closed, or see if a car is coming. What if it gets broken when they are out? It is an "AID"</p>

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		<p>the clue is in the name, these are tools which aid us to try and live lives that are a little more equal and independent. They do not magically make us able-bodied or able to overcome all the societal boundaries in our way.</p> <p>*9. The language and information regarding DLA is badly written and unclear and there are very few official explanatory notes or definitions available. For example “Virtually unable to walk” - this is confusing in the context in which one can claim, using the disclaimers of ‘severe discomfort’ or ‘extremely slowly’ or ‘out of breath’. None of these are explained on the very simple ‘quiz’ which you can use to check eligibility. There also appears to be no official definition of ‘severe discomfort’ - although searching through tribunal reports has come up with ‘it is less than severe pain’. This lack of clear information and confusing language, seems designed to put people off from applying in the first place. Indeed I tried the little quiz and it said I wasn’t eligible, so I didn’t apply for nearly six months until a disabled friend said I would be eligible and explained this better.</p> <p>*10. Evidence from claimants GP, carer, family members, other healthcare providers, specialists. These are the people who are involved in the day to day treatment and care of the claimant and should know them best.</p> <p>*11. • What benefits or difficulties might this bring? I can see no benefits to it, the difficulties will be; additional cost to the taxpayer, additional stress for the claimant, worsening of mental health conditions and stress related conditions, no doubt an increase in refusals of claims and an increase in appeals and tribunals.</p> <p>*• Are there any circumstances location? For those patients whose eligibility is unquestionable, certain mental health conditions.</p> <p>*12. • What evidence and/or criteria ...? The nature of the condition - is it likely to get better, to get worse, to stay the same. Other conditions they also have. The age of the claimant could also be a factor in this, i.e, very young claimants can change as they come out of adolescence. Older claimants may degrade quicker. Evidence from their own GP’s, other healthcare providers and carers • Should there be different types of review ...? Yes - this is obvious.</p> <p>*13. It would probably be better if there was a step down system. If they reported that they were a bit better, they could be moved to a lower award for a while, rather than completely removed, to see if the change was permanent. Or changed down over a period of months, just so the financial change wasn’t so extreme. Many people on DLA would be living in poverty were it not for their DLA. Perhaps offer a financial counseling service to coincide with removal of awards, to help them cope with the reduction in income.</p> <p>*14. A detailed analysis of why you have scrapped DLA, with a</p>

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		<p>cost-benefit analysis showing the administration costs required to scrap DLA and start PIP. Some clear explanatory notes, with definitions of terms clearly given and places where advice or help on filling out forms can be found (CAB, etc).</p> <p>*15. What does this question relate to? Does this mean in relation to applying for the benefit or once the award has been given? This is really not very clearly written at all - maybe you could get someone to proof read your notes for your application, so that they actually make sense.</p> <p>*If this means forcing people to take up support, then no there should not be a requirement. Many people get support from friends and family on an ad-hoc basis. Council services are being severely cut, so many people are ineligible anyway.</p> <p>*16. However they can! Loans, credit cards, DLA - higher rate mobility in exchange for an electric wheelchair, applying for charity funding, NHS funding, saving up DLA over time, loans from family. Most people need their DLA every week for everyday funding, so can't afford to be without it for a while for a big one off cost.</p> <p>*17. That parents of disabled children often have to struggle with more than one child, you are really assessing the parents as much as the child. Besides I thought that you hadn't decided whether you were including children in this reform yet?!</p> <p>*18. Incredibly important, but equally it can be linked a bit too much. Whereby before I got DLA, even though I wore splints and used a walking stick I couldn't access a lot things meant for 'disabled' people because I didn't have DLA. I have only just been able to get a disabled rail card through getting HRM, fortunately I was able to apply for a Blue Badge at my local council and get one prior to getting DLA, but I know a lot of friends with EDS around the country who were not as lucky.</p> <p>*The current DLA entitlement certificate is on an A4 sheet of paper that I have to carry about. Surely a credit card type plastic wallet sized card would be a bit more 21st century?!</p> <p>*19. I would not be able to get a disabled train card, it is linked to my housing benefit, I am eligible for accessible housing because of getting HR-DLA, I get the disabled car tax rate which has enabled me to keep my car on the road, so I am not house bound. For service providers it means they do not have to devise their own methods of assessing people for disability related benefits or discounts, they have a award letter they can look at.</p> <p>*20. DLA assessments should be kept separate as this is non-means tested and does not depend on your ability to work or whether you are in work or not. Likewise the assessment for ESA is looking at different aspects of your abilities and is specifically looking at your ability to work.</p> <p>*21. This could mean that disabled people are less able to take part in society, either through work or socially. By only focussing on those "who face the greatest challenge", you risk</p>

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		<p>condemning a great many other disabled people who currently have 'lesser barriers'. If these people do not get the support they need, then their needs will only increase and you will have increase the numbers facing the greatest challenges. You also only seem to be focussing on physical disability and not sickness, ill health, mental health or learning impairments.</p> <p>*22. These proposals strike me as badly thought out and backed up by purposefully misrepresented data. Your only true goal seems to be to cut out a great swath of the numbers of people who are eligible to claim this benefit - by 20%. This is though the DWP's own reports put the fraud rate for DLA at just 0.5% and also say that it is massively under-claimed.</p> <p>*You say that you want to move the benefit into the 21st Century and move it on from the thinking of 20 years ago. How exactly have the needs of disabled people and those with ill health changed in 20 years? Life is still comparatively more expensive than for unaffected people, therefore there is still a need for a benefit that recognises this additional expense. You also say that there has been increase in the number of DLA claims (by 30% in 8 years), yet seem to have completely ignored the fact that the population grew by 5% over the same period, there was a huge demographic shift with our aging population and there is a hugely increased awareness of DLA because of the internet. Many of the people who applied and where granted DLA 20 years ago will now be over 65, but are still receiving the award (because they are long-term disabled!). There has been no increase in the flow of working age claimants on to DLA, according to DWP figures quarterly on-flows fell significantly over the period from 2002-10, as shown below.</p> <p>*It seems as though the government greatly underestimated the numbers of people who could claim for DLA. Even though the DWP say it is under-claimed to a vast extent, you are saying that you want to slash 20% off the numbers currently claiming. Why have you come up with this number, if this is not simply a money saving exercise. This number was given as the saving months and months ago, long before the consultation was released. To say DLA is unsustainable is to say ill and disabled are unsustainable. This kind of thinking can lead nowhere good.</p> <p>*I would like to copy in some text of a debate from the House of Commons delivered by Mr Andrew Lansley on 8 Dec 2009, when the Conservatives were in opposition;</p> <p>*Mr. Andrew Lansley (South Cambridgeshire) (Con): I beg to move,</p> <p>*That this House recognises the vital support that attendance allowance and disability living allowance provide for people with disabilities; notes that these benefits are intended to meet the additional costs of living with an impairment or long-term health condition; further notes with concern that approximately 2.87 million people in the UK who receive disability living allowance</p>

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		<p>or attendance allowance are not eligible for social care services; acknowledges that some 20,000 individuals have petitioned the Prime Minister and many more have petitioned individual hon. and right hon. Members to ensure that these benefits are secured; welcomes the Government's announcement that disability living allowance for people under 65 years will not be scrapped; and urges the Government to ensure that attendance allowance and disability living allowance for people aged 65 years and over are secured and not abolished as part of any future reform of the social care system.</p> <p>*The House will no doubt be aware that the motion is in exactly the same terms as early-day motion 1.*Reference - Hansard - Commons Debates - Volume No 502 - 08 Dec 2009 - Part no. 12- (Column 154) - Opposition Day - Disability Benefits for the Elderly*As you can see, the Conservative Party have previously supported DLA and fought against scrapping it. Indeed in the run up to the election you promised to support the most vulnerable of us, but now you seem to be attempting to rip all support away from us.</p> <p>*As for your discussion of universal credit - this is relevant to DLA how? Many people with disabilities or health conditions work, so this does not apply to them at all, and you have already explained that DLA will remain outside the UC system.</p> <p>*I have many friends with disabilities or health conditions, and therefore many friends on DLA. Not one of them thinks it is an out of work benefit, in fact the only people who think that appear to be government ministers and Daily Mail readers. It has been inaccurate and misleading governmental speeches by the likes of Ian Duncan-Smith and Chris Grayling that have spun confusion and outright lies around disability benefits as a whole. People who are actually claiming them know what they are for and why they are claiming them. The reason a great many people claiming DLA are out of work is because they are too ill or disabled to work, or because they are under 16 or over 65.</p> <p>*By claiming that the benefit can act as a barrier to work you have shown that your ability to utilise statistics is worse than a three year old. Correlation does not equal causation! Many people on DLA who have jobs use their DLA to keep their job. Whether this is by renting a motability car, using their mobility allowance on taxis, hiring a PA, hiring a carer or getting meals on wheels in the evening. Cutting their DLA will mean they can no longer cope in their job and they will become completely dependent on the benefit system.</p> <p>*People who are on higher-rate awards tend to have the most complex needs or severe disabilities, which is why they are less likely to be in work.</p>
EM668	17/02/2011	1. 1) Abuse and discrimination from the public. In shops particularly, customer service personnel will address my

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		<p>assistants and not me. Few venues, shops and events have adaptations, for people with disabilities.</p> <p>*2) The lack of constant support; when aided I can do much, but little when unaided.</p> <p>*3) The need to rely upon support assistants to perform many tasks. The added expense of having to (often) purchase two admissions, to any event I attend, due to the need for an accompanying assistant and the exorbitant price of adaptive technology.</p> <p>*In addition, Access, communication, information, peoples' attitudes to disabled people, hostile press, physical barriers, lack of accommodation e. g. inaccessible buildings/hotels and in information in lack of accessible formats, lack of money, lack of accessible transport and housing, continued segregated education, lack of education and information for employers who believe disabled people are unemployable, problems in accessing goods and services, the closure of the Independent Living Fund, the withdrawal of the mobility component of DLA from those living in residential homes and centres of Independent Living and Integrated Living under threat from lack of funds.</p> <p>*2. DLA as it stands has served the purpose it was intended for i.e to pay for the extra costs of disability that disabled people face. The allowance should stay the same as a whole. There is no need to change this By the DWP own figures the fraud rate for DLA was 0.05%. There is no reason to change from DLA apart from the cuts agenda and the continued demonising of disabled people.</p> <p>*3. Travel, fuel bills, food (if dietary problems are involved restricting diet), additional wear and tear on clothing and footwear*There are a number of extra costs for disabled people. For me, the principal ones are those such as heating in the winter time. Also there are additional expenses that relate to things to do with issues of dignity an example of these are continence pads. Due to the problems a person might have with preparing food there is also an extra cost in buying prepared food. This would not affect others who do not have a disability because they would be able to buy the ordinary un-prepared version. Wear and tear on clothes and shoes due to the difficulties brought about by awkward movement also presents an extra cost. Transport cost for taxis and so on create a significant extra cost. DLA helps bridge the gap. DLA counts towards the eligibility to qualify for the ILF *I have to buy, repair, maintain, service and insure my wheelchairs. I use extra electricity for charging my powerchair.</p> <p>*My condition worsens when it is cold, therefore I need extra heating throughout the winter.*I have to pay for sundries like cervical collars, support belts, pushing gloves etc.*I have to pay the extra cost of taxis for transport.</p> <p>*4. Your response: Rates proposed are 'daily rate' and mobility</p>

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		<p>rate' this would appear to be abolishing the 'care component' posing the danger that those with higher care needs will be factored down while those with assessed low daily needs will be factored out of the new benefit entirely. Also both suggest that night time care needs will not be catered for.</p> <p>*Any reduction would jeopardise peoples' support needs. Those who require a lower or medium level of support could lose out altogether. Although the higher rate is vital, I can envisage that compressing the rates would be to the detriment of others.</p> <p>*It depends on what the rules governing the new PIP's are.</p> <p>*The DLA does need to be reformed, mainly to include more people.</p> <p>*The PIP appears to be geared to getting people into work, if disabled people were guaranteed a job that would be great for many of us, but the DLA was designed to pay the extra costs associated with severe disability. In addition, a recent survey claimed that only 8% of employers would employ someone who had previously claimed incapacity benefit.</p> <p>*I see this as a cost cutting exercise with the emphasis on getting people onto cheaper benefits. There should be one rate and all eligible people who qualify should get it. This will only benefit the Department of Works and Pensions, it will have dire consequences for those defined as being lower rate recipients, if their benefits are reduced. How is this 'person-centric'?</p> <p>*This 'which box do you fit in' approach is an inaccurate, inflexible and inappropriate method of defining need; the correct question to ask disabled people is: 'What does your disability prevent you from being able to do; which you would normally be able to do?'</p> <p>*5. Yes, as now those with terminal illness and other current identified groups should have automatic entitlement.</p> <p>*6. Your response: See the UN Convention on the Rights of Persons with Disabilities. The European Human Rights Convention</p> <p>*7. Your response: set the criteria at the worse possible day for those with fluctuating and variable conditions. Take full account of individual experiences and their own assessments of their impairment.*8. You are trying to compress two very different questions into one. No, aids and appliances should not be considered, as a disabled person without any aids they may use, is still a disabled person. Stop trying to belittle the effect of disability upon people. A person's ability should be assessed without any aids or appliances', it is the person you are assessing, not their equipment.</p> <p>*You could assess what could be purchased for a person to help them live as normal a life as they can, then purchase it for them. Remembering that technology breaks, stops working, needs batteries (in some cases) and is never 100% reliable. When such aids or appliances fail, the disabled person is returned, instantly, to their unaided disabled state.</p>

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		<p>*No, some people don't use aids or adaptations but you cannot draw the conclusion that support and financial assistance are not required. People with invisible impairments or learning difficulties are still entitled to the benefit.</p> <p>*Assessment should consider the future need for disabled people whether they [aids] are easy to obtain or not.</p> <p>*Aids should not be taken into account the new PIP, does not take proper account of the social model of disability. DLA was meant to take disabled people out of poverty. The rates at which it is paid do not reflect reality.</p> <p>*No aids should be included as this goes against the social model of disability.</p> <p>*DLA helps towards the cost of equipment and maintaining that equipment. Therefore, to argue that using equipment is a reason to reduce the amount of money a person needs is wrong because the need for equipment does itself bring an extra cost.</p> <p>*9. Easy read as standard would make the claim form easier to fill in for all. Information should be available in many different formats and distributed through a number of outlets including the internet, CILs, CABs, Local authorities, Job Centres, Surgeries (Drs and MPs), the voluntary sector.</p> <p>*10. Your response: The disabled person themselves and/or a doctor or nurse that has treated and understands the person's impairment.</p> <p>*Obviously letters from hospital specialists, GP's, physiotherapists and people who know you, will give a clear history of the claimant...but are they taken into account?</p> <p>*You should also consider evidence from carers, social workers and occupational therapists.</p> <p>*Evidence should come from the disabled person themselves. If so-called "healthcare professionals", are to be used, they should be someone who is known to the individual. This could be a GP perhaps. Evidence should come from people who genuinely know how the claimant is affected.</p> <p>*Assessment should be performed by people that actually know the person being assessed. Professionals such as the applicants own General Practitioner, their social worker (if they have one). It should most definitely not be performed by someone who has only just met the assessee, with many more persons to assess before they get paid. Professionals with experience of disabilities and the effects of such, upon the people suffering them, should be used, not paid professionals incentivised to fail applicants (assesseees). * Assessment could be done by self assessment or peer assessment. Disabled people are the experts! Healthcare professionals will be driven by cost cutting and targets as they are now with Incapacity Benefit to Employment Support Allowance.</p> <p>*11. Your response: face-to –face is normally beneficial. However, the interview would have to be extremely well</p>

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		<p>prepared e.g. interrupters/access/loop/systems ect. Also there needs to be recognition that some people can't explain themselves to strangers. Therefore appropriate support should be available or the option for a support person to be part of the process.</p> <p>*Some professionals try to cut allowances, some professionals are good. It's better to meet with them on neutral ground, waiting times and access can be a problem.</p> <p>*If I must be examined by a health professional, I do not want them in my home!*It depends upon the persons' disability, how it affects them, what form the interview takes. If a person's family, co-tenants, or assistants are not privy to the actual medical nature of the person's disability, it may be inappropriate, for this interview to commence with them present. This may seriously compromise ones' privacy and human rights. Assessees' may have gender issues or feel intimidated by the interview process where ever held. In cases of learning difficulties people may not understand the process of assessment, the outcome or the ramifications there of.</p> <p>*The medicals are carried out by private medical services. They do not appear to take into account any proof provided by the claimant, and the assessment is by a stranger over a 15 minute period.</p> <p>*These companies are paid on results; therefore the medicals are skewed in favour of declaring individuals as fit for work, even if it is clear they are not.</p> <p>*Too many appeals are overturned by tribunals, in favour of the individual.</p> <p>*12. Your response: Reviews should be carried out as requested by the 'client'. Medical evidence through the individual's own GP or consultant should be the only criteria. It is unacceptable to do otherwise as reviews cause extra stress and if unnecessary they achieve little and constitute a waste of resources.*No, there should not be different types of review, only in as far as support and access needs for particular individuals.</p> <p>*13. See answer above.</p> <p>*14. Your response: criteria, an overview of the assessment criteria and process for the assessment itself. In addition, clear examples of the types of evidence that can be presented to the 'health professionals'. The length of time the assessment will take, clear and accessible advice on processes for taking an appeal and transparent figures on the ways the system is working i.e. those assessed as eligible for PIP those assessed as ineligible, those winning appeals against decisions where the 'health professional' has declared the person ineligible for the benefit.</p> <p>*15. Your response: Yes. See above</p> <p>*16. Your response: Disabled people fund their aids and adaptations in a variety of ways. Given the prevalence of aids</p>

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		<p>and adaptations, changing needs, breakages and the speed of technology improvements funding a one off cost is unlikely to be satisfactory for most people. The funding of continuous costs would be a better option and a more realistic one in terms of satisfying disabled peoples' requirements, although not in terms of satisfying the 'cuts culture'</p> <p>*17. Your response: These should be obvious. Clearly you need to consult with organisations that support disabled children through the social model of disability and ask the children themselves.</p> <p>*18. Your response: The 'passporting' arrangements work very well, if anything these should be improved, upgraded and extended, but only if all those now entitled to DLA will be entitled to PIP, this seems unlikely.</p> <p>*19. Your response: The implications would be further social isolation, further poverty and a further attack on disabled peoples' independent living options.</p> <p>*20. Your response: none unless the disabled person agrees to share information.</p> <p>*21. Your response: The proposals if carried out will have a obvious damaging effect on disabled people as a whole who endure higher level of poverty than other groups, on those within that group that face the greatest relative poverty, for example women, certain ethnic minority groups, and directly or indirectly children both disabled and non-disabled in families with a disabled parent.</p> <p>*22. As the government has announced a commitment to reduce DLA case loads by 20% despite a fraud rate of just 0.05% based on the Department of Work and Pension's own figures, there is understandable scepticism around this particular consultation. The closure of the Independent Living Fund (ILF) at the same time as disability Minister claims to want to support those disabled people with the greatest needs makes claims of supporting disabled people with the greatest 'need' difficult to comprehend. *In addition DLA at the higher rate is necessary to qualify for ILF, although this is now restricted to existing ILF claimants only, the scrapping of DLA does not appear to have been taken into account for this particular context. *There remain deep concerns at the level and ferocity of the changes to disabled peoples' rights and benefits being imposed by this government in view of the short and long term impacts on disabled people and on the higher long term costs that the removal of preventative and subsistence based benefits to pay for the extra costs of disability (such as DLA) will bring about.</p>
EM669	17/02/2011	<p>We write in relation to the consultation further to the proposed cuts on DLA. We claim DLA for our daughter who is diagnosed with Dyspraxia and Aspergers Syndrome. We feel strongly that the DLA should not be seen as an easy or soft target.</p> <p>*Our Daughter is a very complex individual who can appear to</p>

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		<p>be coping with her life. Consequently she may be assessed as not suffering from a disability. This would hide the reality and may mask the significance of the issues which she faces in coping with day to day life. The impact would be on our daughters future since she is not likely to access the earning potential of others. The protection provided to her by the DLA continuing will make a huge difference to her life in future years and we would not wish to see this cut. We do not see that cutting DLA of the most vulnerable members of society is fair and equitable - it is surely just an easy grab that will be below the radar of the media. The carers allowance should not be means tested. Such an approach would punish those who perform a valuable service in society. If this service had to be paid for by local authorities the cost to the tax payer would be significantly higher. We trust that you appreciate the situation and welcome our contribution to the debate. Regards</p>
EM670	17/02/2011	<p>As a tax payer, it makes me feel better to live in a country where vulnerable people and people down on their luck are ensured good living conditions. The very idea that people go on DLA to dodge a job is ludicrous given the amount DLA pays compared to the average job. And supposing that's the case for a couple of people, then the problem would be with a job that pays misery, not with DLA as it is.</p> <p>*I don't think ill people should be made to work shifts at Mc Donalds for the rest of their lives because employers for the occupation they did before getting sick are unwilling to take the risk to employ them, or to adapt the working conditions for them.</p> <p>* If the government really wants to integrate disabled people more in the workplace, then they should start by making drastic reforms of employment law:</p> <p>*stricter anti-discriminatory law, with more obligations to adapt working conditions for employee welfare</p> <p>*stricter bullying and overworking control, to avoid people getting mental health problems from stress in the first place and ending up on DLA for depression (starting by removing the opting-out of the 48 hour maximum working week). Depression and related problems is the primary cause of people being on long term sick leave.</p> <p>*If they took those steps, I bet many people currently on DLA would go off it by themselves, and the government would save money. And the people still on DLA would just be the people too ill to work, and a civilised country should take care of them.</p> <p>*I am not on DLA, neither a social worker nor a lawyer or any kind of specialist of the issue and am therefore only qualified to comment on general policy principles and not on the practical implementation details discussed in the more technical questions.</p> <p>*I very much hope that the government consults Disabled People organisations, lawyers specialising in discrimination and</p>

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		<p>other specialists of the issue before deciding on changing a law that has direct consequences on the life of vulnerable people. I hope that they do not just ask the opinion of random members of the public eager to rant about social problems they have no in-depth knowledge of. Yours sincerely,</p>
EM671	17/02/2011	<p>1. They are so many and varied, depending on the disability. Perhaps that in itself is the problem. A lot of adjustments made assume that you are in a wheelchair. Take my city's brand spanking new state-of-the-art public library. You have to go down several steps to get into it. Yes, there is a wheelchair ramp but that it a long way around. I can walk.... A little. But every step hurts me. I can manage stairs....a bit.... But it's hard, painful and scary because my balance is so poor. Do I risk the few steps down? Or do I go the long way around, by the ramp, which will take me so very many steps?</p> <p>*Hidden disabilities are hidden. People think you don't look disabled so don't make adjustments.</p> <p>*I think the single change that would be most helpful is for people, employers, the government and the public to realise that disabilities take many forms, may not be immediately apparent, and the sorts of adjustments needed are accordingly very varied. Only the disabled person themselves can say what they need.</p> <p>*A further issue is the blurring of disability into illness. In my case, it is my chronic illnesses that make it hard for me to work, which for me is key to participating in society and leading a "full, independent active life". Whilst disabled people are protected by employment law, the chronically sick have much less protection.</p> <p>*And finally.... Parking spaces!!!! If I can't be sure of being able to park very near to where I can't go out. I can't go shopping. I can't go to the cinema. Not enough spaces are provided and in my city centre, for example, the assumption is that you're in a wheelchair and can park in the multi-storey car park and traverse significant distances.</p> <p>*2. It should remain non-income based, and be paid regardless of whether or not you're in work.</p> <p>*It should be disregarded for assessing other benefits.</p> <p>*It should continue to have a mobility element and a care element, since care and mobility are 2 separate things.</p> <p>*3. It varies so much by disability,*For me, the key additional costs are:</p> <p>*Mobility: I have to run a car, and I have to use it for very short journeys that other people could make on foot. I cannot on the whole use public transport, and if I do manage to get to London by train, for example, I have to use taxis within London.</p> <p>*Care: there are a great many tasks I cannot undertake around the house, and I am dependent on paid carers. The care component of DLA nowhere near covers the real costs of care, but I get funding from Social Services as well.</p>

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		<p>*There are many, many little hidden costs.</p> <ul style="list-style-type: none"> *• It costs me far more to heat my house because I can't move around enough to keep warm. *• I cannot necessarily get to the shops that offer best value. *• I have to buy a lot of things online and pay postage. *• I am more dependent on the internet and the telephone than someone who is able-bodied. <p>*4. The risk is obvious: people who previously qualified for the middle rate will get bumped down to the lower rate. I can't see any fair way of transitioning them.</p> <p>*5. I don't feel qualified to answer this. I would have thought that the vast majority of situation need to be assessed on the degree of disability of the person applying, but there may be some health conditions which should always entitle someone to DLA.</p> <p>*6. Food, shelter warmth, social contact, companionship, physical safety, some meaning that makes life worth living.</p> <p>*One thing that worries me a lot is how fluctuating conditions are handled. A great many – perhaps the majority – of disabled people have conditions which fluctuate from day to day and week to week. Over the course of, say, a 3 month period, their condition may be profoundly disabling, but they may have some good days where they are able to do more than usual. I know people on DLA who are scared to enjoy walking down their garden on a good day, in case they lose their DLA, when 13 days out of 14 they are in too much pain to get out of the house. This is wrong. The benefits should allow for this variation, and should actively encourage people to make the best of what they have on a good day.*By "how do you prioritise?" do you mean "How do we decide how to cut our benefits costs?". The criteria for DLA are already stringent. Short of outright lying on the form, you already can't get DLA unless you really need it.</p> <p>*7. The questions need to ask about bad days, typical days and good days.</p> <p>*8. The assessment should recognise that few adaptations complete remove a disability.</p> <p>*For example, it is very tiring to walk using crutches. Someone who is able to walk 25m on crutches is not equivalent to someone who has no difficulties in walking. Someone who is in an electric wheelchair may be able to motor along on a level pavement without difficulty, but getting in and out of their house may take them ages, their use of public transport is limited (e.g. they need to book assistance in advance).</p> <p>*These may seem like minor thing unless you have to live with them. If you combine being in a wheelchair with a condition that naturally makes you very tired, the extra effort can mean that in practice you rarely go out.</p> <p>*Where aids can help and are genuinely easy to obtain, it is reasonable to expect they are used. However, many aids are</p>

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		<p>not easy to obtain. In my case, if I had an electric wheelchair I would be able to get to places I can't get to now. However, the NHS will not provide me with one since I don't need a wheelchair indoors. I could, arguably, buy one with my DLA money, but I need to use that to run a car which is absolutely essential for me. Thus an electric wheelchair is in effect unobtainable.</p> <p>*My walking is better (but far from good) with orthotic insoles, but the waiting list for these from the NHS is nearly a year.</p> <p>*If disability benefits are in future to assume aids are readily available, there must be an appeal system for circumstances where the aid is not in practice available. The benefit must also recognise the waiting times involved in getting aids.</p> <p>*Finally, personal choice must be respected. For example, a medical condition may be improved by taking a certain drug, but the side-effects, for some people, may be intolerable. They should not be forced by the benefits system to take the drug.</p> <p>*If I take morphine, I can walk to the end of my road. It is NOT reasonable to expect me to take morphine every day.</p> <p>*9. The current system lacks transparency. It is quite clear that if you go to a benefits advisor who knows how the phrase things on the form, you are far more likely to get DLA. This is wrong. Any individual filling in the form for themselves should be able to do so and get the DLA that their condition qualifies them for.</p> <p>*Perhaps there should be some worked examples – anonymised of course – of what applications are awarded what rates of DLA.</p> <p>*I can't see how you're going to end up with a shorter form, much as we'd all like that, since disability is so varied and you have to cover all types of disability.</p> <p>*10. Ironically, GPs aren't well placed to do this. My GP knows what conditions I suffer from and she knows that medicines I take, but she doesn't know that every night my daughter has to help me to bed. In fact the only people who know this are myself and my daughter.</p> <p>*The very first time I applied for DLA I got turned down because a GP wrote that I would find it hard to run to catch a bus. Run??? Run!!!! At that stage I couldn't walk 20 yards down my garden without needing a nebuliser.</p> <p>*However, GPs are good for confirming the the underlying conditions are there.</p> <p>*It is vital to use the supporting evidence of day-to-day carers, who will often be family members.</p> <p>*11. The risk is that it will become like the ATOS work capability assessments – a tick box exercise with targets to meet, undertaken by someone who does not have the knowledge of the particular conditions/disabilities that an individual suffers from.</p> <p>*The "healthcare professional" MUST have specialist</p>

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		<p>knowledge of the conditions and disabilities. This may mean that more than one professional is required in a session. I, for example, suffer from mental problems, lung problems which are highly specialised, endocrine problems that are rare and likewise highly specialised, and physical mobility problems. The idea that, for example, a physiotherapist could assess me is simply laughable.*A “face-to-face discussion” is potentially very degrading – how are you going to protect us from that?</p> <p>*Someone who mental faculties are severely impaired should not have to undergo a face-to-face discussion.</p> <p>*12. For long-term or life-long conditions reviews should certainly not be more frequent than every two years, and for many conditions every 5 or even 10 years would be more appropriate. It may come as a surprise to Joe Public and to the Government that most of us aren’t benefit cheats. We are people who struggle daily with illness and disability, and for whom life is really, really tough. Re-applying for DLA is exhausting and stressful. Face-to-face reviews will be even more so. It is right that the Government protects public funds against fraud, but that needs to be balanced against the stress, and distress, caused to the most frail and vulnerable people in our society.</p> <p>*The criteria should be: how likely is this condition to improve over the next n years? If there is no realistic possibility of improvement then there is no point in keeping making people reapply and go through the stress involved.</p> <p>*Clearly there are other conditions which may be temporary and the review period should align accordingly.</p> <p>*There must always be the option of the review being undertaken in the person’s home since many of us find it impossible to get to a review/assessment centre.</p> <p>*13. By building a greater confidence that assessments will be fair and consistent. I have once notified DWP of a change. In that case, my disability had worsened, and I was advised by both Social Services and the hospital social worker that I should be getting a larger care component. I did in the end advise DWP of the change in circumstances, and was indeed awarded a higher rate, but my fear was that rather than get and increase I might lose what little I was getting.</p> <p>*It is very difficult where a condition improves, since the improvement may only be temporary and the condition may worsen. Again, if people felt confident that they would get their DLA back if their condition worsened, they would be more likely to inform DWP of improvements.</p> <p>*14. • Clear unambiguous information about the criteria for being awarded PIP</p> <ul style="list-style-type: none"> *• Ready access to skilled benefits advisers *• Sufficient time to complete the forms bearing in mind that some of us have illnesses and disabilities such that it can take several weeks or even up to three months to complete the

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		<p>forms, doing a little everyday</p> <ul style="list-style-type: none"> *• The facility to complete the form on a computer, for those of us who find handwriting difficult. *• The facility to complete to form verbally <p>*15. No, I think it would be unacceptably intrusive to require people to access advice and support, and I think it would put some genuinely needy and disabled people off claiming. Perhaps that is the government's intention.</p> <p>*16. It is so varied. Some aids and adaptations are provided by the NHS, some are provided by Social Services, others are paid for by the individuals. We also need to define aids and adaptations. For me, my car is my key mobility aid, even so it is a standard car which has had no adaptations, and I pay for it out of my DLA.*The option exists with DLA to fund a one-off cost, such as an electric wheelchair, so I don't really understand what you are proposing.</p> <p>*If what you want to do is give disabled people independence and dignity, then you should give us maximum flexibility in how we use the disability benefits we receive. Anything that limits how we spend it reduces our independence and dignity.</p> <p>*On the other hand, if what you are trying to do it save money, then I guess the harder you make it for disabled people to benefit from PIP the more you will save. But let's make no mistake here: you won't be helping disabled people be active, fulfilled, integrated members of our society.</p> <p>*17. That their needs are likely to change more rapidly.</p> <p>*18. I was told that DLA was a gateway benefit and once you get DLA it opens the door to other benefits and other forms of help. It hasn't done so for me. The most obvious thing is to inform people when they get their DLA about other things they may be entitled to.</p> <p>*19. I was told that DLA was a gateway benefit and once you get DLA it opens the door to other benefits and other forms of help. It hasn't done so for me. The most obvious thing is to inform people when they get their DLA about other things they may be entitled to.</p> <p>*20. No idea.</p> <p>*21. I think your assessment is realistic. I would be very concerned if there were a trend towards turning down a disproportionate number of people who are approaching their 65th birthday. I can see that turning down that group could save the government a lot of money.</p> <p>*22. It's important to recognise that for many of us our very disabilities are always going to prevent us from leading full and active lives. No amount of adjustments or aids will ever give us a level playing field. Living with chronic ill health and disability is very, very tough. DLA currently goes some very small way towards softening that. I am extremely concerned that these changes are motivated by the desire to save money, not the desire to help disabled people.</p>

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EM672	17/02/2011	<p>1. Barriers include getting around, physical participation, less time/energy to do things as coping with disability takes up time e.g. longer to get dressed, washed, cook. Things that able bodied people take for granted become major tasks in themselves, and leave less time for socialising etc. this is an additional barrier on top of the physical restrictions of the disability. Also assistance may be needed to perform these basic tasks.</p> <p>*2. It should enable people to live their lives as their peers do and not be disadvantaged by their illness. The aim of a benefit to help ameliorate the extra costs and difficulties of living with a disability.</p> <p>*3. Transport is a major expense for people as they may need specialised transport e.g. taxis rather than bus, adaptations to cars and home. Paying others to do things they are unable to from going to the shops to cooking, cleaning and maintaining their home and to assist in personal care. Often unable to benefit from special offers that require travelling etc. at short notice as they need to carefully plan their transport in advance. Delivery charges for things they are unable to get out and buy themselves, such as buying groceries.</p> <p>*4. Two levels doesn't make much difference to simplicity. There are still eight possible combinations which is not much of a reduction from 11. In reality people think about the two components separately so there is not a problem with having so many combinations. Losing the middle rate will make it harder to meet the stated aim of tailoring support to need and could lead to those currently on the middle rate losing out. The main priority should be to ensure everyone gets the support they need, not a marginal simplification of administration.</p> <p>*5. It would be reasonable to say that some conditions should have automatic entitlement. It would be a waste of money to put people who will clearly meet the criteria through an expensive medical.</p> <p>*6. Everyone should be provided with the funds and support they need. Those to whom a small amount of support would make a big difference should not be penalised by this reform, the help they receive can make all the difference between having a full life and not. If they were to have to stop socialising because of a reduction in their support this could make their condition worse, costing the tax payer more in the long run. Personal care, eating, socialising, working and the right to some sort of break or holiday are the most basic needs</p> <p>*7. By understanding the effect that the disability has on their everyday life. If they need help during a typical week they should be entitled to it. Listen to what people say in their assessments and act on it. Be aware that in many illnesses there are good days and bad days and allow for these in the assessment by using a time scale rather than a snapshot of one assessment.</p>

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		<p>*8. Use of aids and adaptations should not affect entitlement as they only provide some assistance to a disabled person. They do not ever fully overcome the difficulties that a disabled person faces. There are still additional costs for instance in getting about, and all aids and adaptations incur costs in the form of maintenance.</p> <p>*9. By listening to the claimant, their medical carer (GP or consultant) and making it less of an ordeal to claim. At the moment the 'health care professional' and the decision maker is looking for a reason not to award benefit. This makes it a very stressful process for someone who is disabled, as they often feel like they are not believed. Change the culture from one of suspicion to one of trust. Make sure it is seen to be fair, and that disabled people truly get the help they deserve.</p> <p>*10. The medical professional who knows the claimant would be the best placed to provide this. In addition evidence from carers, and anyone who has known the claimant for a long time, eg work colleagues, neighbours and friends.</p> <p>*11. Ticking boxes with someone you have never met is not the best sort of assessment. Provides only a snapshot of the effect of the disability. Takes a lot of time to do properly and costs a lot of money particularly where there is plenty of evidence of the disability from other sources.</p> <p>*12. The review period should be only dependent on the likelihood of the disability changing. If someone is permanently or likely to be permanently disabled they should never need to be re-assessed, as it would be a waste of money. No review should take place more than once every 18 months as it is stressful to the claimant and costly to the tax payer.</p> <p>*13. By treated them with respect when they apply in the first place. People do not trust the DWP to act fairly as they are a) not believed and b) refused benefit they are entitled too, which they subsequently win at appeal of course they don't want to inform them of any changes. When you apply for benefit it feels like the decision maker is looking for just one reason not to award benefit rather than trying to understand your condition as a whole and how it affects your everyday life. In contrast the appeals panels take great care to understand your condition and how it affects you and make a much more informed decision.</p> <p>*14. Eligibility criteria should be clearly stated and a free helpline available. Access to CAB and DIAL which are currently being closed or are under threat. Access to free face to face help is essential for many claimants especially as the decision makers do not seem to think about the overall effect of a persons disability on their everyday life.</p> <p>*15. NO! Any form of requirement is an attack on human rights, and directly contradicts the claim that the government wants to facilitate independence for disabled people. It smacks of Orwellian doublespeak. Making sure support is available free of</p>

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		<p>charge, widely advertised and easy to access is what will help people and encouraged them to use it. Disabled people are the best people to know what help and support they need just provide it for them, and signpost it when both with the DLA application form and with any award letter. A free helpline would be a good starting point.</p> <p>*16. Yes. Many buy their own from savings. There should be extra funding for this</p> <p>*17. Making sure they are reassessed before they grow out of basic equipment like wheelchairs etc.</p> <p>*18. Very important it reduces administration by opening doors to other services.*Provide good clear and comprehensive information for claimants and carers and include details of other entitlements with the award letter.</p> <p>*19. It would increase the administrative bureaucracy on other services and create more stress and forms to fill out for disabled people. In all likelihood it would reduce the take up of other services as it would make them harder to access.</p> <p>*20. Nothing combining only works if assessments for DLA are perceived as fair and unbiased, unfortunately people who have experienced poor decision making and have had to go to appeal do not trust the system. Concentrate on providing DLA to all who are entitled and let them choose their care etc.*Information sharing about DLA award is useful for claimants as it makes it easy to access other services if DLA is a passport.</p> <p>*21. Those who are not well informed will be disadvantaged. Reducing the number of claimants by 20% will adversely affect those who have their benefit withdrawn. Taking benefit away does not stop them from having to live with their disability, it just makes their life harder and sends a message that society does not care about their problems or think them worthy of support. This will be very isolating for them and potentially be very costly if their condition deteriorates as a result.</p> <p>*22. I am concerned that the tone of this consultation conveys that in future DLA will become more difficult to claim and disabled people through no fault of their own will be more disadvantaged than at present. Life is difficult enough for them already. The increase in the number of claimants in recent years is not evidence that the benefit is too easy to claim or that it is being abused. It can be explained by a combination of (a) the growth in population, (b) an increase in life expectancy and the date DLA was introduced mean that most of the original claimants will still be alive but people are still becoming ill and disabled increasing the number of claimants, (c) better awareness of the benefit so more people who are entitled to it are claiming it. This means that more disabled people are being supported in leading independent lives which a genuinely progressive government and society should welcome.</p> <p>*It is important that the assessment takes into account the</p>

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		<p>actual difficulties involved in the disabled person's life. For instance the cooking a meal test does not ask how the person bought the food, whether they had the energy to eat it after cooking and if they could manage to wash-up after. Currently it does not take a holistic approach of considering all the activities that a disabled person must do in their everyday life. It is vital that the assessment considers all the activities in combination and not in isolation. If performing one activity leaves the disabled person unable to perform the rest of the tasks that should be taken into account.</p> <p>*It is a sad reality that currently many disabled people use DLA to pay for basic costs of living clothes, heating, food etc. This is because those not able to work are living on a level of other income from benefits that is not sustainable in the long term; they do have not enough to ensure a basic standard of living. Taking DLA away from the most vulnerable members of society would be devastating for them and their families.</p> <p>*I should like to share my experiences of applying for DLA in the hope that the system can be improved. In my experience there is considerable scope for administering both DLA and ESA/IB more efficiently, both in terms of office administration and decision making. Making the correct decision at an early stage in an application would avoid the costs (not to mention the stress for the claimant and loss of trust towards the DWP) of claimants having to go to appeal. While there is plenty of room for improvement I do not believe that the current descriptors are over complicated or arbitrary, rather it is the way they are applied that is the source of many of the problems with the system. If claimants were able to speak to the decision maker directly to discuss the conclusions that they believe are incorrect, point out any evidence that they feel has been overlooked or misunderstood and explain why they believe they meet the criteria it would speed up the process of reconsidering decisions and enable the decision maker to get a better overview of the effects of the disability.</p> <p>*I was initially refused any component of DLA but following an appeal (finally heard nine months after my application) I received the highest rate of mobility component and lower rate care. Having to travel to the appeal left me ill for a couple of weeks afterwards as it was far beyond my sustainable level of activity. This should have been clear to anyone with common sense reading my application. The original decision maker had failed to properly understand my condition and follow the guidelines for administering the benefit. When I received my benefit it was not backdated far enough as someone had made an error entering the information in the computer. I had to press very hard before the person I spoke to at the DWP would accept the possibility that the computer could be wrong and leave their chair to actually check the original paperwork before the mistake was corrected.</p>

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		<p>*Another example of administrative inefficiency occurred when I applied for incapacity benefit. I was told that my form had been never been received and I would have to go through the lengthy time-consuming and tiring application process again. When I later applied under the data protection act for my file I was sent a copy (along with the random national insurance details of another claimant) of the form that it was claimed had never arrived! After staring at it in disbelief for a few minutes and then writing to complain my benefit was backdated (and in the process of rewriting my record to do this my national insurance contributions disappeared and took same effort to get back). Despite my request no explanation was given or any assurance that the problem had been investigated so it could be prevented in the future. Better training and monitoring of staff and procedures would help to prevent poor decisions and maladministration, enabling long term savings in administrative costs and a greater proportion of the welfare budget to go on welfare payments themselves.</p> <p>*On the whole the staff in the call centres try to be as helpful as they can be but are limited in what they can do by a lack of training and autonomy. It is very frustrating that the people claimants get to talk to are not the ones who actually make decisions or have the authority to rectify mistakes. All the call centre staff can do is to ask someone else to actually do what needs doing. If, as there often is, a breakdown in communication between the staff at the DWP it is the claimant who has to phone back and try and get things sorted out. This leads to a waste of staff time through duplication as they end up dealing with the same query twice. There should also be geographic contact numbers available for DWP offices rather than just 0845 numbers. Many people get free calls to geographic numbers as part of their phone contract but have to pay for 0845 numbers. Such a change would save many claimants money and make staff more accessible.</p>
EM673	17/02/2011	<p>I am responding to the consultation individually because I am the parent of a Learning Disabled Lady, aged 59.</p> <p>* The consultation strictly does not apply to her since she lives in a Charity based residential "village" community, but with the present state of flux in Adult Social Care funding changes in which, of which the DLA can be part, the situation of such handicapped people must not be ignored. We care for her for a full weekend every month and on other longer periods during the year.</p> <p>* The ministers statement that the grant to residential providers should take care of transport needs ignores the reality that the LA funding has been pared away at over recent years. This particularly affects nonprofit making charities.</p> <p>*My responses are therefore of a general nature.</p> <p>* 1. Why move to PIP in 2013 when in 2020 the Single Universal Benefit is to be introduced.</p>

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		<p>* 2. Why when there is so little employment available insist on a return to work. The mildly physically disabled will be able to cope but for the more severely disabled and the Learning disabled it will be a very frustrating exercise. By all means return to the old training centre regime and ensure that some measure of benign employment is involved together with useful activities.</p> <p>*3. When working the amount of PIP benefit, make sure that it doesn't take a disproportionate of 'benefit' pot. The needs of those in residential care must not be forgotten.</p> <p>*4. Face to face assessment/discussions should not exclude support for the candidate. Particularly family members should, where possible, always be included.</p> <p>*5. Social Care, this must include residential care as a valid option. See Valuing People (2001) page 73. Intentional communities were stated to be a valid option.</p> <p>* Why can't the PIP be used to fund this, in part or even as whole.</p>
EM674	17/02/2011	<p>To Whom it May Concern, I have unfortunately been unable to respond to the consultation questions in full, as I would have wished.</p> <p>* However in response to the questions –</p> <p>* 1. What are the problems or barriers that prevent disabled people participating in society and leading independent, full and active lives?</p> <p>*2. Is there anything else about Disability Living Allowance (DLA) that should stay the same?</p> <p>*3. What are the main extra costs that disabled people face?</p> <p>* I'd like to say that DLA has enabled me to (exploring barriers, extra costs and why DLA should remain the same):</p> <p>* - Attend social gatherings while at sixth form as the bus was not wheelchair accessible so I used my DLA to pay for a taxi.</p> <p>* - Attend university (by funding the costs of staying in wheelchair accessible halls of residence on campus as I was unable to push over the bridge which lead to the campus, which happened to be the most expensive accommodation offered by the university, without my DLA I would have had to stay in unsuitable accommodation, and not have been able to attend many lectures/seminars) I went on to receive a First Class BSc Hons.</p> <p>* - As my condition progressed it enabled me to put money toward a much lighter wheelchair than the NHS could provide, so I could keep my independence and get around my university work placement.</p> <p>* - As my condition progressed further and I needed frequent help with personal care and unaware of help from Social Services my friends took unpaid leave from work to care for me, I used my DLA to pay toward bills etc that friends were falling behind with due to the unpaid leave they were taking from work.</p> <p>* - It also paid for extra heating as I'm unable to keep myself warm even in summer, extra electricity for my profiling hospital</p>

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		<p>bed I need to sleep in and electric wheelchair, extra clothing from which I stain from dropping food on plus many more things such as paying for expensive hotel rooms when visiting friends as I can't stay at a friends house with stairs to the loo and the buget hotel chains do not f.</p> <p>* - In my early twenties my condition progressed further and leaving me unable to work; requiring a high level of care throughout the day and night..</p> <p>* It was only through DLA, Social Services and the Independent Living Fund who provided me with the funds to employ my own Personal Care Assistants, that I was able to return to work, with my PAs being there to help me with transferring onto the toilet among other things.</p> <p>* For my PAs I pay half of my care element of my DLA to the ILF and the residual amount of my care element pays for the costs of needing 24 hour care such as buying a bed for my PA to sleep in, the extra cost of renting a flat with a spare room for my PAs, the cost of heating the spare room, the money toward paying my PAs travel costs on trains etc when they are with me, to very simple costs that add up from having people working in your home such as buying double the amount of toilet paper etc.</p> <p>* I use the Mobility part of my DLA to pay for taxis to meet friends, attend doctors appointments, volunteer and also save a small amount toward paying for an indoor made to measure hand-bike, so I can get some exercise now that I am unable to push my wheelchair any longer and I am too high up in my electric wheelchair and do not have enough reach in my arms to use the handbikes provided by gyms.</p> <p>* Because of the above reasons which clearly show how my DLA has enabled me to work and live a fulfilling life, I would not like to see any changes in the benefit except maybe more notice to be taken of specialists and doctors reports as I have a rare impairment which is under treatment via a Movement Disorder Neurologist only as it is out of the realm of understanding for a regular neurologist and I worry that a report conducted via ATOS would find it difficult to understand my impairment.</p> <p>* I would like to say thank you for DLA as it has removed so many barriers to work (I am not sure why DLA has been reported as an out of work benefit at times, as DLA makes it possible to work, without it I would have to give up my job which I value dearly) and everyday life. Best Wishes [REDACTED]</p>
EM675	17/02/2011	<p>Dear Sir/Madam, Please find attached my comments on the DLA Reform Consultation.</p> <p>*I am commenting as an individual who suffers from Multiple Chemical Sensitivity (MCS), though I believe that my views will represent the views of this group who are poorly represented and poorly served by the NHS. I also believe that many of the comments that I make will also apply to people who suffer from</p>

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		<p>Electromagnetic Sensitivity, though this is not a problem for me.</p> <p>*With regard to the NHS, the Health Ombudsman is currently considering a complaint that I have made about the NHS' failure to provide "a professional standard of care, by appropriately qualified and experienced staff, in a properly approved or registered organisation that meets required levels of safety and quality" for people with MCS as the NHS Constitution guarantees.</p> <p>*I would also like to point out that my submission is very brief as I have been too ill to work on it.</p> <p>*I do not receive DLA, as its focus on mobility and care means that the problems that people with MCS are not considered significant, or any other Government benefit, as they all suffer from similar assessment problems.</p> <p>*1. For people with MCS, apart from the problems getting treatment from the NHS (even though treatment is available in other countries), the main problems are:</p> <p>*the prevalence in the every day environment and every day products of the chemical compounds that cause them problems, e.g. perfumes and other fragrances, smoke from cigarettes and other fires, solvents from paints and carpets, fire retardants in furniture, man made fibres or other fabric treatments in clothing and bedding, and the chemical compounds used in the manufacture of many electrical products. Many people with MCS also need to eat a restricted or special diet as they don't tolerate many foods. This can make it difficult if not impossible to: go shopping: buy every day goods (especially household cleaning and personal care products, furniture, electrical products, and paint and carpets); work (because it is too difficult for employers to make the necessary adjustments); eat in a restaurant; use public transport; attend social events; go on holiday; or get tradespeople to make repairs, especially in their homes (because most tradespeople will wear fragrance and be unwilling to use specialised products); the lethargy, head aches, cognitive difficulties and other problems that MCS causes that means that people with MCS just don't have the ability to get out and about and participate in what most people with consider a normal life.</p> <p>*3. For people with MCS the main extra costs are:paying for private medical treatment (the good doctors are quite successful in helping people find treatments that help them to manage their condition - though given that there seem to be a large number of underlying causes of MCS, it may not be currently possible to treat all cases successfully); paying for vitamin, mineral and other supplements which most people with MCS find help them manage their condition; paying extra for specialised equipment or goods that they need because standard products are fragranced (e.g. most household cleaning and personal care products) or contain chemical</p>

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		<p>compounds that they do not tolerate (e.g. solvents in paints, inks and carpets, fire retardants in furniture, man made fibres or other fabric treatments in clothing and bedding, and the chemical compounds used in the manufacture of many electrical products); paying extra for specialised foods or just the foods that they can actually tolerate; paying for delivery of goods because they are too ill to shop/they can't tolerate the shops/need specialised products that aren't available locally; and paying for other products that help them to avoid the chemical compounds that they don't tolerate, e.g. air filters and water filters.</p> <p>*6. being able to eat; being able to breathe air that doesn't make you ill; being able to keep clean; being able to think clearly;</p> <p>*being able to shop for food and other essentials (especially goods essential to managing your condition); being able to buy household goods and products that don't make you ill;being able to work (assuming that this is a reasonable expectation); and*being able to participate in social events.</p> <p>*7. The assessment scheme needs to consider the actual problems that a person faces, not take the "put in a ramp, create a Braille version and make sign language available" and "can you walk, can you sit down/stand up" approach to accommodating/assessing disabilities that is so prevalent in UK Government policy.</p> <p>*8. Only if the aids and adaptations are provided by some other government benefit.</p> <p>*10. This is a significant issue for people with MCS. In some cases people will have been able to find the probable underlying cause of their problems (and be able to provide the evidence for this) but others will not. However, given the specialised nature of MCS, the greatest problem is likely to be that the assessors and medical staff will not have the training or experience to be able to understand the evidence that people with MCS present, and I think that it is this issue that needs greatest attention.</p> <p>*11. The main difficulties for people with MCS will be:</p> <p>*fragrance use by the staff in assessment centre;</p> <p>*fragrance/solvent use in the assessment centre (e.g. cleaning products and furniture, paint and carpet); and</p> <p>*use of electrical equipment in the assessment centre.</p> <p>*Home visits are also likely to be a problem as their homes are the one safe place for people with MCS and so they don't readily allow someone who has no understanding (and often no acceptance) of MCS to enter their home. Have you considered using something like Skype video conferencing for the meetings?</p> <p>*15. At the moment this would not be possible for people with MCS as the NHS does not provide treatment.</p> <p>*However, in general I would support this provided that you can</p>

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		<p>get the other organisations to act in accordance with DWP/Government policy. For example, at the moment Government believes that disabled people should work but the NHS does not take this into account in deciding how to treat patients and so often prioritises other patients. So while this seems like a good idea, I think that you may find the practicalities pose significant difficulties.</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?*I do not know anyone with MCS who receives DLA. I only know of one person who has been able to get Incapacity Benefit. Therefore people with MCS currently fund their aids and adaptations from their own resources.*In general I see no problem with using PIP to meet a one-off cost.</p> <p>*22. At the moment people with MCS are excluded from getting DLA and other Government benefits because the assessment systems are not set up to measure the types of the problems that they have. I believe that this is totally unacceptable. The assessment system and the benefits that the Government provides must be set up so that the assessment system looks at the problems that people actually face and then the benefits assist them to deal with those problems.</p> <p>*Please let me know if you would like to discuss any of these points.</p>
EM676	17/02/2011	<p>Dear DLA consultation, Please see attached response. Regards, Senior Occupational Therapist and sister of a DLA recipient</p> <p>*1. Poor access - public transport, lack of accessible buildings. *Societal stigma due to poor education and a lack of visibility of people with mental and physical disabilities at all levels of society. *Financial pressures - cost of privately bought good quality specialist equipment to increase independence when prescription equipment is generally the most basic available. High cost of taxis where supportive schemes do not allow for the fact that many people live busy, productive lives (ie do not just have an occasional hospital visit).</p> <p>*2. The DLA should continue to not be means tested. *3. Higher transport costs – particularly higher costs in accessing workplaces/voluntary placements/college/other meaningful activities. *4. Some conditions are very complex, and it is important that the assessment process really takes this into account in order to ensure there is the appropriate level of support. It is important to consider the long term financial implications to those who will no longer qualify – they may, for example, access the community less and engage in less meaningful occupation. This has a direct impact on wellness, and can lead to an increase in hospital admissions.</p>

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		<p>*5. It seems unhelpful for those with severe mental or physical health problems to have to go to an assessment appointment, or fill in complex paperwork, if the nature of their condition means that they clearly have a high level of need.</p> <p>*6. The most essential relate to self care, but what each person finds meaningful will differ. For some, it may be to be able to independently access the toilet at a time of day that suits them. For some it may be having the money to accessing the work place.</p> <p>*7. It is very important that assessors are properly trained. Those who have an indepth understanding of the many different challenges faced by those with MS, may not have an indepth understanding of the challenges faced by someone with paranoid schizophrenia.</p> <p>*8. There are reasons that some people do not have aids and adaptations – lack of availability, cost, problems with fitting and/or using them, appearance, stigma, lack of information. These factors should be considered.</p> <p>*9. To be in clear, plain English that does not suggest in any way that people have to prove how ill they are. People should be able to receive support in filling in forms by well trained professional staff. Help for those who have communication problems or where English is a second language should be easily accessible. This help should be accessible in the most client centred way possible – ie provided over the phone, internet, face to face and over several appointments if the person has fatigue or anxiety problems. Support should be offered outside of office hours to meet the needs of those who have childcare/work etc commitments.</p> <p>*10. It depends on who knows the person best. This may be the Care Co-ordinator, the Occupational Therapist, the GP etc – ideally, the person being assessed ought to be able to identify who this person is. If a person has not seen their GP or Consultant for many months, whilst perhaps receiving care and advice from other professionals, how can they be the best person to provide information?</p> <p>*11. It is extremely important that people should be treated with dignity and respect by their assessor. It is vital that assessors understand how upsetting it can be to be asked questions about toileting, personal hygiene and mobility. Some people find 1:1 interviews very anxiety provoking, or lack the communication skills to manage these. Assessors should be well informed about these types of problems and should be empowered to act flexibly when necessary. There may be times when it would be more appropriate for the interview to be carried out in another location, or with an appointed person in place of the client. Documentation should be immaculate and available for the client to review at the time of the assessment. In fact, it would be best practise to confirm with the client that you have understood them correctly. Advocates should be</p>

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		<p>available for clients who find 1:1 interviews challenging.</p> <p>*12. Appointments can impact on work attendance etc, child care, and can cause fatigue or flare ups in some cases if travel or anxiety become factors. Therefore, if good quality assessments are completed in the first place, frequent reassessment should be avoided.</p> <p>*There certainly should be different types of review based on the needs of the individual.</p> <p>*13. There has to be some flexibility in this area. For example, those who have certain mental health problems may really struggle to contact professionals. Additionally, ones enthusiasm to contact services is definitely impacted by the service that you receive. If this is efficient, polite, flexible and client centred, people may feel more able to report changes.</p> <p>*14. No strong opinions.</p> <p>*15. Are you truly suggesting people should be compelled to access advice? We do not live in a police state and I find this question offensive. Please think carefully about how you phrase your questions.</p> <p>*16. No strong opinions.</p> <p>*17. No strong opinions.</p> <p>*18. DLA is extremely important in allow people to access services. Without this, many people would not be able to afford travel costs and access meaningful occupations. Social isolation is undignified and ultimately costly, as it has an impact on wellness.</p> <p>*19. See answer for question 18.</p> <p>*20. I'd be interested to know more about best practise in this area? What is working well in other countries? Don't cut forms for the sake of it, but it makes sense that the fewer forms the better. Forms must have the capacity to allow for the fact that we are all different, and cannot fit into a cookie cutter mould.</p> <p>*21. It is important to remember that people have different needs – one person with a specific health condition will not have the same challenges as someone with the same condition. People with some conditions have hidden disabilities and this must be reflected.</p> <p>*22. Please ensure this is a real consultation. Think long term – cost cutting exercises can seem worthwhile in the short run, but it's absolutely vital that you think about the long term. If people end up struggling, and ultimately in hospital, this is far more expensive. Also, remember that it can be the small things that make it worth getting up in the morning. If professionals see you as someone who can walk to and from a toilet and not as a vibrant person who has hobbies or a job and something to say, what's the point?</p>
EM677	17/02/2011	<p>As a disabled person, my health conditions have affected me much of my life but threatening my existence by removing Disability Living Allowance without properly assessing the outcomes risks threatens my existence all together.</p>

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		<p>*I was only diagnosed with my dual instability, from Multiple Sclerosis and Hypermobility Joint Syndrome, later in life. Ten years after my first major neurological event, optic neuritis, I became paralysed I was in my late 20s and I'd missed out on so many of the financial relationship and life mile stones that would have set me up for independent living had I been acknowledged and received support at an earlier age.</p> <p>*I was relieved that the unexplained symptoms were acknowledged at last by the medical profession but I had to go through my teenage years and at university with accusations of malingering and by consequently lower qualifications at degree and postgraduate level. I was assessed for dyslexia in my early 30's, another condition that had previously been overlooked because I managed and compensated, kept going to my own detriment, pushing myself harder, all this adding to my fatigue, pain and deterioration. For years the energy I put in to get an interview meant that I wasn't making any sense at the interview itself because I was so fatigued from the preparation, travel, pain lack of sleep and anxiety leading up to the interview itself.</p> <p>*I paid for my own post graduate course in broadcast journalism. When I applied to Broadcast Journalism traineeships, I was told I was on my own fast track and so did not need help. I would secure interviews for jobs with the BBC/HTV/ITN/Channel 4 that thousands applied for but stumble at the next stage after all my hard work because my conditions were unrecognised and reasonable adjustments for me did not exist.</p> <p>*I have never been work shy. In fact it has been and continues to be an everyday battle to pace and slow down which if I do not do my health deteriorates. I have been down to 8 stone (whereas my weight should be 10 3/4 for my height) and balancing my input and output is so important. This means making choices all the time whether to do something as simple as eat or wash. People who cannot see my difficulties expect more without knowing the consequences including many Drs who do not know me, fail to ask and do not understand the impact of my dual unseen instabilities and their fluctuating nature on my everyday life. When I did have paid work, any money I earned and saved I have had to use to support myself subsequently whenever the inevitable bust came after the inordinate amount of energy it took previously to keep me going and I was unable to work. My family has supported me, my mother cared for me on her own, to the detriment of her own health and ability to earn, for five years without any allowance or remuneration.</p> <p>*Disability Living Allowance (DLA) is by its very name an allowance, not a benefit. DLA is paid to disabled people to help to provide for additional costs, items which are necessary to lead everyday lives in a world that has yet to bring equality for disabled people into this century and threatens a big backlash</p>

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		<p>and economic downturn in throwing the baby out with the bathwater.</p> <p>*DLA is not easy to qualify for especially if you have unseen conditions, MS, arthritis, Chronic Fatigue, Crohn's. I have a friend who has nearly died with Crohn's disease on several occasions and did not qualify. This was because the medic looked at her notes but did not know her or ask her how she was coping. He then wrote the letter from a medical standpoint saying she was OK despite major surgery and its untold psychological impact.</p> <p>*Unseen more often than not goes unheard because it is harder to understand. Chronic conditions that are lifelong deteriorating diseases don't suddenly and magically solve themselves. So why is it that we are being forced to be reassessed when we have gone through having to prove ourselves already, providing evidence from medical practitioners and having to concentrate on the negative aspects of our lives, in a long and rigorous, arduous procedure that is exhausting. I for one do not see how I can or need to go through this process repeatedly. How can reassessing people with long term degenerating diseases, who have been given lifelong indefinite awards, possibly save money.</p> <p>*Both my conditions are fluctuating, acute and chronic and the severity of their impact does not correlate with how I look or perform as I may be able to do something one minute, hour, day, week but not the next. As previously stated, I also have to work out the consequence of what I am doing now on what will happen in the future, sometimes immediately, when I am unable to walk, or speak, or I shake, spasm or it maybe that I become suicidal, as my fatigue and tiredness eclipse everything and I am unable to eat or sleep.</p> <p>*There may be errors in both directions in the current system but this is not an excuse to abandon DLA wholesale or force disabled people to jump through artificial hoops. They are to be judged worthy or not by people who can not understand the costs or effects because they do not have to live with being disabled. Without adequate research and a consultation process which involves a spectrum of disabled people and charities who work on behalf of them, we will not be able to find an economically viable solution but also a responsible one.</p> <p>*Doctors and health care professionals often lack an understanding of the sometimes overwhelming effects of unseen conditions, having studied them momentarily or many years ago, such as MS, Hypermobility Syndrome, Crohn's disease, arthritis, particularly when they affect younger people and multiple or fluctuating conditions and mental health. The tests currently used and suggested are not fit for purpose - why are they then being rolled out further without rethought and advice taken from a spectrum of disabled people?</p> <p>*When I tried to do a part time job at the BBC with assistance</p>

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		<p>from Access to Work, my conditions deteriorated because of lack of understanding. My neurologist didn't think working even up to 15 hours per week was viable for preservation of my health. This was several years ago not because I wasn't good at the job but the effort it took me to do not only the job but to deal with the unkindness, misunderstanding and downright prejudice of others, who for instance wanted to use the accessible toilet because it was nearer, asking why I couldn't use stairs, come in at 0900. This increased risks to not only my mental but my physical health. It is not the case that "it is universally accepted that disabled people should have the same chances as non disabled people" and it is not happening in practice, new builds continue to be inaccessible and reasonable adjustments and disabled employees equal not profitable in many minds despite small steps made In the law.</p> <p>*DLA is used as proof to qualify people for subsidised carer places in entertainment and sports, for a Blue Badge, airport and train assistance and the Disabled Person's railcard. This acknowledges the extra cost of accessing the often "inaccessible" Community for a disabled person who needs to be accompanied, have assistance or specialised car parking.</p> <p>*Other things are sourced with the DLA: specialist clothing, training and education, extra equipments, additional or alternative lighting, anti chlorine devices for drinking/showers, shoes that fit orthotics, non NHS funded medications and bedding to name but a few non VAT discounted items. It is more expensive for disabled people to find accessible places to stay, for hairdressing. There are hidden costs because, if you need access, you need to ring up before hand, to a restaurant, hotel, for bus and train, before considering the cost of cancellation due to ill health or a fall, not to mention how much insurance companies make when we are honest and above board about our health.</p> <p>*The threat to remove DLA from 20 per cent of those receiving it is far higher than can be justified by removing fraud. Necessary assistance with mobility or care requirements is going to be threatened if DLA is removed from many people. Access to life is threatened and even life itself with people being forced into abject poverty.</p> <p>*There is confusion between DLA and Social Care which is overseen by social workers.(This is another area where many disabled people will be hit hard.) The number of hours is assessed and money is spent on a personal assistant for this limited time. This is different from the DLA which allows a disabled person to purchase necessities which they would not need had they not had the health condition. This includes petrol because they need to use a car, additional gas and electricity, because they need to stay inside during the daytime, bad weather. Also it allows for extra water for washing oneself or clothes. Depending on the individual, it can pay for therapies</p>

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		<p>and counselling, not available on the NHS. Many, even with DLA, struggle to pay for the additional necessities for life many rely on spouses, friends, family, charities but many of us no longer have a choice to be the eternal child and be subsidised by our parents and voluntary/charitable organisations are also being hit by cuts. Some do not have anyone to play that role and some like me have relied on their parents for so long before, after and during being diagnosed that the coffers are now empty. Families are forced into poverty and can no longer bail us out.</p> <p>*Having DLA, and the help it affords, helped me to get to a place where I could help myself and others. From contacts made with disabled medical professionals, I have since been involved, once a year, as a paid disability tutor to 2nd year medical students, teaching them about communication and unseen disability; voluntary work listening to a young girl reading in a local school and having taken a council run course, am running a seated gentle exercise class for people with profound learning disabilities. Accessible exercise classes are few and far between and cost more, so I decided the only way I'd find a class is to run one myself. I can perform this role, this work, because I have Disability Living Allowance which helps to sustain my extra costs and my health. Allow me to work and contribute in this valuable way as a volunteer.</p> <p>*So I come to the Government's plans for welfare. It has massively impacted already on my health with stress from these announcements, the threats of ongoing reassessment and the lack of security for the future. When dealing with deteriorating conditions to have this in addition is unspeakable. Writing this response has taken since the announcements were made and the consultation made known. I am shattered.</p> <p>*I know my journalism training is out of date, with consequent lack of confidence. Even with access to work, and sometimes because of it, I got ill working for the BBC and ended up with urinary infections because the toilet wasn't accessible. I had to constantly explain to people why I looked ok but couldn't use the stairs or join in their after hours work events. I just wanted to do my job.</p> <p>*It is not that I do not want to work, I do and certainly not that DLA stops me!. I am an ideas person but sustaining my input long term and consistently is quite another matter. How many employees would take me on for an hour a week, particularly with competition from other people who are becoming unemployed? Is it really worth hounding people like me who have had their life drastically altered by ill health, initially by lack of diagnosis, so they feel further threatened and undermined? Is it economically viable to disable people further rather than enable to make some of us so ill that life is no longer worth living? People who currently can do some work can no longer without support. Those with long term conditions have years of</p>

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		<p>learning how to pace, to manage fatigue and pain, now have to throw this to the wind in the attempt to find work in an economic atmosphere that is massively competitive and “doesn’t want to risk taking on a disabled person as we may cost them money”.*It is almost a full time job keeping up with my health appointments, most of which I pay for and can only do so because I have DLA, one of the purposes of making the allowance and without which I am much worse off physically and mentally. *Carers’ allowances are a small amount for a huge amount of work, saving the government the cost of running the NHS for a year, and this again is an allowance that is seen as income and reduces other benefits such as income support. Even if they are paid more than the minimum wage it is often a hard and thankless job. Not everyone shares the media portrayal, encouraged by talk of “lifestyle choices”, of disabled people as frauds and benefit scroungers or attacked in public for this. The government’s current plans instead of enabling disabled people are more likely to reinforce inaccurate media stereotypes and encourage hate crimes.</p> <p>*I am in my mid thirties, and always imagined that by 30 I would be a senior broadcast journalist, married, with children, a settled home life my own house. I have recently hit one of these targets as a kind and loyal friend who has also seen how unseen illness is misunderstood, feared and discriminated against in this county, asked me to marry him.</p> <p>*I now have the chance to at least to have some of these dreams fulfilled and to help others at the same time through education and information and my personal experience and knowledge and ability to communicate. Just at this high point for the first time in my life, the announcements came and a cold chill ran down my neck. I know I could not cope without help as it is, never mind cutting my support system, my life line, my access to life.</p> <p>*Despite the Government’s promises, there is nothing ‘fair’ about these cuts. The burden will disproportionately fall on disabled people and risks causing them not only considerable anxiety, forcing them into further poverty but also causing them to seriously consider the worth of their lives and indeed whether to end them. The scale of cuts announced is far-reaching and will end up costing more money for society and the individuals concerned. This is not prudent it is Arcadian. There is a difference between money saving and sinking Great Britain without thoroughly assessing the outcomes for all of us and involving those of us who have to bear the brunt of all these changes. Lack of understanding could condemn disabled people to further hardship. There needs to be more consultation with those who live with a condition day in and day out and wider research among charities who work for and on behalf of disabled people.</p> <p>*Even on pure economic grounds, it does not make sense to</p>

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		<p>totally abandon the DLA. It is not a benefit and without it many disabled people will become more dependent, less independent and it will ultimately cost more. The new benefit seems to demean and demote people using a medical rather than a social model.</p> <p>*The Government has yet to publish any form of Disability Impact Assessment. The Comprehensive Spending Review document itself acknowledges that it doesn't know what the consequences will be.</p> <p>*How can the Government make such important strategic decisions without first considering the consequences?</p> <p>*Overall, the Government has failed to deliver on its promise to support disabled people into work. Instead, the Government's plans will penalise disabled people who have been employed in the past, paid national insurance and are now trying hard to get back into work. What's fair about targeting disabled people who want to get back into the job market, even though that market is the toughest in years? Perhaps more attention should be paid to the work place, lack of accessibility, little provision for part time or flexible work, and little or no awareness among other employees about disability, something that needs to start in schools.</p> <p>*Under George Osborne's and Iain Duncan Smith's plans, Local Government will lose out which will also hit disabled people and their families particularly hard. The loss of the mobility component of Disability Living Allowance (DLA) for people living in residential care literally means that many disabled people face the prospect of become prisoners in what is "their own home". What's fair about taking away a disabled person's access to the outside world? This is not the same as being in hospital although some politicians talk about it as if it was.</p> <p>*Disabled people and their families do not have "broad shoulders" so why are they bearing the brunt of these cuts?"</p> <p>*I would urge you to consider a recent report, Destination Unknown, produced by think-tank Demos and disability charity Scope, which concludes that under the Government's plans, a family with disabled children would stand to lose over £3,000 by 2015, while someone moved from Incapacity Benefit to Job Seekers Allowance stands to lose nearly £9,000.</p> <p>*- What is fair about targeting disabled people who have worked in the past and paid national insurance, who are now just trying to get back into an incredibly competitive job market?</p> <p>*- Why has the Government removed ring-fencing of money for social care at a local government level? Will this not simply lead to councils investing less in social care now that the requirement to do so no longer exists?</p> <p>*- What is fair about making disabled people prisoners in their own home by removing the mobility component of Disability Living Allowance (DLA)? What's fair about taking away a</p>

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		<p>disabled person's access to the outside world? Or indeed scrapping and replacing DLA without full and proper consultation and involvement of those it immediately affects?</p> <p>*- And central to all of these points: Why has the Government failed to carry out a full Disability Impact Assessment and admitted that it doesn't know the impact of the spending cuts when the decisions made will have such a substantial impact on so many people?</p> <p>*- And how can Government help change the way that Society views Disability in particular training for teachers, health practitioners and, I might add politicians, by and with disabled people.</p> <p>*The truth is that there is nothing 'fair' about these cuts, coming together as they are which greatly set back equality and opportunity for disabled people. Changing Disability living allowance from its original purpose as an allowance for the additional costs disabled people have, to a benefit is laughable if it were not so serious. DLA is linked with many other subsidies that help disabled people live: Blue badges, accessible housing, railcards, airport assistance, cinema cards.</p> <p>*How is taking away DLA mobility because someone has an aid like a wheelchair right? Has society shifted its views and behaviour so much since I last went out that we are now all equal have equality of opportunity and everywhere has level access and prejudice does not exist?</p> <p>* It is my dream that we did live in an egalitarian society but until this has been achieved in reality rather than merely rhetoric a Disability Living Allowance that assists in redressing the balance is not merely necessary to achieve independent living but a human rights issue. We need to ensure that these cuts do not disproportionately impact on disabled people and push thousands of people into poverty over the coming years.</p> <p>*As I write, it has taken me since the announcements to finish this letter and many more disabled people are prevented from doing so by the medication they take, through ill health, limited support or purely by not being made aware of what is proposed and enabled to have the time necessary to answer.</p> <p>*These issues in addition to cuts in the NHS, local councils, housing benefit, changes to incapacity benefit/income support and rises in costs of daily living, inordinately affect disabled people and our ability to survive, let alone live, our everyday lives.</p> <p>*If real change is needed let it not be change for cuts sake without thought to the fallout let us be honest and transparent about what we are doing "let those with the broadest backs bear the brunt" and let us work together as the "Big society" to a future where we care for our country and all its people without casting unfair and dangerous aspersions</p> <p>*Politics has been much maligned of late there are always those who will cheat the system but blaming the many for the</p>

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		<p>few is a striking parallel for what is happening now by attacking all disabled people. Neither politicians nor disabled people are the route of all evil I trust the democratic system will listen to all of its people act on what we say and not disable us further.</p>
EM678	17/02/2011	<p>████████ Council staff member who works within the Welfare Benefits Team:</p> <p>*1.Disabled people have a wide range of barriers to participate in society; accessing society is travelling to places understanding what is available, communicating their needs, realising and accepting their needs, getting the help they need e.g. aids and equipment and care. Understanding how to use aids, remembering how to do things. ETC</p> <p>*2. Things that should stay the same. *the basic element of DLA care to be awarded if a person cannot prepare a proper meal.</p> <p>*3. Extra costs. *these vary from person to person. *May include cost of domestic help, alternative medicine or treatments, extra food or heating cost, extra travelling cost of help with communication, meals on wheels, etc</p> <p>*4. 2 components of each. *Each component will cover such a wide range of abilities. Believe there will be a tendency to give lower rate when before would get the middle rate so people with middle rate needs will get low rate help.</p> <p>*5. Automatic entitlement *People who are terminally ill should have automatic entitlement this should be reviewed at 6 month stage. People who are blind should have agreed levels of entitlement</p> <p>*6. Prioritisation *Essential life skills should have highest priority like feeding themselves making a meal, taking medication. Accessing the shops and their money and keeping clean should have a high priority.</p> <p>*7. Fluctuating conditions. *Before the medical ask the person to quantify the times that are bad and good E.g. with a diary over a period of time. give the person time to work out how things are. Question them to make sure they have taken into consideration how they are on different days. Encourage the person to describe themselves on their worst days.</p> <p>*8. Aids *This is a difficult one. Proud people avoid using aids. There are often drawbacks to using aids for example a bath lift has to be charged up all the time and it is slow. Although a person can access aids in reality the access may be difficult. May have to wait a long time before they get an aid for example a stair lift.</p> <p>*9. Application process *no comment</p> <p>*10. support evidence *This will vary from person to person. the individual knows who would be the best person to assess them. Maybe their carer.</p>

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		<p>*11. Face to face assessment. *Again this will fluctuate. In medicals at the moment many people are considered much more able than a tribunal finds them. When assessing a person for a DLa if you ask can you do X the person will say yes when in reality they do it because their partner helps them. these assessment should be done with the intention to be fair regardless of the personality of the person. A fighter will declare they can do everything and another person with the same condition will say they cant. The assessment should be more of a discussion that a Qand A. records should be kept of the discussion to be sure they are asked open and clear questions and their answers are listened to and honestly recoded.</p> <p>*12. How reviews are carried out. *People with mental health issues should be treated very carefully because the review if carried out badly could damage their health. In these cases and people with memory and learning difficulties medical reports should be seen first and the bulk of the assessment done on the reports of medical professionals. For learning difficulties there will not necessarily be medical issues. Any care assessment family assessment and where appropriate school assessments should be used.</p> <p>*13 reporting changes *Maybe a review letter should be sent out on a regular basis just asking if their condition had changed since their last review and add date. Also warn then failure to report benefitail changes may result in overpayment which will be recovered. At the moment people think they will get same money until next review despite any changes for the better but if they get worse they report the change .</p> <p>*14. Will need advice on how they should answer if they have a fluctuating condition. Probable need to suggest they should imagine they live alone and consider the help they would need in that situation. *15. Access to advice *Make sure anyone who needs it gets help with the form completion from an independent organisation.</p> <p>*16. Funding aids and equipment *Very often family and friends buy aids and equipment or the applicant buys them.</p> <p>*17. Children. *Must listen to their parent or guardian and make sure a comparison is made to a similar aged able bodied child. Respect mums assessment especially if she has older children.</p> <p>*18. Access to other help *No comment *</p> <p>19. No comment</p> <p>*20 A care assessment could be linked up with a DLA application. I.e. the person doing the care assessment could send the report to PIP and this could instigate an*application for PIP. Also statement fro school children could be used in the</p>

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		<p>same way.</p> <p>*21.Impact</p> <p>*No comment *21. DLA has been abused by some people and this has given it a bad name . It is not necessary to change it completely . the same problem will happen if the new Benefit is not policed properly</p>
EM679	17/02/2011	<p>1. Anyone experiencing permanent, diagnosed mobility issues and incontinence needs have many hurdles to overcome to make a contribution to our economy through sustainable employment opportunities. Having support through mobility elements of DLA/PIP and Access to Work are our rights and vital to ensure disability impaired people can maintain their dignity, human rights and ability to work and enjoy normal lives.</p> <p>*2. Automatic right to DLA/PIP for terminally ill people and anyone with permanent spinal cord/roots injuries and should be legislated for in law from continuous or periodical assessments as decision will be given on indefinite basis. Why should persons with diagnosed, permanent lifestyle limiting neurological and terminal conditions be placed under unfair stresses proposed for periodical assessments as these will continue to trigger reminders of their disabilities and how they limit their lives?</p> <p>*3. Methods of transport to/from work especially if public transport is not feasible due to disability and cost. Need to access adaptations at home and work to be a valued contributors to our economy.</p> <p>*4. Lower rates for Care component for PIP should accurately reflect cost of support for future disability needs as they develop and not based on saving money.</p> <p>*5. Anyone experiencing diagnosed and permanent mobility issues and incontinence needs have many hurdles to overcome to make a contribution to our economy through sustainable employment opportunities. Having support through mobility elements of DLA/PIP and Access to Work are our rights and vital to ensure disability impaired people to maintain their human rights, dignity and ability to work and enjoy normal lives.</p> <p>*6. Living and working with dignity, walking without pain, having difficulties with toileting, cooking and eating tasks. Being able to go out of home beyond local areas with support(mobility car, carer etc).</p> <p>*7. New assessment must take account of diagnosed mobility affected claimants living and working in hilly areas. Current DLA process unfairly disregards this.</p> <p>*Permanent and diagnosed neurological conditions should not be part of periodical evaluation process.</p> <p>*8. New assessment must take account of current allowance claimants adaptations (wheelchairs, walking stick, bathing aids and incontinence products etc) with a view to maintaining their ability to function to the best of their ability for work and lifestyle choices.</p>

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		<p>*9. Have online version with more explanations of each question.</p> <p>*10. Information on medication, adaptations used, medical reports from claimants GP, PDRU specialist, neurosurgeon, practice nurse and Access to Work Physiotherapist should have significant weighting.</p> <p>*11. Will ATOS health professional be knowledgeable and experienced enough to fully comprehend claimants diagnosed condition and how this impacts on their lifestyle and work routines.</p> <p>*Will process be a tick box exercise to save money and not be based on how claimants try to manage their life without pain and discrimination?</p> <p>* 12. Information on medication, adaptations used, medical reports from claimants GP, PDRU specialist, neurosurgeon, practice nurse and Access to Work Physiotherapist should have significant weighting. Certain conditions related to Spinal Cord/Roots conditions are permanent and will not get better even with surgical interventions. Claimants with diagnosed neurological SCI conditions should not be asked to attend assessment process as they will have to relive their trauma and how negatively their condition affects them</p> <p>* 13. Certain conditions can improve with surgical interventions e.g. knee, hip replacements and claimants should have an assessment 12months post surgery.</p> <p>*Anyone with diagnosed permanent neurological mobility issues should be exempt from assessment process. DWP medical conditions already state that SCI claimants should have indefinite awards if condition has existed for 12months already</p> <p>*14. Better link up to welfare rights, Access to Work support if capable of employment(existing or new).</p> <p>*15. Better link up to welfare rights, Access to Work support if capable of employment(existing or new). Referral to voluntary sector for appropriate confidence building support and employment opportunities.</p> <p>*16. Access to Work through employers, self fund walking and bathing aids and seek grants from local authorities, charities etc.</p> <p>*17. What are the key differences that we should take into account when assessing children?</p> <p>*18. Essential for integrating into society, accessing employment through Motability assistance and Disabled WTC assistance-better passport benefits link up where required.</p> <p>*19. Social and economic isolation, regression in mental health, confidence, losing skills base for further education and employment.</p> <p>*20. DLA/PIP recipients who can work but need adaptations should be introduced to Access to Work advisors through usual channels, be advised that free bus pass can be applied for and link up to local organisations offering training and learning</p>

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		<p>opportunities if required.</p> <p>*21.</p> <p>*22. Assessment questionnaires need to be fair and able to accurately identify what disabled people can do all the time and not on 'good days'.</p>
EM680	17/02/2011	<p>I have filled out the questionnaire to the best of my ability and find it refreshing to be consulted. Whether it makes a difference, only time will tell. Thank You.</p> <p>*1. Attitude of employers who don't want someone who will be "off sick" more regularly than an able bodied worker.</p> <p>*Employers don't want to have to involve the Access to Work programme which involves extra expense when there is a "glut" of healthy people who can do the same job.</p> <p>*2. The rates should be at least at the current level.</p> <p>*3. Transport, Food for special diets, Medical equipment not covered by the NHS, Help in strange environments, Batteries for supplied adaptations and equipment, Dental hygiene products, Extra toiletries specific to condition</p> <p>*4. Change is needed to make it less complex and forbidding but the strict levels should be more flexible as some people who are partially eligible for the higher rate are downgraded to the low rate out of convenience.</p> <p>*5. The affect of most medical conditions are as varied as the individual but there are some than have certain symptoms and effects in common that could easily be regarded as the norm as categorised as such.</p> <p>*6. Mobility is essential to our physical and mental well-being as being shut up at home all day can make certain conditions worse.</p> <p>*So help with public or private transport is essential</p> <p>*7. It is essential that medical conditions are viewed in a holistic sense where someone with more than one condition is assessed by the impact of ALL conditions and not just one.</p> <p>*Also, the emotional impact is not taken into account at all at the moment.</p> <p>*8. Very few adaptations cure the problem, they just make it a little more bearable.</p> <p>*Whether or not you insist that the person is forced to use them if available is a matter of conscience not policy.</p> <p>*For example : To say that someone has a hearing aid so can hear and live a normal life is both naive and barbaric.</p> <p>*You need to take into account the fact that some hear loss is intermittent and certainly directional and balance is still an issue regardless, so a "normal" life will never be achieved, only one where you simply adapt and get by.</p> <p>*9. An initial interview by an experienced (friendly) advisor would help.*This could "sift out" the chancers and make the client aware of what is needed in order to proceed with the application.</p> <p>*The advisor could explain it better than the Social Workers</p>

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		<p>who simply help to process a claim without a working knowledge of the process.</p> <p>*10. Medical records are of course a help, but the best people to tell how a condition is affecting an individual is their friends and family.</p> <p>*11. When asked to have a consultation by a Government paid GP you know instantly that they are going to be biased so the whole process is strained and does not portray an accurate reflection of the client.</p> <p>*I personally would say that your local GP would be more likely to do a better job of assessing your needs as they are the ones who see you all the time.</p> <p>*12. This of course is wholly dependent upon the condition.</p> <p>*A 3-6 month review may be necessary for some and 1-5 years for others.</p> <p>*13. That's simple, don't threaten them with massive cuts in their income if they don't comply and ask to have a GP sign a form periodically stating any change in the condition.</p> <p>*14. It is essential that people are informed of who can apply and under what circumstances.</p> <p>*15. Educate civil servants about the process and advertise who people can see for advice.*I have come across Jobcentre staff and Social Workers who don't have a clue how the DLA process works and has left me "under-claiming" but the hassle of seeing them again prevents me from rectifying the situation.</p> <p>*16. Depends on the adaptations, some actually need constant maintenance so the one-off payment would need to cover this.</p> <p>*17. Children do not know what's going on in assessments and are reliant upon the adult to tell them what to do.</p> <p>*They will agree with whatever an adult suggests so you have to be very careful that they are not telling you simply what you want them to hear.</p> <p>*18. Educate those involved in the care of the individual as there are massive gaps at the moment in consistency of help and advice</p> <p>*19. Not exactly sure what you are asking but the current gaps between providers, Government and clients need to be closed in order to prevent further communication breakdown and misunderstandings.</p> <p>*20. Shared information is only as good as those who can be bothered to look at it.</p> <p>*Currently there are many Local Councils and Social Service Departments who are in the same building, share a database but still don't talk to each other.</p> <p>*21. That is one can of worms that I would not be willing to open.</p> <p>*22. I understand that changes need to be made and money needs to be saved but those most in need will suffer regardless of how fair you believe your policies are.</p> <p>*If you make the claiming process too easy then you are</p>

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		<p>overwhelmed with “chancers” and the genuine claimants are left behind broken in the stampede</p> <p>. *If you are too tough it will inhibit the genuine claimants from applying but the “chancers” will be as cunning as before and still get the money.</p> <p>*Providing every individual is assessed on their own merit in a non-judgemental fair system, you have a fighting chance of it actually working.</p> <p>*A policy which embraces a two tier “Black or White”, High Rate or Low Rate system will always leave those in the Grey areas losing out on essential help and assistance. I know this from personal experience. I wish you the very best of luck.</p>
EM681	17/02/2011	<p>Hi Please find my response to the DLA consultation. This one relates mainly to deafness which is very mis-understood by both DLA assessors and ATOS healthcare. Kind Regards</p> <p>*1. No-one realises deaf people who use English have exactly the same communication barriers as BSL users – stereotyping is rife. 30% of words can be lipread – rest is guesswork and yet people think we understand 100% - not true. How can we expect everyone to pay for our support to have a FULL life with what we get at the minute... and even then they don't know they are legally bound to provide it.</p> <p>*Lipreading classes and BSL classes are essential for all deaf people, but most especially those who do not use BSL. They are not a lifestyle choice that most people think.</p> <p>*2. Keep mobility component for those in care homes – it's essential for deafblind people to pay for their communicator guides.</p> <p>*3. Paying for assistance dogs,(insurance, food and vet fees), carers and communicator guides – including communication support for deaf people (not just BSL interpreters, but Lipspeakers and notetakers), extra time(usually 30 mins more for a 5 min voice conversation) needed to make a textphone call on Textrelay – only BT have rebate, I'm on Virgin, they won't give it. Assistive equipment – cuts are making council social services choose the cheapest, but they're not always effective. Some deaf people are being refused aids because they speak!! Personal loop systems are not cheap, and hearing aid batteries (we hear) are no longer going to be free on the NHS.</p> <p>*4. Your response:</p> <p>*5. Deaf and deafblind people should have an automatic entitlement – simply because no hearing person can understand or make a proper judgement on just how much a deaf person can actually “hear” – by this I mean sounds received by the brain with hearing aids of cochlear implants and decoded into words for most deaf people is “garbled”. Deaf people's understanding is always determined by the skills of the person providing the communication as well as the confidence and skills of the deaf person themselves. I have (in my 44 years</p>

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		<p>as a totally deaf person) NEVER seen a deaf person having 100% communication with a hearing person who is not trained in how to do it.</p> <p>*I would suggest that DLA is also used for paying for lipreading classes and/or BSL classes.</p> <p>*6. As Helen Keller herself would say - Communication is the most essential activity for everyday life – without it you can't tell someone your fears, your feelings, your needs, your wants, your response to their dialogue or your opinions.</p> <p>*7. By taking the worst case scenario. At present they make a personal judgement on communication need. Honest! I have the written evidence they are doing that! “you do need support with communication... but not enough of it throughout the day to award you DLA” ... after asking about your typical work day, DLA was never intended to be linked to work! mind boggles.</p> <p>*8. It should take into account the ones they need – whether or not provided by social services. Cuts may mean they won't automatically be provided, so should safeguard the right to choose. And should also include provision even if they already have them, because they DO break down. And what about the training needed to use them? (eg loop systems / computer technology, we're excluded as deaf people because we can't hear the instructions and communication support isn't provided at point of sale, most broadband providers only allow you to get it by phone... impossible with Textrelay not in practise, but in price vs length of calls)</p> <p>*9. The claim form should be easier for those who have sensory disabilities to explain exactly how they cope (you should already know that!). for BSL users, it might also be a good idea to allow them to do it via video messaging/email.*Access to the claim form itself should not be only by phone, need email addresses to contact you too- rapidly being eroded due to Data Protection Act.</p> <p>*10. Definitely not an Audiologist, speech therapist or a GP – they only look at the medical side of things and so often this has no relevance to how a deaf or deafblind person actually communicates. Suggest a communication professional regularly used, or a lipreading teacher who can actually see how much a deaf or HOH person follows would be best person to provide evidence.</p> <p>*Try the Bamford-Kowal-Bench standard sentence lists tests.</p> <p>*11. Deaf and deafblind people will find this extremely difficult without correct communication support. And if the healthcare professional is not aware of how deaf people really communicate, there will be misunderstandings and upsets on both sides. Unless correct communication support is provided, this would be inappropriate. (we asked for a lipspeaker at our appeal, they provided a BSL/English interpreter and nothing was understood properly).</p> <p>*12. Once you are deaf it is impossible to return full hearing,</p>

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		<p>even with a hearing aid or a cochlear implant. So what's the point of a review?</p> <p>*13. Changes in needs for deaf and deafblind people is always likely to be worse rather than better. It is not a curable condition.</p> <p>*14. Access needs for deaf and deafblind people will always require information in a format they can follow. This includes Communication support, BSL videos, Braille, Large print, audio description... and plain English.</p> <p>*15. Yes. Many deaf people at present are not aware of the support that DLA can bring. They are suffering lack of confidence, support and many have mental health issues resulting from this. Social media is making them aware.</p> <p>*The key features of such a system would be the people providing this support should be educated in the communication needs of ALL deaf - and who also understand the differences between those deaf people who use English against those who do not. At present those who do not use BSL are grossly let down.</p> <p>*16. I fund my aids and adaptations from my current DLA – I value the independence this brings highly, without it, I would struggle to pay for them. Some have been provided by Social services, in the past but I have not found them as helpful as I would like. I prefer to be independent and do it myself.</p> <p>*17. Listening to their parents/ guardians.</p> <p>*18. Extremely important. I find travel by train alone extremely stressful unless I have a companion, and DLA allows me access to a disabled railcard.</p> <p>*Many organisations ask for evidence of disability – and DLA is the only way forward because the so called “green card” no longer exists.</p> <p>*19. It would make me stay at home more and simply not go out, it's easier than trying to navigate life without this support. I can see this scenario leading to more discrimination.</p> <p>*20. ESA / Access to work / DLA all together. But only if there is confidence that there will be a FAIR assessment.</p> <p>*21. Your response:22. Your response:</p>
EM682	17/02/2011	<p>████████ Council staff member - registered blind</p> <p>*1. Answer 1. I think many disabled people get discriminated against in many different ways. I personally have been discriminated against for example when I have been refused to be</p> <p>*allowed into a taxi because I was travelling with my guide dog. Also I found have problems in the past with not been given text in a readable format that would allow me to read it clearly.I think it is very unfair that the government are considering cutting benefit for those genuine claimants who have a*genuine disability that makes it harder for them to compete on a level playing field with everyone[Fore example the reason why there are around 90% of blind people are not in work is not</p>

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		<p>because I think they can not be bothered to find work it is because they find it hard to find work and have to face extreme discrimination before they can even get into work.</p> <p>*2. Answer. As a blind person I do think that blind people should not be re assessed for there benefit entitlement as most blind people face the prospect of there sight deteriorating and getting worse. Not getting better as I personally do. Of course if someone does have a sight problem that may improve or could improve with treatment then of course they should then be assessed.</p> <p>*3 Answer. I personally have to spend extra money on computer software to help me read the computer and this is very expensive costing lots of money. For example a good CCTV for reading print costs around £3000 and Jaws for reading the computer costs over £800. Also as I need to get Taxis on numerous occasions when travelling in unfamiliar areas then I need to spend extra money on this.</p> <p>*4. I think could make the benefit easier to understand but on the other hand I think People on the middle rate could find they may get less benefit then before.</p> <p>*5. Answer.I think if a person is registered blind than they should get the benefit automatically as long as they can show they are really blind of course by providing documentary evidence from an eye. specialist. *6. Answer. I think we need to look at what exactly that person can do in terms of getting around on a daily basis taking personal care of themselves and what actual help that need from non disabled people in the community.</p> <p>*7. Answer. If some one has a fluctuating condition than there is a need to assess that person to make sure they are not getting better or worse.</p> <p>*8. I do not agree with this idea because I think it would be unfair for example to reduce a blind persons benefit just because they have a guide dog to help them get around I stress the point that they need those aids to get around.</p> <p>*[While non disable people do not need them and they are still not able to function as a fully able bodied person. .</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>*9. Answer. I think it would be helpful to make claimants feel that where been treated fairly and not treated as though they are automatically guilty of fraud.T</p> <p>*There needs to be more awareness of benefit entitlement and encouragement for people to claim.</p> <ul style="list-style-type: none"> *[• How could we make the claim form easier to fill in? <p>*Answer avoid jargon.</p> <ul style="list-style-type: none"> *• How can we improve information about the new benefit so

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		<p>that people are clear about what it is for and who is likely to qualify?</p> <p>*Answer have open days meetings etc.</p> <p>*10. Gp Hospital eye specialist</p> <p>*] 11. • What benefits or difficulties ...? They may not be fully aware of all the difficulties that person faces in there day to day life's.</p> <p>*[] • Are there any circumstances ... location? Answer. Not sure about this one.</p> <p>*12. Answer. If you have an eye condition that is not going to get better than there is no need for frequent reviews as this would waste time and recourses.</p> <p>*13. Answer send regular reminders notices.</p> <p>*1 4. Answer They would need to know what other pass ported benefits they can claim and when they should report changes.</p> <p>*15. [] Answer. Not totally sure about this one but feel under this new system claimants like myself feel that there standard of living is under threat from this government who appear keen to save money rather than making the system farer.</p> <p>*16. Answer. I would find it very hard to manage without my DLA as it helps me to be more independent and live a more satisfying live in the community as it helps me to pay for special equipment to like Jaws an magic for my computer and CCTV for reading and getting around etc.Yes one off payments could help.</p> <p>*17. Answer not sure.</p> <p>*18. Answer. [Make disabled people more aware of pass ported benefits by holding open days etc</p> <p>*19. Our standard of living would be effected as could be harder to claim other benefits and get access to other essential services that we need.</p> <p>*20. [Answer. Could share medical records gp records etc.</p> <p>*21. Answer. The impact to existing claimants who are genuine claimants need to be considered as I feel some blind people when re-eased] could be worse off due to the changes.</p> <p>*22. Answer Yes I think we need greater consultation before these proposals go ahead.</p>
EM683	17/02/2011	<p>1. Your response: One of the barriers is the use of the word disability, which is essentially negative. At all times the key word to be used is ability and how that can be expanded by the individual to enable them to live life to the full.</p> <p>*2. Your response: DLA should be seen as a temporary support to enable people to exploit there residual abilities. It should not be regarded as permanent or as a step to other benefits, such as a motability car.</p> <p>*3. Your response:</p> <p>*4. Your response: a) Two rates will not make it easier to understand but will introduce lengthy arguments about the most appropriate rate*There will inevitable be a tendency to migrate towards the higher level in most cases</p>

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		<p>*5. Your response: All claims should be based on needs and circumstances and not ever on medical diagnosis</p> <p>*6. Your response: b) Breathing, maintaining nutrition, managing micturion and bowel evacuation, sleeping, moving</p> <p>*7. Your response: Not easily. This will be a contentious area with some claimants saying that "You didn't see me on a bad day"</p> <p>*8. Your response: One should assume that all relevant adoptions are available and in use</p> <p>*9. Your response:</p> <p>*10. Your response: The best evidence is from an unplanned and comprehensive home visit by an independent person</p> <p>*11. Your response: HCP (i.e. GPs) are not unbiased and have little contribution to make to DLA assessments</p> <p>*12. Your response: A standard comprehensive unplanned home visit</p> <p>*13. Your response: Building in a short life to a DLA benefit, i.e. six months. At the end of which a statement of unchanging needs should be forwarded by the claimant to the DWP. If this is not forthcoming or is found to be inaccurate benefit is suspended sine die.</p> <p>*14. Your response: 15. Your response: 16. Your response:</p> <p>*17. Your response: How do their needs differ from otherwise unaffected children?</p> <p>*18. Your response: DLA has frequently been seen as a lever to access other benefits</p> <p>*19. Your response: There would be less abuse of the system</p> <p>*20. Your response: 21. Your response: 22. Your response:</p> <p>*DLA is very much a creation of a non functioning health service. The financial costs due to the mistakes or lack of effective rehabilitation by general medical practitioners and hospital doctors are borne by the DWP in the form of extended benefits. *The concept of a "sheltered " period of six months sick pay was entirely appropriate when Lloyd George introduced his national insurance measures 100 years ago, but is not relevant in 2011. The period of SSP should be reduced from six months to six weeks. Six or eight weeks after the onset of an illness ALL claimants should be assessed by an INDEPENDENT medical person. This would include screening tests for common, treatable conditions such as depression and or anxiety. Those with obvious serious conditions, dense strokes, extensive cancers, would be nodded though. However those with self limiting conditions, such as ongoing low back pain or mild depression should be directed towards effective rehabilitation and treatment. The cost of rehabilitation should be an obligatory charge on the NHS, and billed by the DWP to the NHS in the same way as car insures are currently billed for physically injured motorists.</p>
EM684	17/02/2011	I am responding to this, having been told about the "consultation" by the MS Society, (you will probably realise - I

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		<p>have MS)</p> <p>*I have tried to answer as many questions as I could, but had to do it over several days & ran out of time (and ability to concentrate)</p> <p>*1. Your response: 1) MOBILITY - Especially if the disability is not obvious (e.g. not having a leg in plaster), it can be very daunting just being in a group of people - about a year ago I attempted to board a bus, but the 10 or so other people who were jostling to do the same meant that I had to wait to the end, by which time all the seats at the front had gone, & I had to try & get a seat after the bus had started moving - I then lost my balance & bruised and twisted my thumb badly. This experience put me off trying public transport for quite a while, which meant relying on my car - extremely expensive with the rising cost of fuel. It's all very well telling us we should walk more, or use public transport, but some of us cannot walk or feel safe using public transport!</p> <p>*2) EVERY DAY THINGS - Again, it is not obvious that I have very restricted use of one hand. Paying for goods in a shop, taking something that is passed to me, opening doors, cutting up food on my plate, getting dressed, carrying a bag etc. (all things I used to take for granted) are all things I find difficult - and it tends to knock one's confidence. An example of this was when I was drying my hands under a hot air dryer, not realising there was no hot air coming out of it - amusing to look back on, but embarrassing at the time.</p> <p>*Not being able to walk very far, & having to walk very slowly, losing my sense of balance if I'm in a crowd, saying the wrong words & not realising it - these are all things that make it difficult to have the confidence to "participate in society". Fatigue & pain are also "invisible" problems that can make integration difficult.</p> <p>*2. Your response: Being in receipt of it should still make it easier to apply for things such as "disabled" class road fund licence, the "Blue Badge" scheme and disabled working tax credits.</p> <p>*3. Your response: Mobility - even short distances require the use of the car. Heating - immobility makes it more difficult to keep warm.</p> <p>*4. Your response: Un-known</p> <p>*5. Your response: Some should be automatic for at least the lower rates, the higher rate could be based on needs & circumstances.</p> <p>*6. Your response: Quality of life means different things to different people - one thing I found strange about the DLA form, was the way it took no account of ability (or lack of ability) to do housework - something quite important to some wives & mothers. It did, however, seem to assume that all women want to wear make-up (not easy to do with "twitchy" hands).</p> <p>*7. Your response: Many organisations deal with the effects of certain disabilities (i.e. the MS Society), and they may be able</p>

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		<p>to advise about the different problems that can exist.</p> <p>*8. Your response: Aids & adaptation are not always possible, not always suitable, nor do they always work (I know of a person with macular degeneration who has been given all sorts of gadgets, but he doesn't find any of them useful). A wheelchair, for instance, is no good on broken or un-even pavements (and there are plenty of those around).</p> <p>*9. Your response: Maybe the form could be shorter, or possibly done in such a way as it could be filled in like a diary, giving a fuller view in " a day (or week) in the life of" sort of format.</p> <p>*10. Your response: Supporting evidence from a specialist (e.g. MS Nurse) could be helpful, although they do not see the disabled person 24 hrs a day, to see the full impact the disability has. A GP sees even less of the patient. I know in my own case, I just get used to not being able to do certain things, so don't bother "complaining" about it when seeing a health care person (eg I cannot sleep on my left side, I can't use a knife & fork, I can't walk in the dark, I can't hold an umbrella so I get very wet if I'm out in the rain).</p> <p>*11. Your response: It would be beneficial if the healthcare professional REALLY knows the claimant, not always possible (see previous answer).</p> <p>*18. Your response: VERY important</p>
EM685	17/02/2011	<p>As a disabled person in receipt of DLA I would like to comment on this green paper.*It has been publicly stated that the coalition's intention is to reduce the DLA caseload by 20% but this has been conveniently omitted from this paper.</p> <p>*This equates to 640,000 disabled people losing the benefit. In addition the paper seeks to 'simplify' the system by removing the middle rate of care component. This would affect 460,000 people being re-classed, probably to a lower element.</p> <p>*Therefore over 1 million disabled people will have their benefit totally removed and/or reduced.</p> <p>*The majority of disabled people are, in general, at the bottom of the pile socially and economically and I am not sure how ministers expect them to manage with this loss in benefit.</p> <p>*The paper tries to argue that DLA is somehow a barrier to employment. This argument is a clearly a ridiculous statement and is a cynical attempt to justify these changes. Does the coalition truly believe employment figures will suddenly increase due to disabled people not receiving DLA? In my case, as I am unable to use public transport, if I lost my mobility element it would not be cost effective for me to work at all. How does that help?</p> <p>*The paper paints a poor picture of DLA but the alternative is (from the scant information provided) a lot worse. The only simplification is the removal of the middle care element but provides no answer as to what effect this has on the 460,000 recipients. From the tone of the paper it is unlikely these will be</p>

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		<p>moved to the higher element. Why not just improve DLA? Why waste millions on a system you do not even know will be effective?</p> <p>*The paper provides absolutely no details of the new benefit rates – again how can you measure the effectiveness of a new system against the old if you have no idea (or are unwilling to publicise) these rates?</p> <p>*The key element of the PIP seems to be that although individuals can provide evidence of their disability (usually from their doctor or consultant who knows the condition and its effects) this will be countermanded by evidence from a face to face interview with a ‘health professional’. The paper gives no indication as to who these ‘professionals’ are nor their specific experience. In addition there is no idea of what the questions will be or how these will help determine the level of benefit awarded. If the questions are too vague will the caseload actually increase or if too restrictive run the danger of removing too many?</p> <p>*If ministers get this wrong will the questions be changed along the way, resulting in appeals?</p> <p>*A lot of disabled people find travelling difficult/stressful but it will be necessary for everyone to go to these interviews. This interviewing system will be an additional layer to the administration of the scheme and will increase costs as this work will be subcontracted out to the private sector. What will their remit be? Will they be funded per interview or number of claimants removed from the caseload?</p> <p>*The issue of aids and adaptations is mentioned as though these are some sort of magic wand. They may help a person cope with some aspect of their disability but they should in no way be seen as downplaying any condition and its affect on a person trying to lead a full and normal life. Indeed, a lot of aids and adaptations are never just a one off cost. Many items require maintenance and replacement and are never cheap. Claimants use their DLA for this but there is no confirmation that the new system will cover this.</p> <p>*In conclusion I cannot support any of the green paper recommendations as they are too vague, cannot predict what effect the changes will have. It is clearly Treasury driven with the sole aim to reducing the caseload, no matter what the effects will be.</p> <p>*This is a classic example of poor policy making and will undoubtedly lead to a massive number of appeals and complaints to local MPs.</p> <p>*The prime minister’s reputation with disabled people is now in tatters. As someone who had a better understanding than most of disability issues he has failed to demonstrate the views he held before the general election. Shame on him.</p> <p>*The only positive message is that disability is becoming more politicised and disabled groups are joining together to fight their</p>

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		corner. You only have to visit disability forums on the internet to see how scared and angry disabled people are by these cavalier changes.
EM686	17/02/2011	<p>An individual response to D1a Consultation Document. - Having studied the consultation paper it seems to me that the whole document is full of myths and inaccuracies and political spin.</p> <p>*There is no evidence to support the claims made against DLA. It is just another badly thought through cost cutting exercise that will leave disabled people worse off and will cost far more to administer. Most severely disabled people have been awarded the higher rate DLA for life, now that is to change. The legality of that is questionable and will surely be challenged in the courts by disability organisations.</p> <p>*In her forward, the minister seems to think that DLA is awarded to disabled cannot work. She thinks DLA has become a barrier preventing people from working.</p> <p>*DLA never was and never should be linked to a person's ability to work. How patronising of the minister to suggest that work is the best form of welfare. The vast majority of DLA recipients are to severely disabled to work or too old to work or both.</p> <p>*The minister goes on to say again how committed she is to providing unconditional support for disabled people, can we then assume that she will be increasing the value of the new benefit? Is that what she means by sustainable?</p> <p>*The minister talks about a new benefit that will be dynamic, is that a "bad Spin" or can she really make money dance.</p> <p>*Has the Minister forgotten the last time a review was carried out it resulted in more people being awarded the higher rate this adding more to the overall cost of DLA.</p> <p>*Much mention is made of assessment, who will be the assessors? Will they be doctors or occupational therapists or social workers? All three professions are already overloaded.</p> <p>*The document mentions that disabled people might be required to fund their own aids and adaptations. So does that mean the new benefit will take account of this when the average Wet Room cost 12k, a Stair lift can cost 5k, Hoists average at 10k?</p> <p>*Under the present system there are certain health conditions that are fast tracked to DLA. This was done to save administration costs. The new scheme will require constant re-assessments, how will that reduce admin costs?</p> <p>*In order to justify changing the benefit the document states that people become more mobile when using a wheelchair does that mean people who use wheelchairs don't need so much money as people who don't use wheelchairs?</p> <p>*It is stated that when a person has been assessed for the new benefit, the information gathered will be shared with other agencies. I believe this would lead to mistakes being duplicated and going undetected. It makes no allowance for changes to a claimants health or independence.</p>

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		<p>*RESPONSES TO QUESTIONS</p> <p>*1. My response: Barriers are many and varied. Participation in society is mostly a personal choice, where independence is determined by degree of disability.</p> <p>*2 My response: All the criteria laid down when DLA was first introduced is still applicable*</p> <p>3. My response: The main extra costs for disabled people are transport, small aids, personal care & domestic help</p> <p>*4. My response: Having two rates for each component will make it harder to understand with more opportunity to assess people to the wrong rate</p> <p>*5. My response: Yes some health conditions should have automatic entitlement</p> <p>*6. My response: Different people will have different ideas of full and active lives and essential activities will be varied</p> <p>*7. My response: Assessment must be based on the claimants worse condition i.e. their 'worst day'.*8. My response: Aids and adaptations should not be included in any assessments</p> <p>*9. My response: Why should applying for a benefit need to be a positive experience as with any benefit, the criteria should be laid out clearly, avoiding any beaurocratic mumbo-jumbo</p> <p>*10. My response: It is clear that the medical profession will provide the majority of supporting evidence, occupational therapists could have an input.</p> <p>*11. My response: I think face to face meeting with professional assessors in the claimants own home is essential to help tackle fraud. Claimants should be allowed encouraged to have advocacy help if required.</p> <p>*12. My response: The assessments need to be tailored to suit individual disabilities.</p> <p>*13. My response: It is the law that any permanent change to a claimants condition should be reported. I see no reason to alter this.</p> <p>*14. My response: As is currently the practice, notes to assist claimants to fill out application forms should be available in all formats.</p> <p>*15. My response: This question is rather ambiguous advice and support is available through other agencies and is not in the remit of the DLA</p> <p>*16. My response: Disabled people currently fund small aids themselves and apply Disabled Facilities Grant for larger adaptations, I see no reason to change this.</p> <p>*17. My response: When assessing children assessors will have to take account of changes in the amount of care required as the child grows, lifting and handling becomes more difficult putting more strain on the parents.</p> <p>*18. My response: DLA is currently a useful gateway to other services, this should continue and be allowed to evolve without</p>

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		<p>being an open door to fraud.</p> <p>*19. My response: Passporting makes life much easier for disabled people generally it is also a good way of keeping down administration costs and saving time.</p> <p>*20. My response: It is not good practice to combine assessments for different services. The problem with sharing information is that any errors or changes become harder to correct.</p> <p>*21. My response: When a person is disabled it makes no difference what race, gender or sexual orientation they are that is why these questions have not applied to DLA and should not be applied to any new benefit</p> <p>*22. My response: I realise that in this country our benefit system has been allowed to grow to appoint where it is no longer sustainable. However, why is it always the disabled and people of lesser advantage who are going to bit hit hardest especially when supporting charities are cutting back their services because of their own funding problems.</p>
EM687	17/02/2011	<p>As a parent with two children with rare metabolic disorders which will involve lifelong disabilities I would like to raise the following points and objections to the reforms of the dla.*Dla as it currently stands is based upon evidence from the recipients doctors and specialists which forms the decisions and amounts that the disabled person received. This results in the experts involved with the persons care playing a key role in providing evidence. The interview and review process being discussed will involve decisions being made based on their opinion from a short interview and medical and the staff will probably be targeted in removing people from it.</p> <p>*This is wrong for the following reasons: It is degrading and inhuman for disabled people to be interrogated regarding their disability.</p> <p>*Disabled people with learning difficulties will find the process distressing specially as they will have this inflicted on them on a regular basis throughout their lives</p> <p>*The experts involved in their care should be the key contributors of evidence rather than generally trained interviewers.</p> <p>*This move is just a way of targeting vulnerable people with cuts by another name and the government should be ashamed.</p> <p>*The government rhetoric of people should never be better off on benefits and then targeting disabled people will lead to people with disabilities becoming poorer and poorer.</p> <p>*Where people have disabilities for life what is the point of keep checking up on them. If a person has one leg when reviewed do you honestly think it will grow back. If a person has a birth disability is it going to suddenly get better.</p> <p>*Regular reviews and medicals are both stressful for the disabled person and expensive. The costs of the reviews will not be cheap nor will the cost incurred by the massive</p>

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		<p>increases of appeals etc.</p> <p>*I would also question if the proposals are in the spirit or definitions of the disability discrimination act and the human rights act (or are both of these going to be repealed)</p> <p>*Please leave the dla as it is. It does a good job for disabled people and surely that's what's important than adding £2bn reviews to con the disabled.</p>
EM688	17/02/2011	<p>1. The disability itself is the biggest barrier. Depending upon your medical condition words such as participation can make very little sense. My illness is my barrier to a full and active life because to have such a life I need to be well enough to be active and independent. The very fact I can't manage independently and find the world a challenge requires help from others. Help from others requires money. Taking away finance won't make me more independent it will mean I see less people and become more isolated and that *does not improve the health of any person.</p> <p>* 2. It should be a benefit that helps add value to a disabled person's life in some clear way. If the government has identified through independent research that the benefit is not valuable, then they need to explain why that is the case and where the evidence is for that. If it helps disabled people then it should stay the same or improve.</p> <p>*3. The cost of requiring other people to do things for you because you are not well enough to manage independently, the expense of equipment and or aids, the cost of transportation to hospitals, consultants and specialists many that are spread right across the UK.</p> <p>*4. I think DLA is already a hugely complex form and many of the questions make it very difficult to explain fully the issues one has. Having two rates sand two component will further complicate matters and will mean additional outside help and input will be further required to understand and fill in the claim form. This is at a time when such services are being closed. The current model already distinguishes between a care and mobility component and changing this doesn't seem necessary. What seems most necessary is to fully understand the individual person's condition based upon individual medical history as it relates to that person. Definitions and tightening of language just restricts disability into boxes that people do not fit into. Some people are in wheelchairs but are Olympic athletes, some people are in wheelchairs and cannot cope with day to day living. Each case should be examined on specific medical merit.</p> <p>*5. It should be based upon the needs and circumstances of the person applying. Each person should have their medical history examined and the problems they individually experience addressed with help from the benefit. There should be an exemption for the terminally ill however.</p> <p>*6. That is a question of philosophy which probably can reflect</p>

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		<p>some of the questions one faces on a DLA form. How does one say what is essential to life other than food and shelter. One could live in a cave and have food and shelter but what does the society we live in determine as being essential activities. The key question as a society is are we going to help people who have a disability to exist, food, shelter, toilet, washing or are we going to attempt to involve them by affording them access to things that other able bodied people take for granted. Is the benefit inefficient in doing this, has it been found to be so by research and are disabled people saying it isn't helping.</p> <p>*7. The benefit already does take account of this on the form by asking how often one needs help and for how long and during what periods. It is up to qualified independent doctors ie those employed by the NHS and not those employed by private firms working on behalf of the DLA. That is duplicating and putting a barrier between consultants and doctors who know the patient and an arbitrary doctor whose main focus is to prevent the benefit being awarded. Even very serious medical conditions have periods where they are not fully active and the patient feels better some days than others, if over 75% of the time a patient felt well and able then they wouldn't really be entitled to benefit under the current system, so the benefit is already targeted at the long term sick and disabled. If there is a change in circumstances or a patient gets better then this can easily be monitored through information exchange with their GP.</p> <p>*8. No, if one suffers from dizziness and in order to reduce the sensation of falling they use a walking stick, then this still doesn't make that less of a disability. An aid may help alleviate a problem but it doesn't cure the problem. It is an assessment about a person's illness and how that impacts their life. The aid is not a cure it is a benefit.</p> <p>*9. Simply provide the claimant with full space to list their medical condition (s) ask them to explain how this means they are unable to do certain things. Ask them to provide a full list of doctors, consultants, hospital admissions and so forth and then pass this on to your team and ask for a report back upon these conditions from the doctors that the patient visits. The other questions relating to degrees of doing things and timings and so forth and how far one can walk are really arbitrary and make the form very stressful and confusing. This can all be established later once the person has established they have a valid medical condition based upon independent existing medical evidence.</p> <p>*10. This MUST be independent and come from experts in the field of the patient's illness. That is the patient's current doctors, not generic medical staff employed by the DLA. This is probably THE most important factor ATOS is not there for the benefit of the claimant. The process should be about independent validity of conditions not about biased judgements. A patient's consultant or doctors have no vested interest in whether a</p>

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		<p>claimant receives benefit. Private firms are paid on the basis of performance as it relates to prevent claims being allowed, this is unjust and wrong.</p> <p>*11. This is not appropriate as once again you are duplicating what a patient's existing doctor does. If I go to my Doctor he has the legal responsibility already in place to diagnose and issue treatment. The money involved in this could probably pay for the proposed cuts to the benefit. This is wholly unnecessary and not at all patient beneficial.</p> <p>*12. This should all come from the existing medical team that the patient uses. Why does the government seek to disenfranchise experts already dealing with patient conditions and appoint others to re-diagnose conditions when they will not be qualified to do so.</p> <p>*13. Through their GP's.</p> <p>*14. I should imagine claimants will need as much information as possible in particular in the form of bullet points precisely where this new terminology differs from the old.</p> <p>*15. Sorry I don't understand the question.</p> <p>*16. I should imagine that is information that you would have already. I really do not know how other disabled people fund their lives.</p> <p>*17. Sorry I don't know</p> <p>*18. I don't know</p> <p>*19. I don't know:</p> <p>*20. The patient has medical records. The illnesses have prognosis and pathways and a patient has an existing history. Not employing other doctors without sufficient expertise in the conditions would hugely reduce bureaucracy and duplication</p> <p>*21. Sorry I don't know.</p> <p>*22. The information about patient illness exists already, do not duplicate it, this is not fair and the medical people you employ will not be qualified to make the appropriate assessment of a patients illness. They are not experts and they cost enormous sums of money and waste vast resources in appeal processes which as you know are often decisions that are proven invalid. There is a system in place already, namely the NHS and its patient history.</p>
EM689	17/02/2011	<p>Dear DWP consultation,</p> <p>*I would like to make some important comments on the proposed changes to the way in which DLA may be assessed and awarded. I have just read the paper on the governments proposals, which is quite lengthy and I would be surprised if many disabled people or their carers will have the time and or the wherewithal to read and digest what is being proposed. These changes would be very worrying and appear much more intrusive into the lives of disabled people than would be necessary or that would indeed respect the privacy of the individual. The very nature of disability can render individuals as very vulnerable. Disability is a very complex issue, disabilities</p>

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		<p>can be immensely complex, perhaps particularly learning disabilities. DLA appears to me to work extremely well and is certainly fit for purpose, it takes individual needs and conditions into account. DLA is already awarded to those most in need, very capable professionals are already available to assess the disabled persons level of needs and level of disability. They spend weeks, months and years assessing those who require extra support in society. DLA is or certainly was always an UNDERCLAIMED allowance, it is a well known fact that many eligible *disabled people and their carers are not aware of it's existence. My son was denied at least 2 years of DLA when diagnosed with Aspergers, in fact probably 5- 7 years. In the meantime, we lived in terrible poverty, being a carer makes it extremely difficult to work, and carers already work long hours with little or no respite, saving the government millions of pounds, literally. The 3 components of DLA appear to me to work as part of a fair system. I do not see how the assessors can possibly be using subjective criteria when they have the extensive information in the forms in front of them about the particular personal issues that impacts on the disabled persons life, as well as medical reports etc. For some disabled people face-to-face interviews would be very intimidating, for instance, Aspergers by it's very nature, can very often mean that *the disabled person is easily led and influenced by suggestion, it also means that that person may feel frightened, and it also means that face-to-face is in actual fact impossible for the Aspergers sufferer. Eye contact, environment and surroundings impacts on the person with Aspergers in a detrimental way, which can also be long lasting and harmful in my experience as a mother and carer. The proposal does not state whether the individual would have access to legal and or charitable support if forced to attend proposed face-to face interviews etc. I do not see how a telephone discussion would in any way give an indication of eligibility for DLA, it would not give an accurate picture of the persons needs or of their most complex disability issues. The proposal mentions self report forms, many people with learning disabilities cannot read or write well, if at all. *Who then would be do the self report? The extent to which the proposal seeks to invade the personal and private life of the individual is deeply worrying. As far as I am aware, false claims for DLA are pretty low, it more likely that eligible persons are not actually claiming what they are entitled to, meaning that they are missing out on literally thousands of pounds per year. While the forms as they are at present are long and difficult, and can be very upsetting as it is the disabling aspects of the persons life that has to be concentrated on, with the right help and support (usually available from relevant charities and from already existing professionals) to include relevant and accurate information, it can certainly be less stressful to fill in. It would not make sense to be required to fill in a form starting how</p>

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		<p>wonderful the disabled person is (even if they are!) as it would be an inaccurate picture of how their disability impacts on their day to day life which is why they need the extra support in the first place.</p> <p>*The proposal talks about the reporting of changes in circumstances, it concentrates totally on the chance that changes of circumstances may not be reported in which case overpayments are likely, it is equally relevant surely, to stress that the opposite may happen and that an individuals circumstances may deteriorate in which case they may be being underpaid. It is in my view that needs can change over time, but with those changes, new challenges become apparent requiring a shift in how the disabled person and their carers, manage the disability. A change is more likely to mean a shift in management of needs not in less support being needed.</p> <p>*Disabled people require an incredible amount of support and special care, to be safe, and happy and to live as full a life as possible. The financial support of DLA is absolutely crucial to helping them develop strategies in order to cope with the extra and everyday challenges experienced as a result of their disability. People with disabilities do want to be treated equally, to be given support where needed and not be stigmatised as a result of their disability. The proposal for reform talks of 'enabling people to better manage and improve their situation'. To talk of disability in terms of a 'situation' is to delve into dangerous territory, it implies that the disability is the fault of the person themselves and not an actual condition or illness outwith their control. While disabled persons want to live as independent a life as possible, the support from 'health and social care systems' may not be appropriate or relevant, and in fact these support systems are already in place, where needed or appropriate.</p> <p>*I was extremely worried by a comment about PIP 'recognising individual changing needs overtime to make sure PIP is better equipped to reflect further changes in our society'. The report does not state which way or in what form these changes in 'our society' will take, does it have crystal ball? I am very concerned about this statement which has no supporting evidence or knowledge or any background information on what this means for disabled or even non disabled members of our 'society'.</p> <p>*Our 'society', indeed our rich country, must look after its most vulnerable members, if it wishes to be effective, forward looking, economically successful, fair and compassionate. Caring and sharing are a must for a future with less social divide in which each person can live a successful and rewarding life, which will in turn reward 'society' as a whole. Spending money on 'reforms' such as this, just takes away the emphasis needed on creating and maintaining a fair and just society. If it ain't broke don't fix it'. Thankyou, ██████ Edinburgh mother and carer.</p>

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EM690	17/02/2011	<p>1. : Many and varied. Even within broad areas of disability it is usually a very personal and subjective problem. Ranges from acceptance as a useful member of society through financial inability to compete to mobility to physical obstacle to ignorance and associated inability of able bodied persons to help.</p> <p>*2. : Two things come to mind: the three component levels of care. This cannot be easily measured objectively, as above it is a very personal experience and depends on interactions with family and friends and wider social networks. Secondly, indefinite assessment of need for certain conditions. These realistically have been drawn up on recognition of irreversible conditions which if medically a solution were to be found would be widely and publicly recognised and as such could be easily subject to reassessment.</p> <p>*3. : Again subtly wide ranging. I can only speak from experience of my wifes condition, which is a hereditary progressive blindness. It has not and does not only affect her; it has and does affect our whole family and others financially. Mobility is a big problem, which is bourne by transport provided by myself and others through to public transport, very occasionally, to private taxi. Modifications to our home and contents is ongoing, ranging from improved lighting to access to more visible to more practical items.</p> <p>*4. : Two rates would undoubtedly simplify matters, but if even one person is financially compromised it is a backward step. Financial loss is a big consideration as I doubt that we are the only ones who would be struggling if we were to lose any income. I feel the whole family suffers lower income expectation if there is disability in this situation as certainly my ability to compete is limited by my support for my wife, impacting on the hours, locations and type of work I can do.</p> <p>*5. : As I outlined above, yes I believe certain conditions should automatically benefit claimants.</p> <p>*6. : Can only speak from my wifes perspective, independence is what she craves, as everything else would follow. Unfortunately this will never happen so the best thing for her would be universal support network where every journey didn't need to be discussed and planned in advance. Ability to do more things she used to do like sport, again a 1 to 1 support system would help. Social interaction as gradually you lose contact socially with people you cannot do the same things as them any more. Complete rethink on transport giving back pedestrians priority over cars bikes etc. Education! Disability awareness as a core subject from primary school</p> <p>*7. Your response: Not sure, rapidly varying conditions must be on a worse case scenario.</p> <p>*8. Your response: No way! Because a person has an aid doesn't take away a disability. For e.g. my wife has a guide dog, but it can't read signs, it doesn't make decisions on whether to cross a road, it can make it easier to travel tried and</p>

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		<p>trusted routes, but if my wife wants to go out of town for e.g. she still needs a companion. So the problems of access and mobility and finding things are still there, it makes a subtle but important difference to my wife, it gives her more confidence.</p> <p>*9. Your response: 10. Your response:</p> <p>*11. : Oh yawn! We have already had a string of these, and hate to bring it up again but we have to suffer them as well. Its time consuming and demoralising having to justify yourself every time, like "Oliver". You already have the data many times over. It feels like being penalised for being disabled.</p> <p>*12. Your response: 13. Your response: 14. Your response: 15. Your response:</p> <p>*16. Your response: 17. Your response:</p> <p>*18. Your response: In our experience it isn't worth the hassle filling in the forms lifes too short! If you have any sort of income as a family above the poverty line its our experience you get nothing.</p> <p>*19. Your response: Devastating I would imagine.</p> <p>*20. Your response: 21. Your response:</p> <p>*22. : I believe it is just a cost cutting exercise. You may believe the system is a scroungers paradise but believe me the loss we have had is in no way compensated for by this benefit. Moreover if we could possibly live without this measure we would, by targeting this group you make us feel like the second class citizens you purport to be helping. Please don't think we are not grateful for the help we receive, I just think you should be expanding help not trying to contract it despite the economic downturn. The measure of a civilised society is the way it treats its vulnerable members, otherwise why don't the strongest just take what they want and blow the rest. Hang on that won't work cos we've all got to get old and vulnerable!</p>
EM691	17/02/2011	<p>Dear Sir/Madam My son is [REDACTED] years old and sustained brain damage when he was being born. He has global development delay and is physically and mentally disabled. We are currently on the high rate of DLA for care and mobility.</p> <p>*In answer to Questions 1 and 2 my son will need not only physical aids ie wheelchair or walker, but someone with him constantly to help him understand the world around him. Without this he will not be able to interact in society at all. It is difficult to think about what his life might be when he is older because I refuse to prejudge him and provide limiting expectations, however, it is likely that he will continue to need this for the rest of his life. Therefore, the mobility payment and being able to receive a car that someone else can drive would continue to be an essential need. The application form is difficult to complete - we have had wonderful support coordinators who helped us complete the application - it is difficult for a parent to be blunt about your child's difficulties. It tends to be very distressing reviewing and listing everything and it has been helpful talking it through with someone I already</p>

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		<p>had a relationship with so that they could write it down for you to review and sign. I wouldn't have wanted a stranger to come in and go through this process and if I had completed it alone I always try be very positive and the extent of my son's condition may not have been evident. This needs to be considered when making the payment more individually focused.</p> <p>*In answer to Question 3, the extra costs are fuel to get about but also heating the home; my son's lack of mobility means that he can get cold. Equipment is also a big factor. The big things like wheelchair, supportive chair for the home, walker have been provided for but it's the smaller things; I've spent a fortune on toys - musical toys, toys that light up, sensory toys, cause and effect toys, press button books, books with flaps etc etc. I make use of the local library and toy library but it's impossible to pass a book or toy that might be beneficial and create some kind of reaction from my son. Plus every time he uses something at school for physio I try to get it at home so we can replicate what he does in the class. Then there are the various lights we use to create 'sensory time' and to soothe him at night which is a particularly difficult time. I wanted to attempt potty training so asked Occupational Therapy for an extra supportive potty chair. 3 months later I'm still waiting for it to get the funding agreed. I know it will be agreed eventually but then it will need to be ordered which my experience of new equipment means that I'll be waiting several months once it is ordered. This is why we tend to by things ourselves. As my son gets older he will continue to need equipment to meet his changing needs. Finally there are changes to the home that need to be made.</p> <p>*In answer to Question 4, currently, to receive the high rate of care you have to show significant sleeping problems. Despite us having significant sleeping problems it took 3 appeals to receive it - we had to learn the right way of stating things. It doesn't sound like this would still be a requirement which will be a good thing. However, I don't actually understand why you need the split between mobility and daily living because mobility is a key element of daily living.</p> <p>*In answer to Question 5, my only concern that if you have cerebral palsy, for example, will there be a scale of how 'bad' your cerebral palsy is? & then what happens to someone who doesn't quite meet the 'target' for a higher rate, that they're just not quite disabled enough?</p> <p>*There isn't a question regarding the care home or hospital in paragraph 21 but I have a concern about it. It would be bad enough if, when he older, my son needed to live in a care home but losing his mobility element would disable him further. Just because he's lost the ability to live independent he shouldn't also lose the ability to get 'out and about'. With Motability other people can be named drivers. If we, for example, wanted to take him out we would still need an appropriate vehicle. I think</p>

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		<p>this is a terrible decision as I think it would completely confine people to the home or hospital.</p> <p>*In answer to Question 6, I feel there is something missing from the preceding paragraphs on the consultation. I know that as my son is very young education is high up in my priorities but I'm confident that when he is a teenager, in his 20's, 30's etc he is still going to learning how to do things and that isn't mentioned at all.*In answer to Question 8, all I know is that having aids provided by the 'community' is one less thing for me to worry about, however, I feel that the suppliers of these products seem to be able charge exorbitant prices, provide shoddy equipment (in some cases) with ridiculous lead time for new equipment and replacement parts. I don't fully understand the idea of taking into account/not taking into account equipment. If my son can get around in a motorised wheelchair that he controls will he get less money than if he needed to be pushed in a manual wheelchair. What if learns to walk but with an aid? Will he get less money? However, mobile he ends up it will have been an extremely long arduous process. & what if something happens and he needs to replace the equipment - if he's deemed more mobile and so receiving less support how will he replace them?</p> <p>*In answer to Question 9, I agree that the form is very long, repititious and relies on you being as negative as possible which is difficult to do. Reducing this repetition would be great. Consultants are extremely good at being very negative in their assessments - perhaps this could be included in the application. So far I have not seen anything about people who cannot speak for themselves ie my son will be an extremely vulnerable individual even when he is older. How can he be protected in this process?</p> <p>*In answer to Question 17, the obvious difference is that I'm having to speak for him and I am not just a parent but a carer. Early support and educational needs are key priorities. Currently, a lot of the support appears to rely on a diagnosis which isn't always possible. I have a friend who is not getting the support she needs because her son has not been diagnosed even though a speech & language therapist and a physiotherapist have assessed that he would benefit from sessions. He is struggling through mainstream school with no extra support and is being disadvantaged. In addition, we are still waiting to find out if our request for 'direct payments' has been approved. We would use these payments to pay for babysitting to give us some respite. I don't understand if we have all this other support and we have been encouraged by other professionals to make use of respite that we have to jump through these hoops. I use the DLA we currently get for my son to supplement my income because I could not work full time (I still work part time) and be able to attend all the appointments and provide my son's caring needs. The community offering is</p>

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		<p>not always the best and we have paid for private sessions to supplement this, for example, there are not enough paediatric physiotherapists so you see them infrequently when this is so essential. This means that we still struggle to buy all the equipment (as mentioned early on in my response) that my son needs and as soon as something is labelled 'special needs' it automatically doubles in price. Regards [REDACTED]</p>
EM692	17/02/2011	<p>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, 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. This could be a day where the pain makes a shower brushing ones hair so difficult that it can use up all ones energy made worse its not seen so is quite low on the radar of fit healthy people.</p> <p>*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. It robs a person of their independence.</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</p>

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		<p>minerals and other NHS and non NHS medications Cleaners Need someone to do washing and ironing Need support for making phone calls Taxis to go to GP's, hospitals, shopping etc Taxi's for going out Need support for everyday chores Need support when going out Need carers costs for cooking food, changing bedding, giving medication, washing, bathing, 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 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, *Question 4 • Will having two rates ...? 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 ...? 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 *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 entitlement. *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. *Question 7 All health conditions vary, it is the nature of ill health. DLA claimants should be able to provide letters of</p>

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		<p>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</p> <p>*• Should the assessment only take into account ...? No (see above) A better understanding of what aids are available so a person has a choice when required.</p> <p>*Question 9: Many questions are repeated in the claim form and this is unnecessary. The form is too long. *Thanks for taking the time to read these answers.</p>
EM693	17/02/2011	<p>1. :Mainly the daily challenge mobility,access and finance.</p> <p>*2. :not means tested with generous support for mobility</p> <p>*3. :taxis insurance adapted cars, home adaptations</p> <p>*4. :Clear definitions and sensitive,professional assessments (not cheap tick box versions!)</p> <p>*5. Muscular dystrophies, myotubular myopathies and related muscle conditions should have an element of auto but some individual variation.</p> <p>*6. Nutrition, accommodation,social inter-action..opportunities rather than confinement.</p> <p>*7. :by professional and careful assessment done thoroughly but sensitively.</p> <p>*8. :both.</p> <p>*9. :a sample of real case studies/examples</p> <p>*10. :family and friends</p> <p>*11. :I would want the professional to understand accurately the realities of my condition if they are to be involved in making decisions!</p> <p>*12. Maybe distinguish to some extent between those with a stable or “progressive” condition and understand that on different days or part of days one can do certain tasks but.....conversely</p> <p>*13. :for those with “progressive” conditions one would expect the Dept. to expect to review at intervals and increase support where needed.</p> <p>*14. :Clear explanation with relevant case studies</p> <p>*15. :A personal and human/humane service is always better than the tick-box approach.</p> <p>*16. :PIPs would be validly spent on anything helping their care or mobility.</p> <p>*17. :Their individual needs and social background/context.*18. :Invaluable for reducing pressure from work or family.</p> <p>*19. :Less choice and peronalisation</p>

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		<p>*20. :all to be shared with some system to guarantee it is accurate and up to date</p> <p>*21. Your response:</p> <p>*22. :Make sure they are framed and implemented on the basis of the state acting as a kind of collective insurance to help those who have challenges in their daily life which others do not face.</p>
EM694	17/02/2011	<p>1. Depends on disability. Mine are bipolar disorder and visual impairment. Re bipolar, barriers include ability to self motivate and engage with things, which varies according to episode, difficulties with self care, lack of confidence, problems with accessing transport, lack of focus/concentration, risk/vulnerability – self neglect, suicide/self harm when low, disinhibition, lack of judgment when high, inability to concentrate/plan to cook meals, lack of safety in kitchen due to sharp/hot objects when wanting to self harm. Visual impairment: problems with mobility, difficulties with reading signs, shop prices, letters, digital media, inability to participate in popular culture eg tv, images, newspapers, safety issues when preparing meals, etc</p> <p>*2. The money needs to be in our hands as we are the best placed to know how it needs to be spent. No having to fill in endless paperwork every time we need to spend some of it eg timesheets for helpers, receipts for equipment, taxi fares etc.</p> <p>*No face to face assessments, too stressful, especially for those with mental health problems, difficult to communicate at times and especially when under pressure, difficult to express everything and remember everything that needs to be taken into account.</p> <p>*Longterm or indefinite reviews for chronic illnesses – waste of our stress and your resources – I am not going to get my sight back and recovery from bipolar disorder is very rare, so reviewing me in a couple of years won't yield any new information.</p> <p>*3. Depends on disability.</p> <p>*Care/support – I live alone but am often not safe to be alone so I need to pay people to care for me or pay train and taxi fares to go stay with family to care for me and keep me out of hospital as much as possible.</p> <p>*Transport – I can't drive or use buses so I need to get taxis more often than average. Currently dla lower mobility allows me 3 return taxi fares per fortnight, this is not enough to lead a full life.</p> <p>*Equipment – for example I can only complete this consultation because I have text to speech software so I can read by audio, that cost £370 and without it I have no access to computer or internet.</p> <p>*Ongoing supplies such as contact lens products – get the lenses free but have to pay for solutions etc</p> <p>*Adaptations for visual impairment are always much more</p>

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		<p>expensive than standard items, eg talking microwave costs 3 times as much as normal microwave</p> <p>*Inability to take advantage of advance rail fares due to unpredictability of health, so have to buy on the day tickets</p> <p>*General replacement of appliances and everyday possessions, which would normally be absorbed within earned income but cannot be accommodated within income support, and most of us are unable to work long term so don't have the hope of future income or cushion of recent earned income to fall back on.</p> <p>*Additional heating costs – when you go out to work your employer keeps you warm all day.</p> <p>*Increased cost of food – inability to prepare meals from fresh ingredients or to go to supermarket so must buy expensive, less nutritious food from convenience stores, and eat when possible at café or cheap pub meal in order to get to eat vegetables.</p> <p>*4. This is a bad idea as it makes the benefit less flexible. Instead there should remain 3 rates for care but also 3 rates for mobility. Unless the 2 rates will represent current middle and higher, in which case the idea has more merit.</p> <p>*Many people need the lower rates but can live independently without supervision, and they should continue to be helped.</p> <p>*As things stand dla is inadequate to provide for all it purports to – reducing the number of levels could increase this problem.</p> <p>*Re mobility, I currently receive lower rate, enough for 3 return taxi trips per fortnight. I can walk fine but not drive or use buses. I am far less mobile than someone who can't walk but can drive an adapted car. If there was a middle rate mobility component comparable to the care component it would greatly increase my (and others) independence.</p> <p>*5. Chronic serious disabilities and health conditions should get automatic entitlement as it would save a load of money in processing and admin. People who have conditions which are likely to improve should have to apply in the usual way. Perhaps some conditions should have a requirement to apply, but once awarded there need be no requirement to re-apply. It should be decided according to what is known about conditions and their impact on daily living and the prognosis for improvement if any.</p> <p>*6. Being able to get up, wash, dress and provide yourself with food and shelter are the bare minimum. Both physical and mental barriers to these should be considered. Most days I could not tick all those boxes, even if I had all the support I need.</p> <p>*Then, being able to participate in society, by engaging in community activities, using local shops, just walking down your street, being able to talk to your neighbours, use the internet, go to the library, go to a church or similar if desired, engage in hobbies and pastimes, exercise.</p>

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		<p>*If possible to have the dignity of being able to work.</p> <p>*These may sound like very ordinary things but a life like this seems to me like a shining dream.</p> <p>*7. Build in flexibility. Instead of saying how many times a day, how many times a week, allow space for us to tell you about the variations and fluctuations and if there is any pattern, any trigger, anything we can put in place to keep things in balance.</p> <p>*Bear in mind that the benefit you pay us can keep us more well than we'd be without it (which is the point) so if we seem to improve that doesn't necessarily mean we no longer need the benefit – without it, and the resources it can give us, we may deteriorate again.</p> <p>*Keep the money in our hands so we can spend it flexibly to meet fluctuating needs rather than be overly prescriptive or allocate things for regular weekly purposes etc. Some weeks I don't need the full amount but other weeks I need way in excess, it depends on my episodes of illness, so I need to keep the money by for when I'm in most need of support. If this wasn't possible I would need to have a lot more time in hospital.</p> <p>*8. Yes, eg if someone wears glasses it would be ridiculous to assess them without their glasses. If people have adaptations they should be assessed on the basis of how they cope with those adaptations in place, although leeway should be given for situations when they are away from their usual situation and may not have access to them.</p> <p>*If people don't yet have the adaptations they should be assessed as they are, then provided with the adaptations, then reassessed once they've got used to using them.</p> <p>*9. Some conditions could be exempt from application.</p> <p>*Renewal forms could ask only for supplementary information or to notify of changes rather than having to write everything out again.</p> <p>*Electronic application could facilitate this – people could then edit their previous claim to reflect the current situation.*There could be different application routes for physical and mental health issues – the forms have never been suitable for mental health conditions.</p> <p>*10. Those involved in our care – doctors, psychiatrists, care co-ordinators, support workers, social workers etc.</p> <p>*11. This would cause unnecessary anxiety and distress. Also it's not a good way to gather information. People's conditions and the way they effect them are complex and a lot of information is relevant, and when we're stressed and anxious we will forget it all and not explain our situation well.</p> <p>*Those who are exempt from submitting medical certificates to the jobcentre should also be exempt from face to face interviews as it's the same situation.</p> <p>*12. It should be according to how long the person's disability or health problem is expected to last. If that is a year, review after a year, if 5 years, review then, if it's a lifelong condition then</p>

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		<p>award for life.</p> <p>*Electronic review would make things easier – you can send our previous application back to us by email and we can edit and send back.</p> <p>*13. Make more appropriate review dates (see above) and changes can be reported naturally.*Explain to people that they will lose benefit if they don't report improvements and may be entitled to more benefit if their condition has worsened.</p> <p>*14. What resources are available to them locally eg adaptations, support services, community groups etc. Info about any peer support networks. Info about where to find carers/support workers to employ.</p> <p>*There is a lot to read through already when claiming a benefit. Maybe would be best to include a flyer or similar explaining where people can get this info if they want it.</p> <p>*15. No. This will impact more on the majority who do seek help than it would on the minority who don't. If people are going to sit and wade through 60 pages of questions to get dla I can't imagine they wouldn't bother to seek advice or support, which comes much more easily.</p> <p>*You have to have supporting information from a professional such as doctor, social worker etc to complete the form, so no one can even apply if they have not sought support already.</p> <p>*16. Yes, we already do this. You don't need to invent a system for it.</p> <p>*17. You will necessarily rely on parents and professionals to provide almost all of the information as a child couldn't do it. You can bear in mind that the child will have a lot less say in what happens either with the application or the money, but realistically there's not much you can do about it.</p> <p>*18. Very important, and saves filling in lots of other forms too.</p> <p>*This could be extended to applications for self directed support, where a lot of the application is very similar, so those on dla could be exempt from filling much of it in.</p> <p>*19. Additional stress, additional paperwork for both the claimant and the providers, less security in terms of what we know will be available for us.</p> <p>*20. Self directed support</p> <p>*Disability premiums</p> <p>*Bus passes</p> <p>*College concessions</p> <p>*21. Don't know</p> <p>*22. Completing this consultation has taken a big toll on my energy and time. It is a difficult consultation to ask disabled people to complete. So please appreciate the effort it has cost us to participate and take on board what we have said.</p>
EM695	17/02/2011	<p>1. Loss/lack of recognition of one's value; degree of visibility, tied directly to mobility and access to transport as removal of this option effectively removes the disabled person from the public sphere; public awareness of the hurdles and obstacles</p>

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		<p>facing those with disabilities.</p> <p>*2. Both Care and Mobility components should remain the same, including their graded aspects (Higher/Medium/Lower rates as applicable).</p> <p>*3. Travel, Care and Respite, compounded by varying abilities to earn to support not only these costs, but additionally the costs of living. This applies also to non-disabled carers. The cost of being basically alive is increased.</p> <p>*4. • No. The existing system works.</p> <p>*• As above. The existing system's Mobility and Care rates function well.</p> <p>*5. All physiological conditions (physical and mental) should be treated equally.</p> <p>*6. Activities that prioritise a person's functioning at a most basic (i.e. subsistence) level are perhaps essential but there is not a sense in which an activity beyond this is more or less essential as all are equally essential. To prioritise them is not productive as they depend on an individual's situation, abilities and impairments.</p> <p>*7. By taking into account the evidence of those with direct experience of such conditions as well as by relying on fully-trained, medical expertise that is genuinely impartial (of political, financial and other constraints).</p> <p>*8. • No, as their disability may not require the everyday use of such aids but their lives may nonetheless be greatly impaired.*• An assessment should suggest new aids wherever possible.</p> <p>*9. • The claim form as it stands is not hard to fill in.*• I do not think the form is an issue. If the aim is to improve peoples' understanding of what benefits exist, better information (leaflets and online) may help.</p> <p>*10. My GP and Hospital Consultant were consulted in respect of my case. I believe they are best placed to assess my abilities/situation.</p> <p>*11. • Benefits: none that I am aware, especially if that 'healthcare professional' is not a patient's GP/Hospital Consultant. Difficulties: more room for misunderstanding in the particularities of a patient's clinical situation.</p> <p>*• Unless mobility issues mean that someone is unable to visit their GP, I do not think that it would be appropriate for an assessment to take place in a domestic environment. I believe a patient's GP surgery would be acceptable as it should be in an accessible location.</p> <p>*12. • Any assessment timetable should be based on the direct advice of a patient's GP or Hospital Consultant.</p> <p>*13. As above. Any changes to need should refer to the GP/Hospital Consultant's advice.</p> <p>*14. See point 9.</p> <p>*15. No. As above.</p> <p>*16. Any support can only ever be complementary to an individual's needs. One-off support should be factored in to</p>

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		<p>general support.</p> <p>*17. Everyone should be treated equally.</p> <p>*18. DLA is very useful in terms of access and entitlements. 'Joined-up' recognition of one's current status is extremely desirable.</p> <p>*19. One would be starting from scratch. The DLA form is comprehensive and, subject to data protection, could be used to help - and the stress is on 'help' - a patient's cause.</p> <p>*20. Benefits should not be interdependent.</p> <p>*21. • It is not clear where one can find p28 or your initial assessment. I could not find them from the information provided.</p> <p>*• Points to be considered: Recognition of value, degree of visibility and public awareness of the hurdles and obstacles facing those with disabilities.</p> <p>*22. The questions are too prescriptive.</p>
EM696	17/02/2011	<p>To Whom it may concern</p> <p>**I'm writing to you in response to the Public Consultation Disability Allowance Reform. As a person with Tourette syndrome (TS), I would like to bring to your attention some important points, which I would like you to consider.</p> <p>*Tourette syndrome (TS) is an inherited neurological condition, affecting more than 300,000 adults and children in the UK. The key feature is tics, which are involuntary and uncontrollable sounds and movements. In most cases TS is also linked (co-morbid) to other conditions such as Obsessional Compulsive Disorder (OCD), Attention Deficit Hyperactive Disorder (ADHD) and some mental health conditions such as depression.*My vocal tics include Corporalia (swearing), Echolalia (repeating things I have just heard), as well as many loud screeching noises and complex phrases. While my vocal tics have a big social impact they are only part of the challenge. *My motor tics are just as frequent and affect how I walk – which was described rather unpleasantly but accurately by a doctor as, 'Like the ministry of silly walks.' I have a range of other challenging motor tics that include: hitting my face and chest with my fist, waving my arms around, and throwing my head back abruptly. This frequently results in me hitting my head against walls, doors and people. I tic hundreds of times an hour and am rarely still or quiet.</p> <p>*Many people with TS will be affected dramatically by these proposed changes to the Disability Living Allowance (DLA). I rely on my current DLA payments heavily to help pay for the expenses I incur due to my TS.</p> <p>*I currently receive DLA at the middle rate for care and at the higher rate for mobility. DLA has transformed my life and means that I can take the practical steps I need to remain safe, supported and in control. Without it I would not be able to lead an independent life and the risk of becoming isolated, depressed or getting injured would increase substantially.</p>

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		<p>*The combination of DLA and Access to Work allows me to work fulltime and be actively involved in my community. It means I can afford to buy the practical items I need to keep me safe when I'm working, and that I have the help I need before and after work to ensure that I'm rested and prepared, not distracted or distressed.</p> <p>*Having Tourettes Syndrome can get expensive. Extra costs for me include: padded gloves and hats, plastic cutlery, carer expenses, replacing broken items and probably the biggest expense, taxis. The mobility component of my DLA has given me much greater independence because using taxis means that I'm less reliant on other people to support me.</p> <p>*The proposed changes to which I would particularly like to draw your attention are:</p> <p>*1. The reduction from 3 care component rates to 2 care component rates. This will effect a lot of people with TS that are currently in receipt of DLA, in the proposals the government state that "support should be targeted at those disabled people who face the greatest challenges to leading independent lives" but in order for the government to reach this goal they state "It is likely that some people with lesser barriers to leading independent lives will receive reduced support". I cannot understand how two rates could ever effectively meet the wide variety of individual needs.</p> <p>*2. The use of face-to-face interviews as part of the assessment process. This is a highly inappropriate move as the introduction of such assessments would amongst other factors be for a person with TS a very stressful experience. There are other concerns I have with this proposal:</p> <ul style="list-style-type: none"> *• The use of independent healthcare workers, these healthcare works I assume will be employed by an independent company with set targets with regards to numbers of successful applicants. These healthcare workers will I assume be non-specialists with very little knowledge of TS and the challenges that a person with TS would face on a daily basis. *• Evidence provided by the applicant and their GP, consultant (TS specialist) or social worker would give a more accurate and relevant picture of how TS effects the applicant. *• These face-to-face assessments with a non specialist would be a waste of resources and render the application process longer and more complicated. These interviews would incur additional costs thus diverting available funds away from those who need the services. <p>*For me, DLA provides practical solutions and social support to do what the medical professionals haven't yet been able to do – reduce the impact of Tourettes Syndrome on my life. As you can see these proposals for change will affect many with TS greatly and I urge you to oppose the changes to DLA and to sign EDM 393, to support the call for the Government to reconsider its decision to implement these changes.Yours</p>

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		sincerely,
EM697	17/02/2011	<p>I was unable to download your actual consultation document probably because of poor configuration on my computer but I felt I should add to your consultation wide experience of DLA claimants from different aspects of my life.</p> <p>*I am interested that you do not seem interested in the background of individual respondents. i would have thought a profile of the age, gender, disabilities and social/ educational background fo your respondents would have been relevant. for interest i am a 62 year old, white, professional, Englishwoman, with no disabilities. I suspect that my 'type' is over represented.*I would be grateful for an acknowledgement that you have received this e-mail and an assurance that you will read and consider it</p> <p>*1. Your response: Their own disabilities, people in society's attitude towards those disabilities and an inability to access help, support and aids to overcome or lessen the difficulties in participating in society and leading independent, full and active lives.</p> <p>*2. Your response: it should remain a universal benefit so there is a greater take up and no stigma attached to applying for it. It should be awarded to the recipient to use in whichever they consider appropriate.</p> <p>*3. Your response: The costs of getting around. The costs of installing adaptations into their homes and having specially adapted household goods and furnishings eg special readers for the blind, higher seats for the elderly. The people costs of caring and supporting them, particularly staying in their own homes. The cost of having to personalise their outgoings eg an adapted car, fit for purpose is more expensive than a mass produced car. The costs of not being able to play a full, active well remunerated part in the job market.</p> <p>*4. Your response: It depends on the two rates. It will make no difference to mobility allowance as that is already two rates, albeit a confusing two rates. For the DLA care allowance, it depends how you merge the current three rates and where the cut off points are. If you split the current middle rate down the middle, it will just seem like a money saving exercise particularly if to get Carer's Allowance you have to be caring for someone with Higher Rate DLA</p> <p>*5. I certainly think that would be easier, but the kind of conditions that are likely to give an automatic entitlement are likely to be the easier claims anyway. For instance if you have both legs amputated then you automatically get Higher Rate Mobility, even if you have prosthetics making you relatively mobile (to the point of taking part in the paraplegic Olympics!) Civil Servants should look at the effect of having these automatic entitlements at the moment. I would be all for automatic entitlement to be extended so long as people who</p>

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		<p>were not automatically entitled were treated on their merits. The difficulty would come if certain conditions like ME were left out as there would be a lot of pressure to include them.</p> <p>*6. I'm not sure that you should be prioritising as these are subjective decisions. You should agree on how much is affordable and give that money to those least able to live full and active lives to prioritise themselves.</p> <p>*The most essential activity by far is that people should be able to maintain and make new relationships and friendships; that they should be part of society so far as possible.</p> <p>*It is also a priority to keep people in their own homes to the extent that they want to remain independent. This means installing all the aids and support that they need to eat, sleep, dress, wash and socialise in so far as possible.</p> <p>*7. If the variable and fluctuating condition impacts on average, on a persons life, then it should be treated as permanent. If withdrawing the benefit will lead to such stress that the condition is likely to reoccur, then the condition should be treated as permanent.</p> <p>*8. I think not as those aids and adaptations had to be paid for and the very use of them and the need for them implies that the persons life is impaired by having to use them when the 'enabled' person need not. The question implies that having aids and adaptations can make up for a person's disability and enable them to lead a totally 'normal' life. This is not the case.</p> <p>*9. Get rid of all the 'time' questions which are impossible.</p> <p>*Halve the size of the questionnaire. *Make certain conditions automatic eg if you are incontinent, you should not have to fill out a whole page on toileting, washing and doing laundry. It is obvious and becomes embarrassing to go into in detail. Indeed, the situation and the necessity to intervene to help a person in this situation would be obvious from the simple fact they were advised to use incontinent pads or were under an incontinence nurse.</p> <p>*10. The GP</p> <p>*Support Professionals</p> <p>*Hospital Professionals</p> <p>*The Prescription List</p> <p>*Anybody who lives with/works with the applicant. (this is difficult if the applicant is isolated)</p> <p>*To make it easier to understand, a few illustrative stories could be sent in a booklet giving real case examples of people who have or haven't received DLA and why.</p> <p>*11. The difficulty in my experience is that the so called independent assessors often seem anything but. They seem to be more concerned with keeping people off benefits that giving them the support they need. They do not recognise or understand conditions such as ME or Chronic Depression. Sometimes they are old fashioned and sometimes they come from a different cultural background that does not recognise</p>

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		<p>conditions than are accepted in UK</p> <p>*People who have certain psychological conditions may find it impossible to meet with strangers, may find interviews distressing and stressful, may not be able to keep appointments. I'm sure the wider community of disabled people could find more examples.</p> <p>*12. If a condition is obviously never going to get better and/or get progressively worse, eg Alzheimers, then there is no point reviewing the situation. If someone can't walk because they need a knee replacement, then the situation should be reviewed after the average waiting list + recovery time period.</p> <p>*It is possible just to ask for a GP/consultant letter on a yearly basis to confirm that the pre-existing condition still obtains.</p> <p>*13. By making it as easy for people to go back on to the payment if their needs become greater as it is for them to stop it if their needs are less.</p> <p>*Educating people that if they do not report on changes in their circumstances, then claiming and maintaining claims is more difficult for everyone.</p> <p>*Increasing general disability benefit levels so that gaining DLA is not so significant to maintain a reasonable quality of life.</p> <p>*Helping people improve their income if they are not so circumscribed by disability because their circumstances have changed.</p> <p>*Be clear what the PIP is for and under what circumstances it is awarded. NB people tend to tell HMRC of their change in circumstance when they claim Child Tax Credit and Working Tax Credit.</p> <p>*14. I am a CAB adviser and in my experience, people always need support in claiming DLA. We assess people's probable eligibility before we help them fill in the forms. Certainly providing help and support as part of the Benefit Claiming service would be a good idea. cf The Pensions Service</p> <p>*15. I think that this is the job of the health care professionals. They should be trying to ensure that any disabled/impaired people are encouraged to use any advice and support that might ameliorate their condition. You are also getting into a moral quagmire here of the state forcing people to do what is good for them, at least in the eyes of the state.</p> <p>*16. My understanding is that most aids and adaptations are provided by the local authorities on a means tested basis. It would therefore be unfair to ask everyone to fund one off costs from PIPs. On the other hand there is the motability scheme which seems to work quite well. Once again I think people should use their PIP however they wish and should not be forced into using it in a certain way.</p> <p>*17. The major cost for children is getting people support and this is more expensive. For instance a child with cerebral palsy may not just need a wheelchair but also someone to push it or to accompany the child. Support from people is always</p>

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		<p>qualitatively more expensive than aids and adaptaions. In addition the stress on the principle carers, usually the parents, is such they they need respite, which is also expensive. I do not think disabled children receive anything like the true cost of maintaining their independence and is miniscule compared to the cost of caring for them in a home. Governments rely on the fact that parents want o keep their children in the family home to basically get disabled children cared for on the cheap.</p> <p>*18. DLA has been crucial in getting people such wonderful passports as the disability badge, cheap tickets for them and cheap or sometimes free for people accompanying them but the facilities need to be there. It would be good if some people were 'passported' into clubs and courses, but those things need to be there in the first place.</p> <p>*19. Once again there would be far more paperwork and all the tedium of filling in forms for every benefit and service that has been passported heretofore.</p> <p>*20. While some benefits are to replace income that cannot be earned if a person is too disabled to work, some are compensation eg for work accidents and some are to help people live independently it is difficult to see what can be combined. When DLA was combined with IB some years ago, an epileptic I advised was unable to go to an IB interview as he was having a fit. He informed the DWP who didn't note it and promptly stopped his IB. at that time this meant his DLA was stopped automatically to, though his needs to continue to live independently were unchanged. Disaster. The person was without any money whatsoever after he had run through his small savings and while the CAB sorted it out.</p> <p>*If DWP would treat people as individuals and see the entire person, then it might work, but that would cost money with caseloads for individual employees and minimising bureaucracy and duplication is usually about saving money.</p> <p>*21. Women tend to be more reticent about personal problems and male assessors can sometimes be dismissive of women's claims.</p> <p>*Men are less likely to go to the medical services for assessment and certain numbers of them are too proud to admit they need support.</p> <p>*People with mental health problems will have difficulty with any system like this.</p> <p>*People from different cultures may find it hard to understand or explain their conditions and accept the need to ask for help. For instance, it is my understanding that there is no word for depression in Sanskrit based languages (eg Bengali, Hindi/Urdu). I have found it difficult to explain the phenomena of post natal depression let alone chronic depression.</p> <p>*22. The tone of the consultation seems to imply that there are many people claiming DLA fraudulently and the suspicion must be that the proposals are intended to clamp down on fraud and</p>

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		<p>save money. In my experience there are the many people who do not claim DLA who are entitled to it (or AA in the case of my own parents) because they are too proud to admit their condition or don't want to face up to it.</p> <p>*In fact the money given by DLA for personal care is derisory. The Lower Rate Care amount would give one hours limited support a week, at least in my part of London, Haringey. Usually DLA applicants are relatively poor anyway. They rely on the unpaid efforts of relatives and friends to maintain their independence and rather than cutting down on the amount paid out, these often vulnerable, often suffering, and always disadvantaged people need more support than we give them.</p>
EM698	17/02/2011	<p>1. :My responses are from my experience having Multiple Sclerosis;*Barriers I experience preventing me 'participating in society' are fatigue, an inability to control what my body does at any given time(I really don't want to go into detail)</p> <p>Vertigo/nausea can be a problem where you feel if you get up on your feet to go anywhere or do anything you'll fall over. Concentration can be an issue.</p> <p>* I have problems with pain - when you're doped with painkillers you're too tired to concentrate on much and if you don't take painkillers when they're required you can't concentrate or focus on anything else anyway. *2. : Speaking for myself personally, I had no issue with it in the first place - I've been okay/secure with it. *3. :Transport/travel - the car is an extension of my legs. I live in a relatively remote area and without the car I'd be stuck here. I simply would rarely get out.</p> <p>*Also if I can't afford to run my own car to go places I don't have anywhere I can slink back to when something has gone horribly wrong in the 'inability to control what my body does' department. You really don't want things like that going wrong on public transport - no-one present would, I can assure you.</p> <p>* With this condition you end up going through ALOT of toiletries and hot water.</p> <p>*I spend most of the time feeling cold - inadequate oil heating costs a fortune to run as do the back up electric heaters to make the house less cold.</p> <p>*I buy alot of supplements/capsules etc that I think helps my condition.</p> <p>*I like to buy fresh foods - a healthy diet rather than cheap junk food, again to try and stay healthier.</p> <p>*I have to buy alot of over the counter stronger painkillers.</p> <p>*If my mother didn't see to my laundry I'd be paying someone else to.</p> <p>*4. :I don't think it was was difficult to understand in the first place. MS is a very variable condition and we are all affected differently and at different times - tailored benefit made sense. One size (or two) fits all doesn't seem to suit a disease like MS.</p> <p>*5. :An automatic entitlement would suit me - knowing the way I generally feel physically as a result of MS. I am aware however</p>

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		<p>that that wouldn't necessarily suit everyone.</p> <p>*6. :(When my body is completely wrecked I'll do something about it then I won't cost you a penny)</p> <p>*Re 'most essential for everyday life' - Living as independently as possible in your own home and the ability to get out and away from those 4 walls when you feel up to it. That really does help with your sanity.</p> <p>*7. : Take on board advice from groups like The MS Society, The MS Trust, neurologists and first and foremost the experiences of the MS patients themselves who one day can feel comparatively well but the next can't even lift themselves off a chair to fetch a drink when they're thirsty. The fatigue part of this illness is the most difficult aspect for anyone who hasn't experienced it to understand. Every day is different with MS - one day you can look fine but feel rotten inside - the next you can look and feel weary and then you can have a day when you feel not too bad. Some days I can fix myself something to eat, others I've no energy to do a thing. This is the reality of having a 'variable' illness. On the surface you can look 'normal' but you feel rotten in yourself. It's fair to say that the stress, uncertainty and fear of what may happen with all of this is causing more problems for me and others like me.</p> <p>*8. :I'm possibly not particularly qualified to answer this in that I don't really use any aids as such (probably down to pride). I don't know if it's still a big struggle for them - quite possibly it is...</p> <p>*9. :Give plenty of room for the detail that people with complicated conditions like MS will need to explain. *Put plenty information online, in Charities premises, CAB offices, council offices etc presumably.</p> <p>*10. :Supporting 'evidence' would be a difficulty for a condition where there isn't necessarily VISIBLE problems/disabilities. Organisations like the MS Society, MS Trust and neurologists would be the people able to give advice but again it comes down to the personal experience of the patients themselves.</p> <p>*11. :The ability to talk in confidence to a healthcare professional would be sensible - they would have to have a wide understanding of various, variable and complicated conditions such as MS.</p> <p>*I think the only circumstance where a meeting at the patients home or otherwise may be inappropriate would be if they were feeling too ill that day to be able to cope with a visit.</p> <p>*12. :An incurable health condition such as MS doesn't come into the same category as a temporarily hurt/damaged back or arm for example. It is a permanent problem of fluctuating symptoms which impair your ability to function properly.</p> <p>*Different types of review? With this in mind, yes.</p> <p>*13. :There are variables in symptoms of each persons' MS. Such that there may a specific problem one week and not the next - but then it will be more than likely be an issue again the</p>

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		<p>following week say. I don't believe it would make any sense to report changes on a day to day or few days basis with this type of disease.</p> <p>*14. :They would need every kind of help and advice possible and it probably would be wise to provide it as part of the claiming process - on top of any help and advice from various other sources (ie relevant Charities/Societies)</p> <p>*15. Your response: -</p> <p>*16. Your response: -</p> <p>*17. :I'm not qualified to respond.</p> <p>*18. :The one I'm personally aware of is the motibility scheme - perhaps I've missed a whole host of other things from which I would have benefitted!?</p> <p>*19. :People missing out and possibly suffering hardship as a result I expect.</p> <p>*20. Your response: -</p> <p>*21. Your response –</p> <p>*22. Is there anything else you would like to tell us about the proposals in this public consultation?*Your response:As someone who has a condition that is extremely variable day to day you are making me feel hounded and that I will be penalised for having any 'good days' Living expenses are seriously expensive(Energy bills are costing me nearly 20% of my 'income') The reason someone in my position does not rush to tell the powers that be that we're having an okay day or two is that the following day or two you can be feeling wretched. That is the reality of a 'variable' disease. I am fearful about the state I may be in if you latch onto my 'okay' days and decide I'm suitably able.</p>
EM699	17/02/2011	<p>1. Lack of money</p> <p>*2. Lower,middle and higher rates.People with 'for life' DLA should not be reassessed</p> <p>*3. Constant hospital visits, needing extra help,</p> <p>*4. No it will not be easier to understand. People such as myself will probably just be shifted onto the lower rate,rather than the middle rate as I am on now,purely to save the government money.How is that fair?Life is hard enough living with a disability as it is!</p> <p>*5. Yes, some health conditions or impairments should mean an automatic entitlement.</p> <p>*6. Make sure people with disabilities have enough money to live on, and let them make their own decisions how they spend that money.</p> <p>*7. Have qualified doctors doing the assessment. The persons own doctor would be best for this as they see the person regularly.</p> <p>*8. No it is ridiculous if for example,a soldier gets his legs blown off,learns to walk again with prosthesis and is then penalised for it.</p> <p>*9. The claim form is deliberately set up to make it confusing</p>

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		<p>and difficult to fill in.If you want to save money why don't you make it even harder...</p> <p>*Picking on truly disabled people is not a great way to save money.</p> <p>*10 A persons own doctor,or consultant.</p> <p>*11 If the professional is a stranger,who knows nothing of the persons condition,and whose sole aim is to save money by disallowing a claim then that is obviously a difficulty.</p> <p>*12. People should be looked at on an individual basis.People who have obvious medical conditions for life,who will only ever deteriorate as they get older should not have to go through the stress of constant reassessments if they are already on the higher rate</p> <p>*13. No idea</p> <p>*14. Say at the beginning the type of conditions you are automatically going to turn down for PiP.</p> <p>*The address of local CAB offices etc where people can get help in filling out the forms.</p> <p>*The appeal procedures for when you turn down or stop the benefits of vast numbers of people</p> <p>*15. As above</p> <p>*16 People should be able to spend their benefit how they wish.</p> <p>*17</p> <p>*18. Very important</p> <p>*19. A huge amount of extra stress and worry for disabled people</p> <p>*20 Your response:</p> <p>*21. Your response:</p> <p>*22. It is a disgrace that vulnerable disabled people are being targeted like this.DLA has benefitted many people over the years to regain some dignity and independence, while sometimes dealing with very serious life threatening conditions.</p> <p>*The idea that we are all work shy layabouts with bad backs is a million miles from the truth in 99.9% of cases. Think about the extra stress and worry you are inflicting on disabled people with these proposals.</p> <p>*The fact that this is being done, not to make things easier for disabled people, but to save 20% of the DLA costs is pretty damning.</p> <p>*The idea that you are ot only targeting people new to DLA, or people with temporary conditions, but also people with long term serious health conditions is very disturbing.</p> <p>*Why would you be targeting people who have a 'for life' award? Their conditions will not improve, only deteriorate as they get older. If someone has been classed as 95% disabled with a serious untreatable condition, then why does that need reassessing, unless the plan is to just cut down on money paid out regardless.</p>
EM700	17/02/2011	1-- money, which is needed for transport costs and to enable one to be flexible instead of, if lucky, being dependent on

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		<p>goodwill and timetables of others. This applies to essentials such as visits to the doctor, shops and money is also needed for most social activities, going to the cinema, visiting gardens and stately homes or the bingo hall.</p> <p>*Flexibility is very important as disability usually means it takes you longer and is more time consuming and tiring to do everything from feeding yourself to physically getting out of the door.</p> <p>* Lack of understanding as to how disability affects people, both in making assumptions about what they can do as well as what they can't. Many of my blind friends work, which most people assume they cannot. I sometimes use a wheelchair but not always, a lot of people assume disabled means a quadriplegic.</p> <p>* Disability is hard work, you may appear to be able to 'do' something but only at great cost which is borne in private.</p> <p>* Attitudes--- the old 'does he take sugar' attitude is alive and well.*Assumption that disabled people should always be grateful, should be 'brave'*that they are stupid and not capable of knowing their own minds.*The woman advisor on employment in the job centre who assumed I needed a course to help my English and maths, amazed that I could be a graduate.</p> <p>* This report document places great emphasis on legislation and changes in society attitudes.</p> <p>*Most people I know consider attitudes to have worsened, the idea it should be left to the Professionals , that it is nothing to do with them, not wanting to get involved, seeing you as 'other' not realising you just want to socialise on the same terms as them.</p> <p>*People do not see wheelchairs when you go down the street, young women with babies are often the worse they have a great sense of entitlement and think the pavement belongs to them.</p> <p>* Attitudes have be awful the last few months and I have suffered verbal attacks as a result of the governments policy of presenting all benefit claimants as dishonest and pretending and/or receiving fabulous amounts of money.</p> <p>*I do not smoke, drink and rarely go out as I cannot afford it, I'm about to give up my internet connection as I cannot afford it even though it is my lifeline to the outside world.</p> <p>* Legislation if observed is done more in the letter of the law than the spirit though there are exceptions. eg the lift in a new shopping centre which is only just wide enough for a wheelchair making things difficult especially as the time delay on the door is too short to give you time to enter.</p> <p>* The large pub chain where the lift to the toilet is always broken and the staff see nothing wrong with putting tables in front of the lift. A letter to head office brought only temporary improvement</p> <p>* 2---Some of the so called problems with DLA are not inherent</p>

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		<p>in it and could easily arise with the proposed scheme. If it is not well understood that is a problem of communication*on the part of the authorities. With the new scheme people will find it more difficult not less to find out if they are eligible.</p> <p>*if the new tests are on similar lines to the one introduced for ESA they will suffer similar structural problems , a minimal competence then being carried forward automatically by the computer and distorted to prove other competences which do not necessarily follow. It is a stated aim to make it more response to the individual this wipes it out</p> <p>* 3--- as re question 1 the costs of getting around and being involved in society. Many illnesses can be helped with high quality food but even ordinary fruit is becoming very expensive.</p> <p>*There are care needs or help with housework, decorating, cooking, going shopping, having laundry done.</p> <p>*I find massage and acupuncture helps me, pain wise, but it is expensive.</p> <p>* A lot of disabled people are more immobile which means higher heating costs.</p> <p>*I have to pay more for my accomodation as I can't access the cheaper properties.</p> <p>*Being disabled does not necessarily mean free prescriptions</p> <p>* 4--I don't see much different having 1 less category it makes it less easy to ensure appropriate support as the measurement will be too crude</p> <p>* 5--difficult, if it is automatic some will receive support they don't really need as an individual but I there is a greater danger of things being too subjective, based on the assessors perception or the individuals fluency or vulnerability and ability to express themselves.</p> <p>* 6-- this begs many questions. If someone is profoundly disabled how far can they live a full life , without it being hideously expensive. I am NOT saying great efforts should not be made.</p> <p>*Is it greater happiness for greater numbers to give money to lesser disabled people who could participate more fully and might be able to work or volunteer.</p> <p>*Ideally we do both</p> <p>*Should both be dealt with by the same allowance?</p> <p>* Toilet needs, washing, basic care, feeding.</p> <p>*, reasonable and clean accomodation, Good food--in a life of more limited pleasures more important *Access to the outside world. company, companionship , meaningful(to the person) activity</p> <p>* Ease in getting around indoors and out</p> <p>* 7 fact finding amongst groups of sufferers not professionals to give insights and then evidence from the individualwith them giving empirical examples and perhaps sample diaries</p> <p>* 8 No as it is easy to assume because someone has an aid it solves the problem it does not.. Having a wheelchair improves</p>

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		<p>a dreadful life it does not make it great or easy and carries a lot of problems of its own.</p> <ul style="list-style-type: none"> * Aids and adaptations are just that, aids not complete solutions. * 9 the claim forms tend to be very prescriptive, all or nothing. publicity, give concrete examples, at lesser levels too. make clear for working people too * 10 Difficult if your condition is stable you don't necessarily see your doctor much or want a social worker*Diagnosis, support group descriptions, general descriptions from care and voluntary agencies, personal reports evidence of what did what changed, * 11 what kind of healthcare professional? on what basis being paid. ? could be very subjective , could be personality clashes (professionals are not always neutral) * good allows the individual to explain their situation but should be simply notes available beforehand so they fully understand the process and what required and full implications * Some people with mental illness would find this very frightening * Some older people in particular would dislike this and not claim * 12 long term conditions that tend to be stable much less frequent review most people get very worried about assessments and reviews * 13 send out a simple letter every year asking if changes * Gp report if dramatic improvements in a patient's condition * 14 perhaps a sample form filled in, a dedicated phone line to give advice this to be anonymous * a clear leaflet passed by an average user * 15 no my experience of such so called support is often extremely patronising and simplistic and some of the people think they are entitled to comment on the suitability of a claim * 16 I fund mine out of DLA though some adaptations done by housing association or council. I do without other things for a while * 17 not feel competent to comment * 18 a little, much clear advice could be sent out * 19 for myself not much difference as always found it very difficult to get clear info * 20 not sure * 21 cultural differences and personal differences in how talk about very personal things and even ability to do so shame, stiff upper lip etc * 22 I think they are based on too many a priori assumptions eg DLA inherently so difficult, * that aids and adaptations are more of a magic wand than they actually are, * and the idea that because time has elapsed and with legislation things have changed instead of researching this. * Also that because DLA is expensive it is not necessarily value for money. If it has gone beyond its original remit it does not

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		mean that society would not support that IF the debate was conducted in less partian language, it could mean not just less misery but greater economic benefits eg less treatment for depression and could be used alongside something like access to work although unfortunately that is being cut at present and more onus placed on the employer making them less likely to employ disabled people. h more comprehensive and clear advise could be sent out