

Disability Living Allowance reform consultation – email responses 801 to 849

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| EM801 | 18/02/2011 | <p>1. Mainly attitudes and assumptions about what we can and can't do, both of which can be very damaging. For example, I have MS, which is an extremely variable condition. In my case, travelling exacerbates it. I was told it would be impossible for me to work at a senior level in the civil service from home or to manage staff remotely. However, I demonstrated that, with very few adjustments to existing working practice, both were possible. So much so, that the principles were adopted by non-disabled staff.</p> <p>*2. Being disabled is expensive and places additional financial burdens on top of physical ones. It isn't unreasonable that there should be some sort of allowance that helps disabled people with the extra costs of dealing with their disabilities. For example, as I have MS, I don't qualify for free prescriptions, but take over 10 individual drugs. I have a pre-payment certificate and part of my DLA funds this. I also have to have someone to help with housework as I can't do it myself. All these costs mount up even without needing higher levels of care. So the flexibility of the DLA to use as best suits you should be retained.</p> <p>*3. Almost everything costs more and will be different for different types of disability – we aren't all the same! In my case, I have to use cabs or the car more as I can only walk a very short distance without it becoming very painful and being very tiring. I would love to be able to walk, so if you can make that happen, it would be great. As I have been known to black out, I have to have someone with me. This is usually a friend or family member, but even then I feel it is only fair to buy them a coffee for their trouble. I also spend more on food as sometimes I need to buy ready prepared food as I can't do the cutting/peeling etc as I don't have enough control in my hands. I have to buy clothes that are easy to get in and out of with no tricky fastenings. This usually means more generous cuts and that tends to be costlier. Because I can't get out and about as much as I would like, I probably spend more on telephone calls. I do more shopping via the internet and can't get to sales. Because I drag my left leg, my left shoe wears out quickly even with resoling. So being disabled costs more generally.</p> <p>*4. I thought there were already different rates in each component anyway. The devil as always will be in the detail and in how the rules are applied.</p> <p>*5. It would be much simpler and cheaper to administer if some were automatic, but there would be a real risk of unfairness I suspect. Perhaps there needs to be a combination of condition and time. For example, MS can present in different forms; one</p> |

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| | | <p>which can 'get better' but may leave some impairment (relapsing-remitting) and one where impairment is permanent (progressive). To say everyone with MS should have an automatic entitlement would be generous, but could deprive another equally deserving group, but to assess every individual with the enormous range of disabilities and impairments that MS presents would be a mammoth task, and that is just one disease.</p> <p>*6. Being made to feel valued. We still do very little to support disabled people in the workplace. Employers will still take an able bodied person over a disabled person any day. Partly this is a lack of understanding; partly a fear of 'not being able to get rid of them'. There isn't a magic bullet for this, although there is room for much improvement. Beyond this, it is vital that people are able to maintain contact with others and not become isolated. Being disabled and alone can be terrifying.</p> <p>*7. How variable and how fluctuating? What are the upper and lower limits of a persons ability? What proportion of the time do they have good days and bad days? What can a person do on a good/bad day? On a bad day, I can't move or think. Sometimes I can hardly see. On a good day, I can sit at a PC and fill in a questionnaire. I would like to be able to go out and work or visit friends or see an exhibition, but that would have to be a once in a blue moon day. See my answer to 5</p> <p>*8. Aids and adaptations are add-ons. They are not part of the person. I receive DLA for mobility as I cannot walk any distance. If you follow your argument logically, by having the car the mobility aspect of my disability has been resolved. Therefore, I should be assessed as not requiring help with mobility. Take away the DLA and you take away my car, so leaving me with a mobility impairment, which would logically make me eligible for help with mobility. Many disabled people use their allowances for scooters and wheelchairs and the same applies here.</p> <p>*9. Impossible to say without seeing proposals.</p> <p>*10. Medical and social work professionals. Possibly employers, but that could raise all sorts of problems.</p> <p>*11. This is fine as long as the healthcare professional has a good understanding of the particular disability the person they are meeting has. It would be impossible for all healthcare professionals to be knowledgeable about every condition.</p> <p>*12. I would have thought cost would be a major criterion. To do this properly and handle all the potential appeals is going to be very expensive. Especially as, given the option, many disabled people may opt to have the assessment done in their own homes. There are some conditions that are unlikely to ever improve and it would make sense if these were reviewed less frequently than those that often do.</p> <p>*13. Encouragement usually works better than penalties, but if people are being dishonest then that won't work. I am</p> |

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| | | <p>pleased it will be easier to understand, although a little sceptical.</p> <p>*14. Can't answer this without more detail. In any event, the whole voluntary/public sector is undergoing changes, so any information on this is likely to be out of date. At very least direct people to a maintained web page.</p> <p>*15. Not sure what this means. Are you saying 'how do we get disabled welfare scroungers who make no attempt to get jobs to visit the Jobcentre?'. If so, I would love to have a discussion with someone about the one size fits all approach. If I had been unfortunate enough to lose my legs in an accident, it is possible that the Jobcentre could have helped, but I have a condition where even I can't tell from one day to the next what I will be able to do – even down to speaking coherently. When I could work, I did and I loved it. But what employer will take on someone who might be able to work one morning a week, but can't say which one? I think you have to accept that there may be some people who genuinely cannot work and that placing such a requirement on them may have a detrimental affect on their health.</p> <p>*16. I can't claim to speak for all disabled people, but there are a variety of routes to fund A&As. Until now, council provided help where they could, for example loaning equipment and putting in stair rails. I don't know whether this will continue. Otherwise, there seems to be something of a lottery. Some GPs/specialist will know of ways to get A&As and others won't. I pay for some myself from my pension.</p> <p>*17. Their needs change more rapidly and so responses need to be quicker.</p> <p>*18. Being disabled can be very tiring. Everything takes a bit more effort and energy. The fact that you can tick a 'I am in receipt of DLA' box and not fill in the rest of the form is wonderful. Until the full details of the final version of the welfare review are available, it is difficult to see how this could be improved, but I would urge you not to lose it.</p> <p>*19. See 18. It would mean more form filling, more photocopying, more expense. For example, in order to get my Blue Badge, I simply tick the 'DLA mobility component' box and send my last statement of entitlement. Otherwise, it would be a far more complex procedure.</p> <p>*20. It should be possible to sign a waiver for all information to be shared between appropriate individuals.</p> <p>*21. Haven't read page 28.</p> <p>*22. Being disabled is hard. Spending your entire life fighting a disease is hard. Don't make it harder.</p> |
| EM802 | 18/02/2011 | <p>Dear Sirs I am responding to the consultation on the changes from DLA to Personal Independence Payments - I have attached a word document containing my comments.</p> <p>*My role is both as a father of a young daughter with both a learning disability and a physical disability who has a Statement</p> |

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| | | <p>of Special Educational Needs and also as a 'professional' in the field of social care and housing for 20 years. I currently work for ████████ who is both a Housing Provider and also a Support Provider specifically working with adults with either a learning disability or a mental health problem.</p> <p>*I would be happy to offer further comments once more details of the proposed changes are published.</p> <p>**DLA consultation responses</p> <p>*1) Barriers facing disabled people. There are many problems and barriers that prevent disabled people participating in society and leading independent, full and active lives. Some of these are : the lack of understanding and awareness about people's disabilities from society in general; discrimination and a sense of being made to feel second class citizens by those without disabilities; if you are unable to work the sense of being made to feel like a scrounger; the sympathy vote of those who do not have disabilities; people thinking that they know what is best for a person with a disability rather than asking what the individual wants; a lack of support funding; lack of independent living options; benefit cuts that prevent people from accessing amenities; Commissioners wanting to group people together due to cost savings rather than enabling people to have independent viable packages of support; Treating people as disabled first rather than as a person who happens to have a disability.</p> <p>*2) Things that should stay the same. These things should stay the same: passporting to other benefits and services; not necessary to have a 'medical' assessment; ensuring that people who have a disability can access the additional benefit that they require.</p> <p>*3) Main extra costs. Some of the main extra costs that people with disabilities face are: paying for those whom they receive support from support costs when they are with the person with disabilities e.g. entrances, food etc.; aids and adaptations that should be met by the state e.g. a wheelchair that is fit for use, adaptations to a car to enable access to it; Assistive technology and healthcare monitoring – the payment that is made for a monitoring service – used to be funded by SP or social care; having to fund additional rent for extra space in a property and also the extra costs of utilities; the need to purchase clothes more often due to way people move around or if people are supported in large homes where clothes may become lost or not washed properly etc.; paying for specialist clothing; paying for continence material; the cost of living in a home where you may spend more time than someone without a disability or you may not be as mobile as people without disabilities and so you have to heat the property more due to your disability.</p> <p>*4) If there were only to be two rates. This seems that it will not make it any simpler as the individual is still being assessed</p> |

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| | | <p>against criteria set by the Government. It will make it cheaper for the Government as there will be fewer people on one of the components i.e. at the moment there are three care levels so some claimants will be on low and some on middle with only a few on high. If this changes to only low and high then those in the middle will 'drop' to low and so not get as much in benefits – the associated costs of their disability will not decrease. If the low rate is abolished then those currently on low will not get any care component. If the starting level is in between these two levels then the average will mean it is cheaper for the Government as those on middle rate will lose out. It has to be assessed as to whether this is fair – again it seems that the Government statement that 'our welfare reform plans are designed to protect people in the most vulnerable situations, including disabled people' is just political rhetoric with no foundation in what the reforms do in reality to 'the most vulnerable in society'. *The disadvantages are that people will be squeezed into a level and there will be little chance of this increasing if their needs only change slightly – however a slight increase in someone's need may have a large financial cost. It may be better to increase the number of rates/levels to reflect the fact that people with disabilities are individuals and not just try to fit them into a four boxes of need.</p> <p>*5) All claims should be based on an individual's need as long as this can be objectively assessed and measured against criteria that are meaningful. It may well be that a person with a certain condition that entitled them to a certain level were then not assessed for a higher level as they were automatically given the level that corresponded to their named condition. Assessing everyone, if done fairly, will provide a more individualised approach that can be measured.</p> <p>*Application process. Some people who have high needs but their disability does not fluctuate are not likely to have much input from professionals. If this is the case how will the evidence be collected? The information contained in the consultation points to a much more medical model and physical disability assessment even if the 'rhetoric' of the document suggests otherwise. If this medical model is followed then many people with Mental Health problems will not be accurately assessed as their disabilities can be as much psychological rather than medical and physical. It is hard enough at the moment for people with MH to accurately be able to show what barriers and additional costs their disability has. The real issues with such a new assessment route will only become apparent when the detail is known (if the current challenge to this assessment is anything to go by then MH service users should be concerned).</p> <p>*6) This is a question that shouldn't really appear in the consultation document. It is about the Social Care assessment model for providing daily support and is not part of the DLA</p> |

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| | | <p>assessment. There are obvious support areas such as activities to keep people alive that would be seen as the most critical but after this it is very much an individual's needs that should dictate what is essential for them to live an everyday life.</p> <p>*7) Fluctuating condition. A person who knows the applicant well and how their disability affects them on a day to day basis should be asked to provide information. The use of a 'healthcare' professional who sees the person once on what may be a good day is not an effective way of gathering evidence.</p> <p>*8) Aids and Adaptations. The extra costs of using these should be taken into account for an assessment as many people have to pay extra costs and they do not receive financial assistance for this. If the intention of aids and adaptations is to assist a person in their independence then if this is an outcome the benefit that they receive should not be reduced just because they can now be more independent using the aid and therefore don't require the same level of paid support. The monitoring service for assistive technology and also the costs of 'hiring' such equipment should be considered in the assessment. Part of the assessment should be looking at what people's independence would be like if they had no aids and adaptations.</p> <p>*9) Experience of applying. People will need to say how their disability affects them as this is the only way to give the necessary evidence to show how their disability is a barrier to independence. This will mean they have to be real about what negatives there are due to their disability. People will be concerned that if they are being 'positive' about what they can do then they will not receive benefit that they should be able to claim. Many of the questions are currently very repetitive but this is not necessary. Many of the questions ask about support to the nearest minute – why is this necessary?</p> <p>*10) Supporting evidence. Evidence provided by a person who has known the individual for a long time is better than just gathering information from a form completed by a 'healthcare' professional who hasn't really know the individual.</p> <p>*11) Face to face interview. This is likely to be very intimidating for many people with Learning Disabilities and people with Mental Health problems. There is likely to be a great deal of distrust in the 'healthcare' professionals as they may be seen as trying to stop someone's claim for benefit (cf. The number of successful challenges concerning the incorrect healthcare professionals assessment of an individual in the work capability test at the moment). The 'healthcare' professional is unlikely to know the individual at all and is assessing someone in a snap shot – this may be very misleading. What qualifications will the professional have – will they be psychologists and psychiatrists? People who are unable to attend such an interview may not have any benefit paid at all – is this likely to</p> |

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| | | <p>be the case (cf. not attending JobCentre Plus meetings or work focused interviews)?</p> <p>*12)</p> <p>*13) Reporting changes. Do not ask them to fill in a whole new form again if they feel that their needs have changed. This could be done in a simple review form rather than spending hours completing a new form.</p> <p>*14) Types of advice. These could include signposting to Social Care services and also local authority resource organisations. Information on local enablement services and aids and adaptation advice services. Advice on Disabled Facilities grant and how to apply. Assistive technology information and assessment services. Personal budget information and how to access this.</p> <p>*15) Requirement to access advice and support. Why would you want to link the claiming of a benefit to having to ask for advice and support? This is not a good idea.</p> <p>*16) Current meeting of aids and adaptations. People very often use their own funds/savings or use family money to pay for aids and adaptations. Other sources include DFG, NHS/PCT, borrowing money, local charitable funding and some Registered Providers offering limited adaptations. It is highly unlikely that the Personal Independence Payment would be enough to fund the aids and adaptations that are required by many disabled people. However if there was an additional on-going payment to help meet some of the revenue costs of the aids and adaptations e.g. assistive technologies then this may be useful.</p> <p>*Generally thinking about a child's support needs and mentioning linking it to the SEN provision we should be very worried if this is considered as providing funding in place of the Personal Independence Payment funds. Most of what is provided for children from public funds by other institutions is for a very specific reason and not to enable children to overcome barriers in society e.g. SEN funding is to enable children to overcome barriers presented by the education system and Personal Independence Payments shouldn't be paying for this nor should SEN funding be seen as paying for what Personal Independence Payment should be used for.</p> <p>*17) General point about reassessing existing claimants. If the criteria were to change and if the levels of the two components were to change then what measures would be put in place to financially protect existing claimants who may have had to balance their budgets using the DLA money that they receive? If people were to then lose their entitlement to the new benefit purely because the criteria has changed (this is comparable to the SMI changes) how would this sit with the current benefit claims for other benefits due to the current passporting to certain benefits.</p> <p>*18) Other services and entitlements. People with long term</p> |

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| | | <p>disabilities have additional living costs that should be reflected when assessing their entitlement to general benefits. Reducing the amount that people with disabilities can receive through premiums would be a very 'backward' step and would place people back into poverty.</p> <p>*19) No passporting to other benefits and services. If this were to be the case then the administration of the other benefits would increase greatly. There would be an increase in form filling; providing the same information many times for different benefits and services; additional call on healthcare and other professionals' time; anxiety while waiting for claims; having to prove your need several times over; people giving up due to the increased burden placed upon them; possible loss of motability vehicle.</p> <p>*20)</p> <p>*21)</p> <p>*22)</p> <p>*General observations. It seems that the changes are very much around making the continuing of such a benefit affordable (for this I read cheaper) i.e. the Government want to reduce the costs to society. There may well be more people who fit the disabled person's definition under the DDA than was anticipated when DLA was introduced and so it is bound to be more expensive to the Government than anticipated but is this the fault of people with disabilities !! It seems wrong that the Government are saying that too many people are accessing DLA and they want to reduce the numbers claiming – this is not said explicitly but certainly seems to be the under current especially in only having four components rather than the current five (from looking at the consultation document it seems that the criteria for the Care component may be increased so fewer people can access it). Having filled in a number of these DLA forms both for clients and also my daughter I can certainly say that the forms are too long and very cumbersome to complete. They are very repetitive and make you feel that the person reading the form is looking to 'trip you up'. They can take many hours to complete and then you need to get other people to fill them in as well as getting further evidence from professionals. They need to be simplified but still ensuring that a person's situation is adequately assessed.</p> |
| EM803 | | |
| EM804 | 18/02/2011 | <p>1. Your response: 2. Your response: 3. Your response:</p> <p>*4. Two rates may be insufficient to reflect the diverse range of disabilities</p> <p>*5. Your response: To consider those in care homes as akin to someone in hospital is to underestimate their needs. Those in hospital are less likely to be able to be taken out because of medical needs. Those in care homes do not necessarily have acute medical problems that a hospital patient would have.</p> |

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| | | <p>Instead their problems relate more to social and living problems. Being taken out is an important part of their well being. If the mobility element is withdrawn it will undermine this and treat many of the more physically disabled like patients in a Victorian psychiatric hospital and lead to institutional behaviour. Being able to go out into society and interact with other people is therefore an important factor in their well being and the mobility element of the DLA is the catalyst which enables this to happen.</p> <p>*If the mobility element is withdrawn from all those in care at the same time it will also undermine Motability and the work it does in making vehicles, in particular ones which require adaptations, available under a lease or HP arrangement. The reason for this is that where a vehicle is provided and the entitlement to the mobility payment ceases the vehicle is returned to Motability. If this happens to a significant number of vehicles in a short period of time there will be a sudden reduction in their cash flow and the value of the vehicles returned will reduce because there is a limited second hand market for vehicles which have been adapted. The Government will have two options. One to financially support Motability. The other is to stagger the change by allowing current agreements and arrangements to continue until the current lease or agreement comes to an end. This would then allow the time for the market to adapt to the change.</p> <p>*6. Your response: 7. Your response: 8. Your response: 9. Your response: 10. Your response: 11. Your response:</p> <p>*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> |
| EM805 | 18/02/2011 | <p>Firstly, let's be quite clear, as much as you dress up this "reform" as being about helping and supporting disabled people to be independent and to be able to actively participate in society, everybody knows It is pure and simple cost cutting driven by Tory vindictiveness towards one of the groups in society which faces the biggest challenges in their daily lives. This idea has been devised by toffs who have been handed life on a plate by rich mummy and daddy, and who cannot remotely relate to the daily reality and difficulties of living in this country as a disabled person (or even as a non disabled person). It is abhorrent that the government can give untold billions of ££££ to your Tory banker chums while disabled people are made to pay – is this what you call equality in the 21st Century ?</p> <p>*I have a serious visual impairment and as a result have faced big challenges, mainly relating to mobility, living in a relatively rural area with poor transport (we don't all live in London with good public transport as you may think). This not only means that I am limited in the type of work I can do due to my visual impairment, but I am also limited in where and when I can travel</p> |

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| | | <p>to work. This is a very familiar situation for many people with a disability, making it much more difficult to find work at all and even more difficult to establish a worthwhile career with a reasonable salary and gain true independence. Despite the challenges and difficulties faced I have worked exceptionally hard to overcome them and have worked all of my adult life (although not sure how much longer this will continue with the Big Tory decimation of Society), DLA has helped me with some of the additional costs incurred, particularly with travel and mobility. Judging from the proposals, I and many thousands of other partially sighted people would lose all assistance and not qualify for any "Personal Independence Payment", exactly how is this going to help people like me with visual impairments (or other physical disabilities) gain access to work and to be able to live with a reasonable degree of independence and quality of life, the simple answer is it won't, it will have completely the opposite effect of placing yet more obstacles in the way of people who already face very real difficulties every day.</p> <p>*Also, far from making the system more efficient, assessing each claimant individually will actually make the process far less efficient and resource intensive. It is perfectly reasonable to assume people with the same disability and level of severity face the same challenges and difficulties, and should therefore receive the same level of assistance without the need for individual assessments for all. But then we all know the truth behind these proposals in cutting ££££££££ from some of the least privileged members of society. The vast majority of disabled people would (and in many cases do) gladly work and help themselves to live as independently as possible given the opportunity, but in many cases they just need a small amount of additional support to achieve this which DLA provides in meeting additional costs. The only thing these proposals will achieve is to simply make this much more difficult for tens or hundreds of thousands of genuinely disabled people, isolating them even more from mainstream society.</p> <p>*I am not political but frankly the way the least privileged groupings of society e.g. the genuinely disabled, are being specifically targeted by these politically motivated vindictive cuts disgusts me, especially when it is by proposed by people who have no comprehension (or care) of the difficulties faced by these groups. Thanks to the destruction of society by the Tories it is difficult enough for somebody without a disability to find work, imagine how much more difficult it is (x100) for somebody with a disability such as a visual impairment. This proposal is nothing but a cut as everybody knows, you are fooling nobody and I am disgusted by it.</p> |
| EM806 | 18/02/2011 | <p>Dear Sir/Madam I am writing in regard to the public consultation on the proposed reforms to the Disability Living Allowance (DLA). Both my brother and my partner have disabling genetic conditions currently one is receiving DLA and</p> |

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| | | <p>the other has recently applying. This means that I have seen both the application process and seen the benefit that DLA can give in supporting and removing some of the barriers that disabled people face in their daily lives. I will try to answer the questions asked the best I can.</p> <p>*1. I have found that one of the biggest barriers that people face is the attitude towards disabled people. Many people see disabled people as a burden on society and see them having no role to play in economic success. This is impart due to the attitude from both employers and the general public that disabled are somehow inferior to any able-bodied person even though they could possibly possess skills and knowledge that make them far more of an asset than some able-bodied people. This attitude means that in finding work disabled people have to justify why they should be hired even though they might have the best qualification for the job. Employers also believe that disabled people will have more sick days and will need more time off, they also believe that they will have to make expensive changes in order to make their premises and/or workstations in order so that they are accessible, some believe that they will have to make as what they see to be unreasonable adjustments for example different start times, more breaks as they fear it could lead to a hostile working environment. This is what creates the myth of DLA being an out of work benefit as most people who qualify for DLA declare their disability and so find getting work harder driving up unemployment amongst disabled people. Disabled people often feel forced into justifying their disability, especially if, as in the case of my partner, the disability happens to be unseen. People assume that as my partner is young and looks fit and well that she should not have the chronic pain and difficulties that she does have. In the case of seen disabilities this often means that people try to help but end up becoming patronising and talking to partner or carers rather than the person themselves. Also there is the physical side of having a disability there are some everyday tasks that my partner finds hard to do such as pouring a full kettle and making pasta due to their disability. My brother also finds sometimes finds it hard socially as he doesn't have the same energy levels and tires quickly as a results he cannot always go out and join in all the activities he would like to do as he doesn't have the energy.</p> <p>*2. I feel that this question is a very difficult one to answer as the consultation documents do not provide you with the information to make an informed decision. It could be the case that DLA does need to be reformed however it may not. The consultation seems to only show how much DLA is costing the government and that is why it needs to be change. There is also no mention of how or why these changes are being made and also the proposed change are very vague and before the changes should take place they need to be made more clear.</p> |

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| | | <p>There are however aspects that I feel should not change, In the consultation documents there is the proposition to get rid of the lowest care rate I feel that this should be kept as it does make a difference to those people who, like my partner, would find affording things like an easy pour kettle which currently retail at around £50-£90 pounds a little easier but make such a big difference to their quality of life. Some people have trouble walking long distances yet do not qualify for the medium mobility rate, and only need the lowest care rate the money could go towards petrol costs in order to help them have a more active social life. The right to automatic entitlement for some conditions also should not change as there are some conditions when people will not change and so this would mean spending public money and time (both of the professionals and the claimant) on an assessment that will end up with no change to the entitlement.</p> <p>*3. I feel that this question is not very well phrased. It is implying that there are common costs that all disabled face. What may be considered a main cost for one person might not be a factor for another even if these two people have the same disability. For some people this will be perusing an active social life while others this could be added travel costs or making their home more accessible. In me and my partner's case this is the added cost of travel taking of using a car in to allow my partner to visit places and give them more time to enjoy them and also to provide us with a way to get home if they run out of energy, as well having to buy good seating in order to minimise the pain that they get. As well as getting appliances that make my partners life easier, which incur an extra cost as they are generally more expensive to purchase. It is the entire extra little extra expenses that when spent make a big difference to the quality of life of disabled people.</p> <p>*4. I do not believe having only two rates per component will make the benefit any easier to understand and administer. In all honesty it appears to be a cheap way of saving money taking it from those who actually need it. In the short term this will look like a big saving however in the long term it will lead to increased spending as people will increasingly rely on the health care system and have longer stays in hospitals as they will not have appropriate support at home. This has been shown to be the case in other countries where they have made similar reforms. It will also leave a lot of people just outside of qualifying for PIP and therefore will end up driving them below the poverty line as a result of extra costs, and in some cases drive them out of work. This in turn will increase the payments of out of work benefits and put some people on them permanently as employers do not wish to hire disabled people manly due to sigma in an already very competitive job market. In short this is a very bad cut back that will end up costing the country as a whole a lot more in the long term.</p> |

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| | | <p>*5. I believe in automatic entitlement. Due to the fact that people who fall into these may not need the benefit at time of applying however many of these are degenerative conditions meaning people get worse as time increases. In some cases this can be very rapid and claimants may end up not have the energy to fill the form out with. Second the annual review of payments for claimants will be a waste of public money as the need for the benefit will never change so time and money will be wasted on unnecessary reviews for nothing to be changed.</p> <p>*6. An active life is very subjective and can be change depending the individual saying it. For example this could mean doing a lot of activity or having an economic active life. So this question is extremely vague. If you are looking at life as whole again this is very hard to judge as in fact someone who for example is in a wheelchair or has MS may lead a more active life than someone with what appears to be a lesser disability. Also different people have different views on what is an “essential activity” for some it is sex while for other it is washing and dressing independently. In short the government is in no position to decide what an essential activity is, nor is it in a position to tell someone this is what an active life is. This is why getting rid of the mobility payment for people in care homes is very bad as in effect the government will be trapping people inside care homes and robbing them of something that might be essential for the individual. My partner’s condition means that they will never be able to make a meal for scratch including shopping independently or even cleaning. There will have to be some yard stick but I would urge you to take in to account the beliefs and values of the individual who is applying.</p> <p>*7. The answer is you can’t. This is because an assessment will only see a short glimpse in to an individual’s life. The only way round this would be to have the assessors properly trained in these conditions so they understand that the day they meet the claimant it may be one of the claimant’s better days. This means that there will have to be a level of trust by the assessors in order to take what a person is like on their worse day.</p> <p>*8. No it shouldn’t. This is because some may assume that means if they can in theory get an aid i.e. wheelchair. In some cases this will be a yes but in practice they may go on to a very long waiting list. This can sometimes be the case with bath and toilet rails having to wait for a time that is convenient for the person and a day when people are free to do the work. This would be worse for unseen disabilities where some people might not look as if the need is there. Also you are not allowing for extra costs that might occur when getting these aids as the DLA currently covers if someone already has something it does not mean it will never in the future need to be changed, repaired or replaced. Some people find it faster and more convenient to buy the aids themselves rather than to be put on</p> |

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| | | <p>to a waiting list and lose some time that they would rather be doing something else than waiting for an aid. Even with aids in place there is no guarantee that a person will be able to function equally as an able bodied person. There is also no taking in to account if the aid can actually be used by a person some people may not want to use an aid or might find that aid actually makes their condition worse for example some people using crutches might find it cause their arms to have problems and so do not use them even though in theory it should be helping them.</p> <p>*9. The forms do seem straight forward but there is so much information to fill in. The online form doesn't have enough space to allow a person to say everything that they want to say. Maybe also include the set criteria to show what people can qualify for what rates.</p> <p>*10. Evidence from specialists and health care professionals however not all long term conditions are best managed by a GP. Sometimes the only people who know just how the disability effects a person are the person themselves or their family who see them day to day. So they should make a big part of the assessment the current DLA application applies these statements.</p> <p>*11. I can see this depending on the condition for some people this will be a very good thing for others it will be bad. In the case of partner, a lot of health care professionals have not heard of their condition and some believe that it causes no long term problems even though the evidence says otherwise. This could possibly cause more stress, anxiety and some cases even depression for those who feel that they are not being listened to. There will also always be those who are too proud and hide how much their disability is affecting their day to day life. My brother for example will often push himself too far so as not to lose face with his peers, however when he is on his own he then will suffer for trying so in a situation where people might ask him how his disability affects he will more than likely play down his disability because he is too proud to show it. Also a face to face interview will only give at most, an hours worth of time in to a person's life. This will not show the full extent of the disability. If the claim is going to be heavily judged on this meeting then this will put fluctuating conditions at a big disadvantage as on a good day these people will appear to function like a non disabled person although they might tire quicker or suffer from increased pain. As mentioned earlier in some cases the decision can be made without the need for a face to face interview. In these conditions it would be a waste of time and resources that could be better placed elsewhere similarly with reviews for these people. In some cases, an interview might be appropriate such as a case of suspected fraud however, the fraud level of DLA is around 0.5%.</p> <p>*12. Current evidence on the each condition would give a rough</p> |

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| | | <p>guide to the frequency of reviews for fluctuating conditions more reviews will be needed than in a stable condition so as to get a full picture of health. However the only person who truly knows how they are is the claimant themselves, a level of trust is needed to rely on people to tell if there condition is getting better or worse and in doing so trigger a review or have a way of requesting a review. In some cases the review could be done by the GP as part of an annual check up that most people with long term health conditions have. To save money reviews should only be carried out if necessary. There does need to be a way of getting a review if a person health does deteriorate rapidly.</p> <p>*13. This is a double edged sword. On the one hand there are people out there who do not report their condition getting better, while others do not report getting worse and in so doing would get more money. A balance will have to be found in explaining to people the consequences and potential benefits of reporting changes. There should be a simple way of reporting changes, an online form for example. I also know that there are some people who do not report getting better out of fear that they will get worse again and so feel that they need the money in order to be able to cope if they do deteriorate without having to wait for what could be a long time for the money that they need to help them. For these people to overcome this fear the government will have to show that they respond quickly to changes and are there to support people. Finally the government will have to have a level of trust in the claimants and in so doing it will have to create trust for it in claimants.</p> <p>*14. This depends on the nature of the disability and on the claimant filling out the form. Having different ways of filling out the application form and having clear simple questions would help a lot. Also, having who are trained in disability to fill out the forms and be on hand to explain to people questions that they struggle over, they could be based at a local job centre or library.</p> <p>*15. I think people understand their own needs. If they do not wish to claim then they shouldn't have it forced upon them. In some cases however people are unaware that they are eligible to claim. People should be made aware that is there choice to claim or not and also if foreseeable how long they can claim for. People also should not be made to feel as if they are cheating the system but rather that they are claiming what they are entitled to.</p> <p>*16. Usually people fund their aids using their own money the money from DLA does help with this. For some aids however social services, occupational health and the NHS provide some aids. PIP should be used in whatever way a person feels like in order to give themselves a better quality of life for example saving for a mobility scooter, or making their home more accessible. People should be able to use PIP in order to help</p> |

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| | | <p>support this.</p> <p>*22. While there are some good points in the proposal I would say that this has gone through unprofessionally at the time of writing this reply to the consultation the government has already published it intended welfare reforms, of which PIP is a part of. There is no possible way that the data from these replies could have been analysed and looked at. It gives the impression that the government is looking for ways of making a short term saving. This means that the consultation was a waste of money and time that could have been better spent.*The claim that DLA is confusing is untrue changing the system will only lead to more confusion. A better way is to provide people with clear information on the system and educate people on how it works. Also the media try's to show this benefit as one only claimed by those who are too lazy to work rather than a benefit that people use to help them find, stay in and advance in work. People are unaware of the good DLA does as well as the general public having a complete misunderstanding of the benefit.</p> <p>*There is going be a lot of work and time put in to re-assessing people who are currently on the DLA in a lot of cases this is going to prove to be a waste of time and resources and it will mean people will be treated unfairly as they will have to justify themselves to people who really should know better and people will get taken advantage of especially those who do not have the energy to fight any wrong decision.</p> <p>*Judging from the reaction of disability groups many of whom feel as though this is a waste of time and money I would urge you not to go ahead with the proposed changes, and make DLA better at doing what it is doing well at the moment making disabled people's lives easier and more for filled. Yours Faithfully, [REDACTED]</p> |
| EM807 | 18/02/2011 | <p>Please find attached my comments on the proposals. Please acknowledge receipt. I would like to say that many people have not been able to respond as they do not have internet available or are unable to use it, notably older people.</p> <p>Regards [REDACTED]</p> <p>*1. In order of importance: Money, transport, accessibility, dignity, peoples indifference/embarrassment</p> <p>*2. Eligibility, life entitlement for certain disabilities. 3 tier system. The two tier system will mean many people will go to the lower one with less money.</p> <p>*3. : Transport, including rising fuel and maintenance costs, less free parking available due to local councils now charging. Costs of mobility equipment including hoists for cars etc. Housing alterations, including the need to move sometimes.</p> <p>*4. : See Q2. It will not be any easier to understand, it will just reduce some peoples benefit.</p> <p>*5. : Yes. Some always have a big impact on your life.</p> <p>*6. : the important elements of living are 1. The access to essential services and goods and 2. The social integration of</p> |

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| | | <p>people who can be very lonely.</p> <p>*7. : The individual is well aware of changes, the problem is that if they get worse they are scared in the present climate of witch hunt to ask for more, and if they improve they are actually unable to see how they can survive on a lower income, they realistically cannot work to improve this, they are still too disabled and there is little or no prospect of viable work. So they do not ask for reassessment.</p> <p>*8. : The use of aids is NOT a replacement for impaired ability or mobility. It is difficult to equate say the loss of a leg with the availability of new items like the blades that one sees being used by Parolympians. So if you are athletic and get one you lose benefit? This stops people trying. They are scared that someone will see them or report them – there is a real witch hunt mentality out there. I can foresee that having a wheelchair means that you are mobile and do not get benefit! That is not right because that person still has a whole lot of other needs that an able bodied person has no problem with and should not be penalised for using a wheelchair or other aid. Many aids are not new or improved – they have been in use for generations, e.g. the walking stick.</p> <p>*9. : The form just needs review by people who have experience, the charities and help groups are well placed to do this – something for the Big Society? You need to get people on side with you. The answer to the countries money problems do NOT lie with the disabled but it does feel that many will be affected. There is a great unease at best among the disabled at present and at worst absolute terror that they are being hounded out of money.</p> <p>*10. : The charities and help groups can help assess.</p> <p>*11. : The healthcare professional MUST be appropriate. Many do not understand the problems people face and do not realise the profound effect this could have on the person concerned.</p> <p>*12. : Reviews are very traumatic. The person involved will no doubt see different assessors and there will be anomalies. While the assessments and reviews are perhaps of a stylised nature there must be some flexibility. Maybe the person should simply state there has been no significant change in my their situation.</p> <p>*13. : I go back to the witch hunt syndrome. Things are getting so bad that you will find it very difficult to encourage people to report change – I don't see how this can be done.</p> <p>*14. : They need all the support and help possible, but of course many are very worried now. Of course, yes, they will need advice on how to deal with this new set of rules and I would presume that has been allowed for in the costings.</p> <p>*15. : I don't really see hoe you can force people to access advice. I get the distinct impression that the whole object of the exercise is to reduce the number of claimants and the overall cost.</p> |

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| | | <p>*16. : They try to manage their own budgets, allowing for these sorts of costs. There are still many people that although they get mobility allowance still cannot afford a motability car – they buy second hand and try to run on a reduced budget, using the left over money to help with their everyday costs for instance.</p> <p>*17. : The main thing to remember is that you are going to help that child for maybe a further 100 years, and the way they are treated now will affect them forever. They often need a system that will serve them when their parents are unable to be carers or have died.</p> <p>*18. : There do not seem to be that many other services that are available. The most useful has been the Blue Badge and the Warm Front but also other health professionals, for instance Occupational Therapists and Podiatry. However these things seem to be under great pressure at present so I imagine that just maintaining the status quo would be a success, let alone improving matters.</p> <p>*19. : The people concerned would simply either pay or not receive help. They would then become an even greater burden on society.</p> <p>*20. : Not too sure what current bureaucracy and duplication there is, so cannot be too sure how much combining can be done – I can see great problems arising with a system that is unable to fully work, first time and correctly.</p> <p>*21. : There is a great range of understanding of the current system, and that is often a function of different equality groups. However, it does seem that sometimes word spreads quickly among certain groups when there is a chance of making some money.....</p> <p>*22. : It is quite clear that the whole object is to move the goalposts to remove 20% of the claimants and lower costs by 20%. There will be practically 100% of all those that face a reduction asking for a review and then all these going for appeal. These proposals have caused great concern and worse. There will be people having breakdowns at the thought of this being done. I fail to see how taking money from vulnerable people and causing great distress will turn the countries finances around. Just put up income tax for the well off, those that can afford it, including the bankers.</p> |
| EM808 | 18/02/2011 | <p>Dear Sir/Madam Please find attached response to consultation. Please note that I am responding on behalf of an individual, not organisation. Having said that I believe that the issues I raise will be common to many other disabled people, in particular wheelchair users. Regards</p> <p>*1 • Physical, barriers: deriving from their medical condition and external environment • Social barriers: deriving from attitudes, perceptions, policies• Economic barriers: disabled people face higher costs of living with a disability and at the same time have lower than average incomes</p> <p>*2. Automatic qualification for some conditions.</p> |

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| | | <p>*3. Medical and mobility equipment. Most wheelchair users will buy the best wheelchair they can afford in order to maximise their independence. A top end lightweight manual wheelchair costs around £3000. In my own case, an NHS voucher covered around half the cost; I paid for the rest. My wheelchair now needs replacing and I expect to face similar costs (contributing around £1500) to obtain a chair suitable for my needs. Many wheelchair users are prone to pressure sores. These can be life threatening and result in extended hospital stays and weeks off work. I spend an average of £550 a year on roho cushions (a type of pressure relieving cushion) and covers. After around two years the cushions wear out (become unrepairable) and need replacing. I need one cushion for the wheelchair and another for the car. The Wheelchair Service agreed to pay for just one cushion six years ago and in addition to paying half the cost of my wheelchair they provided a single lump sum to cover maintenance of around £200 for the lifetime of the chair. In reality, the annual cost of maintaining the wheelchair is £200 a year plus the cost of cushions as described.</p> <p>*Medical costs: in 1994 I spent £1200 on essential medical equipment which the NHS was not able to fund (I can supply further information on request).</p> <p>*Higher heating costs – susceptible to hyperthyroid, respiratory and circulatory disorders</p> <p>*Care and support – this varies depending on the nature of the condition</p> <p>*Transport – for many disabled people door to door reliable transport is essential and public transport is not an option. Additional costs include paying for a reliable car, taxis and car adaptations.</p> <p>*Housing costs Costs of adaptations to make property accessible can be prohibitive: installing ramps, widening doors, replacing external doors, accessible bathrooms and kitchens. Having room to accommodate a carer.</p> <p>*Holidays Sometimes the only accommodation suitable for disabled people is considerably more expensive than that available to the able bodied. Some years ago I attended Darlington International Summer School where the only accessible accommodation they were able to offer me happened to be their most expensive - more than double the cheapest available and well over £1000. I told them I was not wealthy and since able bodied people could choose an option from £400 would they be able to charge me an equivalent amount. They eventually offered a 20% discount on their top rate but I still ended up paying more than than the four other grades of cheaper accommodation available to other students.</p> <p>*4. At least two rates of component will need to be offered if the benefit is to be responsive to differing needs. For some, modest levels of support may be enough to facilitate their</p> |

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| | | <p>independence whereas others will require more extensive support.</p> <p>*5. Yes. Some health conditions, such as complete paralysis of the lower limbs, should mean automatic entitlement to higher rate mobility payment and at least the lower rate care component. Quadriplegics should receive the higher rate of both components. This approach will reduce tape and assessment costs make the process more objective and transparent while helping to tailor benefits to needs, benefiting system users and administrators alike.</p> <p>*6. In order to prioritise support to those least able to live full and active lives, consideration should be given to meeting the following needs: personal care, medical equipment, participation in everyday activities, safe living environment, and mobility.</p> <p>Personal Care needs – support for activities such as eating, washing, toileting</p> <p>*Participation in everyday activities: assistance to participate in work, going to the shops and leisure, including holidays. The level of assistance required will vary depending on the activity, nature of the individual's disability, access to aids and other support, and wider environmental factors.</p> <p>*Clean, warm living environment – consideration should be given to meeting the cost of employing a cleaner, gardener, and paying higher heating bills. Many disabled people need to heat their homes at a higher temperature on medical grounds.</p> <p>*Mobility – safe independent transit providing access to work, whether paid or voluntary (paid employment is not an option for all disabled people, while the work of volunteers makes a huge contribution to society and can be personally fulfilling despite paying no financial reward to the volunteer), recreation and services, visit friends and family, participate fully in society</p> <p>*7. Rather than re-assess unnecessarily on a regular basis as the consultation paper proposes, consider the evidence on various conditions and request review where appropriate. The assessment needs to take into account additional costs such as eg higher heating costs, ie to prevent hypothermia, and the costs of paying for cleaning, gardening, paying for an occasional carer where necessary, eg as a result of illness or need for assistance with a task that an able bodied person would normally be able to do themselves.</p> <p>*Disabled people can face massive costs should they become unexpectedly unwell and may require full time care for a period until they are well again. Potential solutions could be giving support to pay for a carer or for convalescence in a nursing home when someone leaves hospital. Under the present system, this support is means-tested and only available to those on a low income with little in the way of savings.</p> <p>*8. No. Out of all the proposals in the consultation paper this is the most disturbing. An adaptation or aid is a prerequisite for</p> |

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| | | <p>independence, it is not sufficient alone. for a wheelchair user, this requires an environment which is always wheelchair accessible: the terrain must be flat, no hills, steps, steep slopes or uneven terrain, properly dropped curbs (most are too steep or uneven to safely use). Ice, snow strong winds and heavy rain present major obstacles. I cannot wheel at all on snow or ice, and heavy rain/wind limit the distance I and many other wheelchair users can manage, for example.</p> <p>*<input type="checkbox"/> • What aids and adaptations should be included? None. Please see answer to Question 8. •</p> <p>*Should the assessment only take into account aids and adaptations where the person <input type="checkbox"/> already has them or should we consider those that the person might be eligible for and <input type="checkbox"/> can easily obtain?</p> <p>*I agree that successful use of aids and adaptations can increase an individual's ability to lead a full, active and independent life. Although the assessment of a person's ability should not take into account aids and adaptations it should, however, take account of the fact that many people rely on DLA to pay for aids on which they depend in the first place The NHS contributes towards the cost of aids, but does not cover their full cost. Loss of DLA would leave many people unable to pay for the aids and adaptations on which their independence and mobility depend in the first place. Aids, such as wheelchairs, are expensive (mine cost £ 3000), wear out and need replacing every few years. Grants for adaptations to properties are means tested. Most properties are not wheelchair friendly and require tens of thousand of pounds to be spent on adaptations to achieve this – on ramps, wider doors, building an accessible kitchen and bathroom, installing a wet room, hoist tracking and lifts. A wheelchair user looking to move automatically faces substantial additional costs amounting to tens of thousands of pounds compared with an able bodied person.</p> <p>*9. • How could we make the claim form easier to fill in? Automatic qualification for certain conditions would make the form easier <input type="checkbox"/> to fill in • How can we improve ...? As well as automatic qualification for some conditions, a comprehensive list of the types of activity/support/costs that would be covered by PIP would be helpful. This need not be an exhaustive list – you could indicate that it does not cover everything that might qualify – but it should cover most items that people would be likely to claim for.</p> <p>*10. The starting point should be evidence from a person's GP together with any specialist clinic/health care provider they are under.</p> <p>*For PIP to be tailored to individual needs two types of evidence will be needed. First, evidence from someone with a specialist clinical understanding of a particular medical condition (ie knowledge of related associated complications)</p> |

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| | | <p>and second, evidence on socio-economic barriers, what is needed to overcome these and the additional expenses incurred in order for someone to live a reasonable quality of life with a particular condition.</p> <p>*11. Consideration should be given as to whether a face to face assessment will be needed in the first place. Some conditions, such as complete paralysis of the lower limbs give rise to identical mobility needs. It would make sense for these to qualify automatically on the basis of medical evidence submitted.</p> <p>*While many individuals are experts on their condition, the assessment process can intimidate even the most well informed and articulate person. It will be crucial, therefore, that as well as considering evidence from someone's GP and specialists familiar with their needs and long term condition, that assessors also have a good understanding of these.</p> <p>*This would require assessors that are both doctors with a thorough clinical knowledge of a particular condition as well as someone familiar with the lifestyle implications and barriers to participation that arise as a result of that condition. It is highly unlikely that a generalist would be able to carry out such assessments effectively and fairly. A clinical specialist with a good knowledge of rehabilitation (for that particular condition) might be a starting point, although their assessment should always be informed by medical evidence from the person's GP, specialist hospital reports (eg from a spinal unit).</p> <p>*Many people may find the assessment intimidating and as a result may fail to supply relevant or accurate information or even bother to apply in the first place. All applicants should be allowed to have present independent advocates to support them in the assessment process and provide guidance in completing the application form.</p> <p>*12. Basing the frequency of review on categories of disability would be most cost effective. Eg someone with a condition that is stable or permanent would need reviewing less often than someone whose disability fluctuates or is progressive. Medical evidence on a person's condition should inform how often reviews should be carried out.</p> <p>*• Should there be different types of review ...? Yes. Someone with fluctuating needs would need more frequent reviews than someone with a stable, ie permanent condition. Consideration should also be given to issues arising from ageing with a disability and additional complications and needs this gives rise to.</p> <p>* <input type="checkbox"/> • Should there be different types of review ..? Yes - see answer to previous question</p> <p>*13. Some conditions are stable and do not change. A spinal cord injury is permanent. There is no known cure. It is unlikely that needs will lessen over time, although these might become greater ie as a result of ageing with a disability.</p> |

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| | | <p>*14. Comprehensive guidance should be made available on the assessment process, criteria and a list of items for which support may be claimed. Access to independent advocacy will also be important providing support for people to navigate the application process and helping to ensure that applications accurately reflect their needs.</p> <p>*15. See answer to Question 14.</p> <p>*16. The NHS wheelchair service and Access to Work may contribute towards paying some costs but do not cover them all. Eg DLA has helped me to pay for a lightweight wheelchair and covered around half the cost of this (I contributed the remaining £1500). Over the years, I have spent several thousand pounds on pressure relieving cushions without which I cannot sit in a wheelchair (average spend £500 a year) receiving little in the way of financial support for these. Funding for adaptations to make homes accessible is means tested so only those on low incomes receive support. This is a massive cost (replacing external doors, installing level thresholds/ramps, a wet floor shower and accessible kitchen) but essential for wheelchair users as most property is inaccessible.</p> <p>*Disabled people fund their aids and adaptations in a variety of ways. DLA enabled me to obtain the lightweight wheelchair of my choice and helps cover the cost of other aids, such as pressure relieving cushions. It does not make a huge difference where major adaptations to property are concerned, eg installing a level access shower, upwards of £ 5000, although any assistance is better than nothing. There might, therefore, be a case for a one off payment to cover the latter. With regard to wheelchairs, these are not a one off expense, but need replacing periodically (in my experience, every five to seven years) and incur ongoing maintenance costs described above.</p> <p>*17. What are the key differences that we should take into account when assessing children?</p> <p>*18. Disabled Persons Railcard, Blue Badge, Freedom Pass are all valuable concessions.</p> <p>*19. This would significantly increase costs among already physically and economically disadvantaged groups so there would be more trade offs: choices between heating or eating, inability to pay for transport, increased isolation, increased dependence and ill health.</p> <p>*Areas formerly accessible to disabled people would be so no longer to people who lose their entitlement to a Blue Badge. Wheelchair users who require extra space in order to get out of their car or need to park in a particular spot on accessibility grounds will lose parking concessions granted by the Blue Badge Scheme. Loss of using PiP as a passport to other benefits and Services would curtail mobility and independence unless measures are first put in place to address this.</p> <p>*20. Automatic entitlement for certain conditions</p> |

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| | | <p>*21. Those who are not in full time paid work or those in residential homes will be particularly badly hit.</p> <p>*22. DLA and its forerunner, mobility allowance, far from being a barrier to employment has played a huge role in my quality of life and independence and was my passport into paid employment.</p> <p>*After I left hospital after becoming spinal cord injured in 1986 I spent 18 months in a residential home before moving into independent accommodation. At the residential home I learnt independent living skills and gradually regained my confidence. I used Mobility Allowance to pay for a lightweight wheelchair (not available on the NHS at the time) and subsequently to pay for taxis to go out socially, visit my mother and see a counsellor. Taxicard covered the cost for two journeys a week at most and the mobility allowance covered the remaining travel expenses. *The biggest transformation for me was learning to drive and getting a car. This opened up a world of opportunities. Without Mobility Allowance I would not have been able to afford driving lessons (I lived on benefits at the time). After I passed my test and got my first car with Motability, I took an Open University degree. The car enabled me to attend tutorials and summer schools. Subsequently, I began a voluntary work placement with a research institute. Parking close to the institute (or some other form of door to door travel, such as a taxi) was essential as the nearest bus stop was some distance away up a steep hill - out of the question for most wheelchair users. The voluntary work placement lead to a short term paid contract. Following that, I did a second work placement and relied on my car to get to and from my place of employment. Access to Work does not fund travel costs for voluntary work and while my employers offered a small contribution to expenses, this was not enough to cover the cost of taxis or running a car.</p> <p>*DLA does not meet all the additional costs of living with a disability, but it does make a valuable contribution. I have never viewed it as an out of work benefit, although it provided the support I needed to enter the labour market in the first place. Despite improvements to access in the public realm and transport, we are a long way from achieving full access, which will always be impossible in some conditions and areas, therefore a car continues to be vital for many wheelchair users. Those who aren't working and on a reasonable salary would be unable to afford a car (or pay for taxis) without DLA and its loss would devastate their quality of life and independence. In my experience, Dial-a-Ride, Taxicard and community transport do not offer a comparable service to public transport which is still not an option for someone like myself, who require door-to-door transport in most circumstances.</p> <p>*I hope that you will reconsider the proposal to remove entitlement from those living in residential homes. For many, it</p> |

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| | | <p>is their only means of visiting friends and relatives. Some people living in residential homes do go out to work and while Access to Work may cover the cost of travel to paid work, it does not pay travel expenses for volunteers.</p> <p>*In my view the name 'disability living allowance' is more empowering than 'personal independence payment'. The latter implies barriers are unique to and derive from the individual. Crucially, PIP fails to recognise common shared barriers some of which are a direct consequence of the way society organises itself. Although there has been progress, barriers continue to be shared with the able bodied community, eg parents navigating inaccessible environments with small children.</p> <p>*What is important is that the ethos of Disability Living Allowance, ie a benefit that recognises and contributes to the extra costs of living with a disability, continues to lie at the heart of the new benefit. ██████████ 18/02/11</p> <p>**ADDENDUM*Dear Sir/Madam</p> <p>**Further to my response to the consultation on Friday, There an error in answer to question 16. Please note that the second sentence should begin 'Eg the NHS has helped me pay for a lightweight wheelchair...' rather than 'DLA'.</p> <p>**I would be grateful if you could make this correction. Thank you ██████████</p> |
| EM809 | 18/02/2011 | <p>1. : access and prejudice, shortage and cost of equipment, support, accommodation</p> <p>*2. : don't understand what this means by "anything else"</p> <p>*3. : accommodation costs, equipment costs, transport costs, caring costs</p> <p>*4. : no – two levels will not make it easier to understand but will cut the cost for the Government –that is the whole intention of the change</p> <p>*Care needs change as the illness progresses so 3 rates are still essential</p> <p>*5. : For diseases like Duchennes Muscular Dystrophy, other muscular dystrophies, and others that will definitely progress then the entitlement should be on the diagnosis. For ones that can improve or be managed then there can be justification for basing on needs</p> <p>*6. : the order of needs should be - Adequate accessible warm comfortable accommodation, adequate and appropriate equipment, the best education possible, transport, additional care so the main carers can have a break, consideration to the impact the illness has on the other members of the family,</p> <p>*7. : include the consultation and experience of the qualified medical carers</p> <p>*8. : the assessment should take into account the need to use aids and adaptations, not the fact that they have them Aids and adaptations are not easily obtained</p> <p>*9. : fewer questions</p> <p>*10. : reports from all concerned with the care of the person</p> |

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| | | <p>*11. : the face-to-face should not be with “a “ healthcare professional but the one who has had the responsibility of the care In some cases the experience of the healthcare professional should be questioned/and or taken into account</p> <p>*12. :The number of visits etc to or from medical profession and healthcare professionals and an assessment from the main carer should be adequate</p> <p>*13. : you can only encourage people to report changes if they are capable of understanding the requirement. Very rarely do people get better – usually the problems progress and increase</p> <p>*14. : simple, straightforward statements, not gobbledegook designed to confuse</p> <p>*15. : there should be a link between the healthcare providers and the claimant – many are not able to take control of their situation for a number of reasons</p> <p>*16. : No, the PIP should not be used to meet a one-off cost. Their others needs in the week they make that payment do not decrease Applications to charities, benevolent funds and family are usually the main source</p> <p>*17. : this is a ridiculous question – if you don’t know the answer you shouldn’t be in charge of this consultation</p> <p>*18. : DLA doesn’t usually provide access to other services or entitlements – people have to find out for themselves</p> <p>*19. : what do you mean by “passport”. As I understand it “passporting” means allowing the progression to other benefits and services, it doesn’t mean it has to be used to pay for that service</p> <p>*20. : a link between the health care providers could cut out a lot of the bureaucracy and duplication</p> <p>*21. Your response: 22. Your response:</p> |
| EM810 | 18/02/2011 | <p>1. The disability of the person, financial resources, lack of services to suit their needs, unsuitable building layout, 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>*Carers to assist them and to keep them safe. The lack of support for the disabled person impacts upon the whole family. This creates a vicious circle of the whole family becoming impoverished and having to depend on the benefit system.</p> |

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| | | <p>Unless proper care can be provided for the disabled person the cycle will never be broken and more families will fall deeper into debt with no means of escaping it unless that family member is taken into care and thus freeing up the parents/carers to work and not depend upon the state for support whilst being in the position of not being able to care for their disabled family member. It is a no win situation.</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.</p> <p>*Company, stimulation, being a part of the world, access to shops and services, being safe in the community.</p> <p>*Provision of quality care and not anything will do so that the families do not worry themselves sick about their family member when they are with carers.</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. The family social worker should be able to provide honest accurate assessment of the family needs, there is a need for better training throughout social workers. Our experience is very poor and has put us in a far worse position than we could have ever dreamt of being in. The social workers should be experienced and help families to access first class support but there needs to be quality services available in the first place</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. Many people with needs do not require aids, maybe the aids create a false picture. A child with extreme challenging behaviour may not require specific aids, but may cause enormous problems for the whole family. The physical and emotional effort put into caring for these individuals cannot be measured, but the amount of extra</p> |

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| | | <p>income needed to stay on top of the chaos caused by aggressive violent outbursts is immense.</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. Well trained social workers to fill in the forms or adequately experienced people who understand the process. The existing forms just make me feel that they are trying to catch me out by repeating the same questions over and over.</p> <p>* 10. Person, GP, Specialists dealing with person, School, Social Worker, Support Worker, Paediatrician. Parents/ Carers who are living in the situation 24/7.</p> <p>*11. I can't see any benefits. Only costs. If the health professional involved has no knowledge of the persons condition and how they can be affected then it could be dangerous.</p> <p>*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.</p> <p>*Besides there are many other ways to get enough information from other sources.</p> <p>*A face to face interview could be very distressing and off putting for some people with learning disabilities or mental health needs.</p> <p>*12. Look at developmental milestones, recovery rates for surgery/diseases, set them around that.</p> <p>*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>*Life long conditions are life long and they will not improve, why rub the families noses in it at regular intervals.</p> <p>*If there is a miracle recovery then the social worker should inform the DWP</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>*The care system should be taking care of all those people in need and they should not be made to feel like they are begging</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>*Again the care system should know about the people it needs to care for and should have access to appropriate information.</p> |

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| | | <p>*Social services should be pro active GPs should get their patients into the loop and hospital specialists should be getting their patients into the loop.</p> <p>*16. They either have to wait unacceptable lengths of time for equipment or go without or pay themselves or their friends and families hold charity events. This is very demoralising for people and families in genuine need.</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>*Everything is being cut back. They social divide is widening.</p> <p>*We treat out animals better than the people in need.</p> <p>*18. DLA just about covers the person's basic needs. There is nothing left for accessing anything. There is no understanding of individuals needs who do not fit standard care plans.</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. All information should be securely stored in an appropriate place. It should only be accessed by people who understand what they are doing and how to meet the person's needs. There should be no need for assessment after assessment on the same person.</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> <p>*Train the decision makers and social services.</p> <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</p> |

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| | | <p>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. The increasing cost of living is not being addressed for our vulnerable people and their standard of living is already falling and taking their carers and families down with it.</p> |
| EM811 | 18/02/2011 | <p>Dear whoever, this is my response to the dla consultation.</p> <ul style="list-style-type: none"> * q1. Answer. Barriers are social medical and economic. * q2. anser. DLA should remain as it is. persons on it will be more dependent if they lose income. will cost NHS more. * q3. answer. Mobility - both aids and transport such as taxis for those unable to use public transport, heating, communications - internet and phone, good food, ready meals if yu cna't cook, supplements such as cod liver oil, physiotherapy, ultrasound treatment, painkillers and gel or cream for painful joints, psychotherapy, exercise or yoga classes, replace essential itmes like cooker and washing machine, social support, social activities, and even things like sunscreen for those on psychiatric drugs, pay for keeping company of a pet to prevent suicide, hobbies, education, gardening help, housework help, good mattress and pillows etc etc * q4. anser. Two rates for care means people will lose right for carers to get care allowance if people from the middle put onto lowest rate. Not good to put three rates down to two as many peopel will be downgradede and lose money. * q5. ans. Conditions which are sever, enduring and incurable should not be re-assessed. It would be pointless, distressing for the claimant and expensive. Information from specialist consutlant should be enough for people to avoid wrongful and horrible reassesemnts. * q6.peopel have individual complicated needs. that is why the DLA forms were long and detailed. * q7. medical evidence should suffice. if there is remission there is also relapse int hese conditions, and that must be recognised. cyclical conditions are very unatractive to employers. for sever mental illness relapse can be fatal. * DLA must not be reformed. The reasons given for reform were not based on evidence. the reason so many recipients are out of work is because it is claimed by those most affected by their condition. Basing claims on a forty minute interview may allow fraudsters in. it looks to me like the govenment already decided to get rid of DLA even before the consutlation closes. |

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| | | this is wrong wrong wrong. |
| EM812 | 18/02/2011 | <p>1. Your response: Complex & many & question itself fails to address that many people will continue to struggle to live at most basic level and that the level of participation , fullness and activeness implied by question is in fact a discriminatory projection. While working, I've supported a paraplegic individual who was also deaf and blind , I held his hand all day, he was reassured by physical presence but I was forced to leave that job when I got depressed again as it undermined my ability to hold his hand with the confidence and positiveness he deserved , I was unable to support him to be in the world as comfortably as he had every right to be as the world was just full of causeless , meaningless icy black pain, suffering and sorrow for me that I had no right to impose on anyone else and he would have sensed that vast cold distance and it was unfair to inflict that on him. You will probably never care for anyone like that but you can acknowledge that disability , mental and physical is a bit more complex than your opening question suggests.</p> <p>*2. Your response:</p> <p>*3. Your response: The costs of living.</p> <p>*4. Your response:5. Your response:</p> <p>*6. Your response: This is too big a question for DLA reform alone but since the aim of this reform is mainly to save money there is no point addressing the systemic problems that fail people with disabilities , the lack of accomodation because the new groupthink is that we can somehow engineer people to fit in rather than create genuine ways to support them to opt in through purposely prized open gaps in the barriers that keep them out.</p> <p>*7. Your response: Talk to people instead of trying to bully them.</p> <p>*8. Your response: Lets assess how well we're helping those able , ready and desperate to get into education and work first.</p> <p>*9. Your response: People need help with forms.</p> <p>*10. Your response: Consultant and GP and person themselves. Society has generated problem where disabled people are viewed as the number one problem to tackle.</p> <p>*11. Your response: Some disabilities simply don't lend themselves to this. Paranoid personality disorder person not only likely to fail assessment, most likely to fail every other formal social encounter /interaction and job scenario if left to own devices too. How do you support when you are triggering disability?</p> <p>*12. Your response: ATOS are paid to perform. David Freud gave that game away.</p> <p>*13. Your response: By rewarding them to.</p> <p>*14. Your response:</p> <p>*15. Your response: Personality disorder , severe autism and</p> |

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| | | <p>physical disability not cookie cutter conditions, often multiple conditions, person centred approach required from professionals independent from system who understand it is not their job to manage clients but to share information with and assist them.</p> <p>*16. Your response:17. Your response: *18. Your response: This is failure of other services. Has successful has tax system been at getting people more involved in sport? *19. Your response: All or nothing question again. *20. Your response:21. Your response: *22. Your response: I do not believe the proposals conform to the Human Rights convention , and think the stated target for reductions shows disability is being targeted rather than assessed .</p> |
| EM813 | 18/02/2011 | <p>please find consultation response attached, (please note, responses only to qns 1, 3, 5, 17)</p> <p>*1. Your response: • Regular medical appointments/operations can disrupt family life, *• Employers do not like the prospect of workers with a disability or parents of a disabled child taking time off for appointments (even when it is annual leave). Taking unpaid leave for appointments and sickness will leave workers out of pocket. *• There are also accessibility issues with regards to public transport. *• Attitude that the only disabilities that ‘count’ are those which are visible can undermine some serious problems.</p> <p>*2. Your response: *3. Your response: travel costs, especially if there is a need for reliance upon taxi etc. Unpaid leave from work taken to cover hospital appointments / procedures /sickness (esp. for parents of a child with a disability). *Prescription costs, especially for people who suffer from chronic life-long illnesses which can only be controlled by medication. (This could be more of a problem if a condition is generic or familial in nature). Often conditions are complicated, e.g. a heart condition may require specific (costly) diet alterations or mean that the person is more sensitive to extreme temperatures and needs to be kept warm (higher fuel/electricity bills). These are issues which, for disabled people and their families will eventually become ‘normal’ expenses, but they are examples of additional costs which DLA helps with.</p> <p>*4. Your response: *5. Your response: I think that there may be some instances where an automatic entitlement to benefit is appropriate. For example, terminal illnesses, life-limiting, chronic/progressive illnesses. Also I think transplant recipients should remain entitled to DLA AFTER the transplant - sadly a transplant is not a fix, he transplanted organ often has a short life-span (eg.</p> |

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| | | <p>10years), the recipient will require immune suppressants for the rest of their lives to avoid rejection (they are likely to pick up more infections etc. because of this), there may be other complications and there will be many more hospital appointments to attend etc.</p> <p>*6. Your response:7. Your response: 8. Your response:9. Your response:10. Your response:</p> <p>*11. Your response:12. Your response:13. Your response:14. Your response:</p> <p>*15. Your response:16. Your response:</p> <p>*17. Your response: Children who have congenital conditions or who were diagnosed at an early age will not be able to participate in face-to-face discussions and questions regarding how their disability affects their lives – they will not know/understand any different. For example, my 3 year old daughter has a serious chronic heart condition and accepts her physical limitations, hospital appointments, related illnesses, daily medications etc. as ‘normal’. Adults and other healthy children realise that they are NOT usual for a young child, but she has never known any different. Obviously this will change as she gets older and begins to query why she cannot keep up with peers etc...</p> <p>*Also young children may feel intimidated if asked to demonstrate their mobility etc and also may be uncooperative. I do think that young children should not be made to go through a face-to-face examination as it may cause distress, especially if the child doesn’t really understand the concept that there is anything ‘different’ about them. In these instances I think the considered opinion of the child’s consultants should be taken into account.</p> <p>*With reference to the ‘healthcare professional’ who reviews the cases, I think that it is essential that they are someone who has experience of those specific health problems in children –for example paediatric heart failure tends to present and progress very differently from adult heart failure. In such cases I feel consultant/doctors reports should also be used to determine eligibility.</p> <p>*In conditions which have ‘good’ and ‘bad’ days, the reviewers should take into consideration that just because a child is having a ‘good day’ or looks ‘well’ it does not automatically follow that they ARE well or that good days outnumber the bad.</p> <p>*Often, an awful lot of effort (time, money, care) is put into making poorly children well enough to participate in society. In order to do this, parents may have to cut down working hours to care for the child, take unpaid leave for periods of sickness and hospital appointments or hospitalisation, spend time organising medications, arrange daily life around restrictions and medication times, pay extra money for travel costs etc. - DLA is key in ensuring these disabled children (who are already starting off at a disadvantage in many instances) are not</p> |

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| | | <p>isolated further.</p> <p>*18. Your response:19. Your response:20. Your response:21. Your response:22. Your response:</p> |
| EM814 | 18/02/2011 | <p>1. : People with mobility problems have problems simply getting out of their homes. If they do not have access to a car they can become trapped in their homes. Using public transport is often impossible due to the difficulty in boarding buses and trains. In rural areas bus services are infrequent and this is likely to become worse in the near future when some rural bus services will be cancelled altogether.</p> <p>*2. Your response:</p> <p>*3. : Disabled people have to pay for people to carry out quite routine tasks which able bodied people take for granted. Gardening, house cleaning, window cleaning, taking out the rubbish, dog walking are among the many tasks which disabled people have to pay for. Even simple tasks such as changing a light bulb are impossible for some disabled people.</p> <p>*4. Your response:</p> <p>*5. : Some condition such as blindness should mean an automatic entitlement to allowance.</p> <p>*6. : Any activity which an able bodied person is able to participate in is essential for a full and active life in a disabled person.</p> <p>*7. : The assessment should include opinion from a qualified medical practioner with specialist knowledge of that condition, e.g. rheumatology.</p> <p>*8. : This question seems to indicate a lack of understanding of disability, and of the Disability Discrimination Act.</p> <p>*9. : By not starting from the premise that every disabled claimant is fraudulent.</p> <p>*10. : The disabled persons self-assessment and the input from an independent medical practitioner who receives no financial payment from the DWP.</p> <p>*11. : No benefits. In most circumstances</p> <p>*12. Your response:13. Your response:14. Your response:15. Your response:</p> <p>*16. : You don't know this? Basic research, surely.</p> <p>*17. : Their need to lead a life where they have the same mainstream opportunities as other children.</p> <p>*18. Your response: 19. Your response:20. Your response:</p> <p>*21. : Your proposals will significantly discriminate against disabled people.</p> <p>*22. : I would like to tell you that you are posing too many questions, that these are skewed towards justification of your proposals, and you are not doing enough to engage directly with the views of disabled people like me. I feel threatened, distressed and helpless.</p> |
| EM815 | 18/02/2011 | <p>1. There are numerous problems and barriers that disabled people face in everyday life. They include access to buildings and transport. Communication can also be a barrier. People's</p> |

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| | | <p>preconceptions and attitudes are a big barrier in becoming involved in things. People stare and shout things which can be very difficult to deal with and discourage people from going outside.</p> <p>*2. The 3 part care component should be kept, because otherwise the two sections are going to have to widespread criteria, and possibly make it more difficult to understand and many people who would have previously had middle rate care will be worse off financially.</p> <p>*3. Costs are very widespread, and include transport costs, specialist food costs, prescriptions for medication and medical equipment. Costs of carers is also a considerable cost.</p> <p>*4. Offering two different rates will probably not make the benefit any easier to understand or administer. This is because there will be wider criteria that people will need to fit into and people may cross over the higher and lower care rates and would have suited the middle rate care that is given with DLA. It will be harder to understand due to the wider ranging criteria that will be applied to each group.</p> <p>*5. It is only fair that everyone is assessed as an individual. Every sufferer of a given condition will be affected differently and have different needs and abilities which should be taken into account.</p> <p>*6. Prioritising those who are the most restricted will be difficult. Priority should also be given to those who with some help would be able to go to work and be active in society, as they may be able to come off of other benefits, such as ESA. Prioritising those most in need, will be done based on their original paperwork and their medical assessment. The most essential activities include, breathing, eating, drinking, toileting and movement. These are followed by very important activities, of washing, dressing, and communicating. There is a wide variety of activities that can be considered essential to basic functioning that must be considered as well important activities that are required.</p> <p>*7. Taking into account a variable and fluctuating condition can be very difficult. Probably the best way is to look at either end of the persons spectrum of ability and then base it on the criteria that fit most of the time, whilst ensuring that the person being assessed will have enough support for the times when their condition is at the more severe end of their spectrum of functioning.</p> <p>*8. This is a very delicate area and a number of things need to be considered. For example, if someone who uses a wheelchair and this is taken as them having no problems with mobility, this is unlikely to be correct. Opening doors, travelling along uneven pavements, crossing busy roads and maintaining and repairing the wheelchair are all important costs that mobility DLA are used for. Without this benefit many people would not be able to have their wheelchairs, thusly rendering them less</p> |

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| | | <p>able to take part in society. Many who can work, would stop being able to.</p> <p>*Few people who use aids no longer have problems. Aids are not a complete problem solver. Aids, therefore, should not be taken into account, especially those that need regular maintenance and repair.</p> <p>*The assessment should signpost to aids, that would improve the persons' life, but unless it can be proven that the aid completely negates the problem, then it should not be taken into account.</p> <p>*9. It will always be difficult making the application process more positive, as it needs to focus on what cannot be done, as otherwise the assessors will not be able to assess the problems people have.</p> <p>*It would be better if there was a question by question guide book to the application form, as then people would be more clear as to what they needed to put, making it easier for everyone including the assessor.</p> <p>*Reducing the number of tick boxes would make it easier too, as for many conditions the tick boxes are not very helpful as people do not fit into these narrow tick box conditions.</p> <p>*10. Supporting evidence should come from a variety of people, including a persons' GP, hospital consultants, other health care professionals, friends and family, as these will provide a variety of inputs and opinions, and an accurate assessment of needs and abilities.</p> <p>*11. There are a number of problems with a face-to-face assessment. These include, the fact that the healthcare professional will not be a specialist in the condition presented to them, and therefore they may not understand the nuances and peculiarities of the condition being assessed and may not be able to do an accurate assessment as they could have preconceptions and prejudices, regarding the condition.</p> <p>*12. The reviews should be carried out dependent on the condition, and the persons' abilities. For example those with progressive conditions may need more regular assessments to see if they need higher rates, although this should also rely on the person to report changes. Those with fluctuating conditions should be assessed regularly to check that the person still needs the PIP. There should be a clause in that if it is stopped, and then they worsen, they should be able to have a shorter review to return to the PIP. Those with conditions unlikely to change should have less regular checks, as there is little point in adding stress to their situation unnecessarily and it will be cheaper not to assess them unnecessarily.</p> <p>*13. People are concerned about reporting changes because they fear they will lose their complete benefit even if there is only a change in one part. Perhaps a clause that means they keep their money until a decision is made that does not need to go to appeal etc... That way they will not have financial scares</p> |

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| | | <p>until the final decision is made, giving them time to sort things out. Perhaps sending out a regular form, just reminding people of their responsibility would help. Additionally, offering the option to email when a change in circumstances is made, would make it much easier to report the change.</p> <p>*14. People are most likely to need detailed advice as to what they are meant to put in the form, a guide to the form as such. It would be helpful to either provide this with the form or explain where the information could be gained.</p> <p>*15. It could help some claimants, but it could just confuse other people and make them worry unnecessarily. It would have to be carefully explained. It may be difficult to identify those claimants that need the support and advice without alienating others and putting them under undue stress. The key features of any such system, would could include a series of work focussed interviews, there should be sessions on writing a CV, how to act in an interview and prepare for one. Encouragement and support to find a job, and assistance with any adaptations and an access to work scheme, would all need to be included. Things to avoid would include unnecessary, stress and forcing people into a job/ threatening to cut their benefits if they didn't find a job/ make a concerted effort to stay in work.</p> <p>*16. Many people fund their aids and adaptations through their DLA. For example, wheelchairs that people have to buy privately because they don't qualify for an electric wheelchair on the NHS, those who have to privately buy manual wheelchairs because they need extra light wheelchairs. Others have to buy ramps, and pay towards bigger changes to their houses, like new bathrooms. Many depends on the DLA mobility to buy wheelchairs, and cars, that are specially adapted to their needs. For the motability scheme to work people need their DLA mobility component, as it is the only way they can afford to keep their cars which are essential for their interaction within society, especially those who have Wheelchair Accessible Vehicles.</p> <p>*17. When assessing children it is important to consider exactly what a parent should be expected to do for their child, within reason, and anything else should be considered as relating to the disability. For example, although changing the bed is an activity a parent may do, changing it because the child's jejunosotomy tube has leaked, every night, is a disability related problem. A parent should not be expected to change the sheets during the middle of every night. So it is necessary to look beyond what is a parents' role as to what is disability related complication.</p> <p>*18. This very much depends on the person involved. Although it is good at getting people a Blue Badge if they receive higher rate mobility, but there is nothing in the paperwork that tells you how to go about this. It needs to be more widely known. A lot of the entitlements rely on other people telling people what</p> |

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| | | <p>they're entitled to, rather than the DLA paperwork explaining to people who have been awarded it. Listing the services and entitlements on the award letter would make it a lot easier to access these other things.</p> <p>*19. For those that are in contact with other people who know the opportunities within the system, then it is not such a problem, but those that are isolated from other disabled people will have absolutely no idea what else is available, and may suffer both practically and financially if they are not made aware of these other opportunities.</p> <p>*20. Combining information for things like DLA and ESA, would have to increase the length of time for the assessment, because of the area of interest within each of these. Passing assessment information onto social services may be useful as they could have some idea as to the needs of the person before they meet them.</p> <p>*21. If all equality groups are treated the same, then there should be no problem, as long as all are assessed fairly in terms of their disability.</p> <p>*22. These proposals need a lot of work, to make sure that people are treated fairly and are not worse off due to the changes. DLA is an essential form of benefit for those with disabilities to meet the additional costs they meet. Any cuts in this additional money will further isolate people with disabilities preventing many from attending work, which may force them to claim other benefits such as ESA, making the reform totally pointless and costing the government more in the long run.</p> |
| EM816 | 18/02/2011 | <p>1. Your response: Walking, travelling/ transportation, lifting weight, get tired easily (can't do a lot of activities), getting pain all the time, depression due to illness, blindness, need people to help (making sure things are ok & safe, house chore), equipments/ adaptations needed for work and home, all of those could be difficult for the disable.</p> <p>* 2. Your response: I think DLA should remain basically the same but with modification. It would probably be cheaper for the government to admin or implement. As the country's budget is tight, the level of benefit could be reduced for everyone and that claimants are required to reassess every now and then to ensure things are up to date.*In term of things that should stay the same, I think the 3 rates system should remain the same as it will give a better gradation of the level of disabilities rather than just a black and white "slightly disable" or "totally disable" which I don't think is fair.</p> <p>*3. Your response: Travelling – can't do normal walking like normal people so need help with transportation cost. Need help with lifting things – need help to get shopping done, house chores etc. Need special equipments. Need people to make sure you are ok & safe. Helping with cooking.</p> <p>*4. Your response: The current three rates system is not particularly hard to understand. In fact, I think by making things</p> |

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| | | <p>in two rates will makes thing worst as it will mean a more black and white approach to disabilities, there is no gradation. So you are either slightly disable or you are totally disable. The people in the middle band will suddenly become 'slightly' disable and their needs may not be met due to the new rate. Also there is a possibility that this may resulted in only a very few people actually will be getting the top rate as the requirement for top rate maybe set much harder than previously.</p> <p>*5. Your response: I think it will save the government time and money if certain disable conditions are automatic entitled – the condition is so obvious that it will be wasting everyone's time and also causing a lot of unnecessary stress to the very disable or ill. Of course clear evidence of the condition must be provided.</p> <p>*6. Your response: The basic survival should have key priority. Help with daily chore at home (cooking, people looking after you, shopping, taking you to hospital etc.). Helping with travel cost, especially for getting to work (if they have jobs). As money is really tight, I would rather has less social/ leisure activities.</p> <p>*7. Your response: Some disease does resulted in the disable person having a lot of ups and downs (say joints inflammation) resulted in the good and bad days. I think therefore it is important that the “bad days” must be taken into account. In the assessment day, the person maybe in a “good day” so it would be unfair to just assume that is the normal condition of the disable person.</p> <p>*8. Your response: Wheelchair, walking stick/ frame, special shower/ bath, railing, special beds, special chairs, wedge/cushions, helping hand, socks aid, special pc monitor.*The assessment should take into account both the aids/ adaptations already used and also taken into account of aid/ adaptations that they are eligible. The reason is that it would be unfair if someone living in a poorer council or area where they do not have the budget to get the equipments and those people will be penalised simply because of this.</p> <p>*9. Your response: Making claim easier to fill in would be good. Form should not be too long and instruction must be very clear. It would be helpful if there is clear guidelines and also setting out some examples.</p> <p>*It is very important that the reply after an application should be quick and not overly long. There should be some clear set time scale for reply after application, review and appeal procedure.</p> <p>*By giving clear examples of qualification requirement and make guide line very clear will save everyone's time.</p> <p>*10. Your response: Hospital consultants, Physio, OT, doctor, social worker, nurse, people who look after the disable person.</p> <p>*11. Your response: As there are a lot of claimants, it would mean a lot of delay waiting for an appointment for a face to face discussion before people could get their benefit. Getting there</p> |

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| | | <p>to see the healthcare professional could be a problem as well – is the building disable friend? Is it far and is there transportation? Very importantly, do the healthcare professional actually qualify to understand & be able to judge every medical conditions or problems associate with a particular disabilities? Should they not referral those complex cases to some specialist (who are better qualify to judge) in those situation? How do you ensure that the assessment is fair? There was problem with assessment in Incapacity benefit assessment where it was unduly harsh. Also how impartial is the healthcare professional? As they are hired by DWP, will they end up like what happened in Incapacity benefit with harsh assessment and resulted in a lot of people suddenly no longer entitled to the benefit? This in term would lead to a lot of appeals (and thus more delay before people (those who are deserving of course) get their benefit)? I am concern this could be used as a form of delay tactic to delay payment to those who are deserving the benefit. It would also caused a lot of stress which could damage the health of some of the disable who has stressed related illness.</p> <p>*For disable person who is very ill or bed bound it would not be reasonable to expect them to travel to meet the healthcare professional. Rather they should see them at their home.</p> <p>*12. Your response: It would depend on what medical condition the disable person got. A prognosis from hospital consultant should give a fair idea of what would happen in the next few years to that person. This should form a basis of frequency of reviews. I think it is unfair and damaging to the disable person if the frequency of assessment is too frequent. Some of the disable has condition that is stress related and by going though assessment all the time will actually worsen their condition and making them unwell. And some of those people might decided not to claim any more simply because of all the stress even though it would be to their detriment. I am concern this could be used as a form of bullying on the disable by stressing them out so they won't claim disability benefit.</p> <p>*Different types of reviews probably would be useful depending on the condition of the disable person but at the same time, wouldn't this also making the application process more complex and confusing? I think for this to work, very clear guidelines must be in place, otherwise this could resulted in unfairness – i.e. claimants with same type of disabilities may end up with different type of assessments, or that similar condition claimants will end up with different assessed result.</p> <p>*For this to work, clear and transparent guideline for assessment for different categories of medical condition should be set out. In special cases (where there are special needs or reason), different type of review could also be used but there must be some special procedure (& reason to do so) that must be followed.</p> <p>*13. Your response: This is difficult as some condition actually</p> |

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| | | <p>has a lot of ups and downs all the time, no one really knows how long those temporary improvement or worsening is going to last in the coming weeks or months. How are those people going explain the changes?</p> <p>*14. Your response: Clear instructions guidelines on form. Examples and guidelines about what qualify. People should have access to CAB for advice if required.</p> <p>*I am not sure it would be helpful to make this a prerequisite to making a claim for PIP – it could put people off as it could make the process intimidating and long. I think this should only be an optional service – i.e. only if the claimant want to ask about something rather than it being forced on them. Plus there is possible issue of conflict of interest/ impartiality if PIP is giving the advice as well.</p> <p>*15. Your response: People has a right to access advice and support. To create a barrier to support and advice would not be reasonable. Where there is a conflict between claimants and PIP, they should be advice by PIP that they could and should seek out independent help like CAB. Maybe provide claimant with information sheet where they could get help or advice in such situation.</p> <p>*16. Your response: Social services, hospital OT & Physio department. Access to Work to get equipments & adaptation for work place. Wheel chair service via hospital, Motability for car hire, dial-a-ride, car modification is self financed. There are already departments that are doing this and I do not believe it would be useful, appropriate or beneficial that PIP should be making those payments as they are not qualify to assess, judge or advice on equipment needs of a particular disable person – they are not the ones who treats the patient. I would imagine PIP will be rather busy and may not has enough resource/man power to handle so many claims for equipments as well as all the PIP applications. This will just create unnecessary delay and layer of bureaucracy as well as giving PIP too much control & power over the life of the disable. i.e. patient may not even be able to get a walking stick from the hospital simply because they are not qualify for PIP!!</p> <p>*17. Your response: Can a child be able to fully communicate about their problem? Would the stress be too much for them?</p> <p>*18. Your response: Very important, like travel (Freedom pass), housing, council tax exemption, Blue Badge, Access to Work (work equipments & adaptations), getting help from Disabilities Employment Advisor support in Jobcentre Plus etc. Without DLA passport, the disable person would be at a lost. I am concern that a lot of people who were previously classify as disable might suddenly become “non-disable” under PIP, this would caused a lot of hardship. I think that to be on DLA one cannot be perfectly normal and due to the passporting arrangement, under PIP some disable people who were on DLA previously may suddenly lose a lot of those support</p> |

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| | | <p>systems. So someone may end up cannot go to work, stuck at home as they cannot go out due to lack of transportation support, cannot park a car in a disable bay in street or might even ends up on the street as a result of PIP. I think there could some extremely harsh and unfair consequences due to PIP & the passport arrangement. I think those supporting services need to also allow people to apply even though they do not get PIP.</p> <p>*19. Your response: It would mean extra work & delay for the disable to get the supporting services. However, the consequence would be even worst if passporting arrangement is linked with PIP as that would mean a lot of previously 'disable' person under DLA suddenly lost all their support services which would be extremely harsh and unreasonable. It would cause tremendous hardship and suffering. It is probably better to separate out the passporting arrangement from PIP. Maybe for existing DLA claimant the passproting arrangement should continue for sometime after the end of passporting arrangement. An alternative is that the passporting arrangement could continue but the supporting services must also consider other applicants who do not qualify PIP or on lower rate on PIP.</p> <p>*20. Your response: There is the danger that information is misused by other departments or other organisations that have no real need or right to such sensitive information. There is a security and privacy risk here – I certainly don't want some unknown services or departments or personal to assess my very personal information without my consent.</p> <p>*What if the assessment process turn out to be unduly harsh like in Incapacity benefit which resulted in a lot of people losing their Incapacity benefit? Is it fair and reasonable that a large group of disable people suddenly lose all the use of those essential support services simply because they have been reclassified from being 'disable' to 'non disable' or put into a lower rate band in PIP? And all this from just one assessment which may (or may not) be even fair? The level of hardship & suffering caused to the disable would be tremendous – it certainly will not help people to be independent or getting back to work. Shouldn't those supporting services have an option to use their own independent assessment of the claimants as well as relaying on PIP's assessment? I would imagine there will be a lot of appeal if suddenly a large number of people losing essential support services which they need to survive.</p> <p>*21. Your response: Ensure there are support for languages for some people during application to assessment. Also for some female applicants, they may want to have a healthcare professional who is also female as personal/ sensitive questions maybe asked during the review.</p> <p>*22. Your response: I think that this is just a cost cutting exercise. I am very concern that a lot of people who are</p> |

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| | | <p>previously classified as “disable” will suddenly become classified as “non disable”. They would suddenly lose all their DLA benefit and also all their essential supporting services as a result of PIP. Not only this, other government agencies would now treat those people as if they were “normal people”, which would not be fair or reasonable, all this simply because the government wants to implement a cut. This would create a lot of hardship and suffering – disable people may end up in the street, force to do work they are not able to do as they are now “non-disable” all of a sudden, they would have problem with travel or going to work, and may end up stuck at home, they will not get support to cope with daily life or even be able to ensure their personal safety. Being disable is not like unemployment, it doesn't go away. It is with you for life. And being disable is not easy - from getting by day to day to finding an employment that would actually give you a job.</p> <p>*Assessment can be very stressful and traumatic. There is a danger that this could be used as a way to dissuade disable people from reapplying due to all the stress which damages their health (some disease are stressed related and could worsen their condition). Also I found it odd that for some medical condition where the disability does not improve or change much, I cannot see why those cases will still require to undergo frequent reviews.</p> <p>*There is also the question of whether the assessment is going to be fair or not. Is the health professional truly independent as they are employed by PIP? Is he/she qualify to assess all the medical conditions? The situation in Incapacity benefit is an example of problem with assessment being overly harsh and I am very concerned. Unlike unemployment, disability is disability, it doesn't really go away. People will still be disable and will not suddenly become 'normal' again even if all their DLA payment are removed.</p> <p>*I am also concern that assessment (face to face) could be use as a mean to delay payment, with so many claimant it will take a long time before one get assessed and get paid. Also if the assessment is anything like Incapacity benefit, there will probably be a lots appeal cases as a result, which would be yet further delay on payment for those who deserved the payment. All this changes cost a lot of money to implement. I think as the country's budget is already tight and I understand that cost must be cut. Would it be more sensible to just modify current DLA and reassess claimants every now and then? They could also reduce the amount of money on DLA for everyone? It would probably be cheaper and simpler for everyone. This is going to cause a lot of changes (probably for the worst) to a lot of venerable people, as a disable we cannot just get a job or do everything ourselves, it doesn't go away, this new proposal is going to cause a lot of problem and hardship for the disable.</p> |

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| | | This is an experiment fought with a lot of unknown and its main purpose is simply to implement a cut. I fully understand the country's situation, is there something a bit more sensible than this proposal? |
| EM817 | 18/02/2011 | <p>1. : The willingness of others to consider the needs of the disabled, particularly those with physical disabilities not always apparent or where additional needs are not obvious, such as those needs associated with sight loss.</p> <p>*2. : The recently introduced automatic right to higher mobility to those with Severe sight loss</p> <p>*3. : Transport costs, additional clothing, replacing household goods that may become damaged/broken, additional heating, housing costs</p> <p>*4. : Two components in itself is an artificial divide since many costs are inextricably linked. An individual may be capable of caring within their own home for themselves but cannot prepare a meal if they cannot easily carry groceries home, for example because they are using a mobility aid such as white cane, walking frame etc. They could be capable of walking significant distances but be unable to carry things.</p> <p>*5. : Some impairments do automatically incur additional costs, which an individual may not be aware of because they are "part of their normal life". Basing entirely on individual circumstances can lead to those who are better able to articulate needs being able to obtain assistance where others similarly circumstanced do not.</p> <p>*6. : By considering what the cost to society would be if the individual had to be cared for in a fully funded care institution and potentially was unable to earn their own living.</p> <p>*The ability to undertake personal care, associate with others, participate in the work place wherever possible.</p> <p>*7. : By attempting to assess what proportion of a day/week/year the condition prevents an individual from undertaking daily activities that would be normal for someone of their age without disabilities</p> <p>*8. : Aids and adaptations should not be taken into account. While these may enable an individual to do things they could not without them they will never remove all financial barriers to full participation in society.</p> <p>*9. : By not asking questions that apply only to majority of individuals/ assume particular difficulties will be faced. An individual may be capable of dressing but need assistance to ensure clothing matches/ is not stained etc so questions requiring a yes/ no answer do not actually capture the needs of all individuals.</p> <p>*10. : Someone who spends extended periods with the individual such as a care worker, family member or friend.</p> <p>*11. : For some this may show the true extent of disability but for others an interview on one occasion with a health care professional will not show the true extent of the</p> |

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| | | <p>disability.*Where an individual is unwilling or unable to acknowledge their disability it would be inappropriate.</p> <p>*12. : Reviews should only be undertaken where there is a genuine possibility that the condition may improve over time and or is managed by medication and where medical advances could alter prognosis.</p> <p>*13. : By being clearer and having simpler rules about what does affect entitlement.</p> <p>*14. : Not able to comment on this except to say that other advice and information is unlikely to be taken on board during a claim process.</p> <p>*15. : Not in a position to comment on this</p> <p>*16. : These payments should not be considered as a way of enabling individuals to fund aids and adaptations</p> <p>*17. : The effect of having a disabled child on the whole family, especially other siblings.</p> <p>*18. : Unable to comment on this</p> <p>*19. : Unable to comment on this</p> <p>*20. : Assessments for DWP income replacement benefits, social services support and aids/ adaptations should all be combined with those for this payment but receipt of one form of assistance should not automatically entitle or disallow other forms of support.</p> <p>*21. Your response: No comment</p> <p>*22. : Consideration should be given to hidden costs of disability on family life, for example if a parent is unable to drive due to disability this can incur additional costs for the family in paying for other forms of transport not only for the disabled person but for family members such as children if they are not to be excluded from after school activities etc.</p> <p>*No mobility aid has yet been devised that can prevent a totally blind person being struck on the upper body by obstacles as they walk. This not only injures the person but can damage clothing beyond repair. It is this type of additional cost that payments should aim to cover.</p> |
| EM818 | 18/02/2011 | <p>1. From my own personal experience, I have found it difficult to convince some prospective employers that I am capable of holding down a job. Since my disability became more profound (I wear a leg calliper and now need to use a walking cane), I have noticed that, in an interview situation, the panel simply stares at me and doesn't listen to what I have to say. Having unexpectedly lost my previous lecturing job at a local FE College, I was unemployed for a year and found that while prospective employers made ample provision for their users, they were reluctant to employ disabled staff.</p> <p>*2. In my opinion, it should remain a non-means tested benefit.</p> <p>*3. Taxi fares-I can become tired very quickly, and having to stand and wait for a bus is not always a realistic option. I also need to make regular visits to hospital to hand in and collect shoe and/or calliper repairs.</p> |

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| | | <p>*Clothes-wearing a calliper full-time tends to cause damage to trousers etc., so that I need to replace things regularly.</p> <p>*4. As long as these changes are explained clearly and succinctly, I do not think there will be a significant problem.</p> <p>*5. Yes, there are definitely conditions where it is obvious that there will be no improvement, so an automatic entitlement to the benefit is justified. Obviously, appropriate supporting references from medical staff should still be required.</p> <p>*6. Does this mean financial support alone? Existing mobility and care components are still most important.</p> <p>*7. I think reapplication for the benefit, after a specific period of time, is still the best option.</p> <p>*8. Yes, especially mobility aids. If it is felt that the applicant might benefit from other aids, I would expect medical practitioners to provide guidance.</p> <p>*9. Reduce the length of the form by non-duplication of very similar questions, and provide a guide to explain exactly what information is required for each question. I found the length of the questionnaire very daunting.</p> <p>*10. GPs, Consultants, Physiotherapists, Podiatrists etc., but also it is important to take notice of the applicant: he or she knows the problems faced on a daily basis as a result of a specific condition.</p> <p>*11. I'm not convinced that a healthcare professional can make a balanced decision on the basis of a short discussion-this only provides a snapshot of the applicant's life. I think if supporting medical evidence is provided, a face-to-face meeting is unnecessary.</p> <p>*12. Updated reports from medical profession. There should be a standard review, suitable for all conditions.</p> <p>*13. Include an appropriate form when responding to an individual's original claim. It is not always easy to contact DWP staff by telephone because of long waiting time.</p> <p>*14. Clear and concise information should be provided as part of the claiming process.</p> <p>*15. This would be appropriate, if handled sensitively. I think information, personal advice and support could be offered at Health Centres/GP practices.</p> <p>*16. At the moment, my calliper, surgical shoes and arch support are provided by the NHS. I was provided with a walking cane, but preferred to buy a more modern and foldable one to meet my personal lifestyle requirements. An option to use PIP for a one-off cost would be appropriate.</p> <p>*17. Take note of what the child says, not just the parents or guardians.</p> <p>*18. It has been very useful for me, in terms of a free bus pass and a disabled person's railcard. These have allowed to keep on working, especially as my job requires me to travel to different areas of the town on a daily basis.</p> <p>*19. Implications without other benefits and services I would</p> |

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| | | <p>find it very expensive to meet the needs of my job.</p> <p>* 20. I do not have sufficient information about other benefits or services to be able to answer this question.</p> <p>* 21. No comment</p> <p>* 22. I think it would be a good idea to invite a random selection of disabled people to meet up with David Cameron and/or DWP personnel to have an open forum on the proposed changes.</p> |
| EM819 | 18/02/2011 | <p>Please find attached a consultation response form completed as a family carer of a person with a learning disability, on the Autistic spectrum and with a chronic health condition</p> <p>*1. Your response: Lack of funds. The Government squeeze on LAs grant funding without proper direction on how cuts are to be achieved has resulted in our LA carrying out a consultation on changing the criteria for receipt of services from both Critical and Substantial to just Critical only. The impact of such a change people with learning disabilities and Autistic Spectrum conditions as well as on family carers will be huge. The lack of investment in alternative housing options also prevents people with learning disabilities from living independent lives. The way in which most things for people with disabilities are lumped together with things for older people often means examples and questions are loaded in favour of older people. *Also people with learning disabilities have their particular needs for support to participate in society, which the Government fails to deal with.</p> <p>*2. Your response: People with Learning Disabilities who live in residential homes still need the DLA Mobility allowance as they are not being double funded and if they lose this allowance they will lose their house cars and the PEA of £22 per week will not be sufficient to fund taxis to attend essential trips let alone "Leading independent, full and active lives"</p> <p>*3. Your response: Transport for people with learning disabilities. Because they are unable to access public transport – which in rural locations is non-existent all journeys have to be accompanied either in house cars or by taxis.</p> <p>*Other cost due to disabilities are in extra heating, washing clothes, additional clothes, mobile phones for safety reasons, broadband connections costs and many other things associated with health conditions, allergies etc.</p> <p>*4. Your response: Two rates mean that many more people will fall below the level of support needed according to their own specific disability.</p> <p>*5. Your response: I believe there is strong reason to have certain disabilities with minimum levels. This should also include disabilities that are not physical. For example there are people with a Learning Disability, also on the Autistic Spectrum and have a chronic health condition. Such combinations result in needs that are clearly above the level for maximum support, yet the current guidance makes no recommendations for</p> |

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| | | <p>complex cases. None of the tests so far seen take any account of such issues and check only the physical ability such as being able to pick up a £1 coin from the floor.</p> <p>*6. Your response: To use “prioritise” and “live full and active lives” in the same sentence is meaningless. At present people with learning disabilities are not able to live full and active lives so prioritising support means reducing those who get support so the situation will be worse. What is needed are mechanism and benefits that deal with learning disabilities alone away from the worlds of physical disabilities and older people.</p> <p>*7. Your response: People with Learning Disability and Autistic Spectrum conditions are never going to vary so once again by trying to have a one size fits all benefit will put undue strain of the most vulnerable in our society, something the Government should avoid at all costs.</p> <p>*8. Your response: Once again this is only thinking about older people and those with physical disabilities. People who have a learning disability and who are on the Autistic spectrum may not have any aids yet they are still the most vulnerable people in our society and need the maximum support. The one size fits all benefit will fail those people with learning disabilities and on the Autistic spectrum.</p> <p>*9. Your response: For people with a learning disability then Easy Read is the acknowledge way – but I am not aware of the form being in Easy Read format. The process of assessment is about people disabilities yet we are encouraged to talk about peoples abilities. The form could be made very transparent by having tick boxes and scores given with a total score equating to what level of benefit will be awarded i.e. a transparent system. At the moment no one has any idea how it is assessed.</p> <p>*10. Your response: The Family Carer for those people who have learning disabilities is the most knowledgeable person, after the person themselves, yet is never properly consulted or listened to when assessments are being made.</p> <p>*11. Your response: For people with a learning disability and on the Autistic Spectrum this will be nothing short of a disaster. There have been many reported cases where face-to face assessment carried out by “professional” have resulted in all services being taken away from a person with a ;learning disability when it was clear to any sensible person that this was wrong. People on the Autistic spectrum have their own specific needs and routines and such a meeting would be so different for them that it could not be proved that the correct information has been gathered. Also very few healthcare professional understand the needs of people with learning disabilities and on the Autistic spectrum. To get them to attend a few basic training courses does not raise the level of awareness and understanding to sufficiently high level to make judgements. The information in the public domain of the types of question being asked by health professional is so worrying the all the</p> |

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| | | <p>people with learning disabilities and on the Autistic spectrum are rightly very frightened of the proposals and how they are going to be left isolated in our communities without the necessary support. This part needs to be totally rethought.</p> <p>*12. Your response: For people with learning disabilities and on the Autistic Spectrum the conditions are lifelong and cannot be cured. Reviews are therefore unnecessary unless other factors are relevant. Reviews for physically disabled people may also be unnecessary as people do not generally grow another leg if one has been lost.</p> <p>*13. Your response: People with learning disabilities and Autistic spectrum do not have major changes in their needs unless becoming physically disabled as well. By having a one size fits all approach means these groups of people are unnecessarily challenged as to their changing needs. They are the most vulnerable in our society and deserve to be treated with respect and dignity in their benefits as well as living aspects. It is obvious that certain claims are for conditions that can change and therefore reviews can be made for these conditions only. If people blatantly lie then it does not matter what sort of system will be put in place they will always try to defraud the system The only recourse is as at present by investigators looking into the cases and encourage people to lodge concern over possible fraudulent people.</p> <p>*14. Your response: Advice and support should be available in a format appropriate to need. For people with a learning disability then this should be in Easy Read format. Also local specialist help e.g. CAB could have people trained to be specialists on learning disability and Autistic spectrum conditions in order to assist in completing the form correctly.</p> <p>*15. Your response: There will always be people who don't claim even if their need would be at an appropriate level. LA staff who carry out assessments unfortunately do not give good advice about benefits as they concentrate only on those parts that result in payment being made to the LA for services rather than looking at the individual and their total needs.</p> <p>*16. Your response:.. The adaptation system using Disabled Facility grants is not fit for purpose. There are many cases where the person has died before the adaptation has been provided as it can take over 2 years to get one. This whole area needs to be taken away from local councils as they are inefficient. Also different local councils may have very different demographics and these with higher numbers of older people are the worst in getting grants approved.</p> <p>*17. Your response:</p> <p>*18. Your response: Motability Cars and Blue Badges are hugely important for those on the high rate of DLA Mobility and are essential for disabled people to get around. It would good if on sending the award letter that a list of all possible passporting services are listed so that the person in receipt of the benefit is</p> |

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| | | <p>made aware of what can be considered.</p> <p>*19. Your response: People would become isolated in their homes, which in rural location is already a major problem.</p> <p>*20. Your response: As the assessment should include all the persons disabilities and health issues then the sharing of information is a huge concern. This would be particularly so when it comes to everyday living issues such as insurance. It can be foreseen that disabled people could be targeted with much higher premiums etc. The Government has a terrible record of keeping personal data safe so no amount of assurances that all data would be kept safely unfortunately wouldn't reassure anyone. Combining assessment may seem to have things in favour but it can result in losing the key factors of someones disability. The one size fits all criteria when it comes to learning disabilities and Autistic spectrum condition does not work and I believe that there is a good argument that these should be taken out the system and be dealt with separately and appropriately to the needs of these most vulnerable, people.</p> <p>*21. Your response:</p> <p>*22. Your response: This proposal would appear to be about reducing the number of claimants. People with learning disabilities and Autistic spectrum conditions are the most vulnerable groups in our society and therefore it should not be an aim to reduce the number claiming the benefit but making sure there is the proper support to ensure that they claim and get all the benefit which they need in order to lead full and active lives. This is not the case being put forward.</p> |
| EM820 | 18/02/2011 | <p>1. Your response: Please see - ONS publishes Life Opportunities Survey Interim Report - 9 December 2010 *Coverage: Great Britain Theme: People and Places Issued by: Office for National Statistics, Government Buildings, Cardiff Road, Newport NP10 8XG [REDACTED] *Website: www.ons.gov.uk</p> <p>*2. Your response: Do I presume by this questions that it is stating that nothing about DLA should resume the same? If this is the case why are you conducting a 'consultation'?*It must be kept non-means tested and requiring medical evidence from GP and/or other relevant qualified and experienced medical staff.</p> <p>*3. Your response: Dependent on the nature of the disability(s) Loss of income Home services Support Services Transport Diet Heating Clothing Laundry Telephone Chemists' supplies, Aids Adaptations *Equipment Access</p> <p>*4. Your response: This will make it much easier to reduce the numbers of people qualifying for one of the current Care Components which is the object of the exercise.</p> <p>*5. Your response: Yes, I think you will find that some disabilities/diseases are permanent, for life, and quite often</p> |

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| | | <p>progressive.</p> <p>*6. Your response: See response in question 1.</p> <p>*7. Your response: Using appropriate medical evidence from GP and/or other relevant qualified and experienced medical staff.</p> <p>*This should be assessed by appropriately qualified and trained staff.</p> <p>*8. Your response: Emphatically not – too many variations and presumptions which would be discriminatory if applied</p> <p>*9. Your response:</p> <p>*10. Your response: Evidence from your own GP and other medical staff who have contact with you such as Consultants, Specialist Nurses, Physiotherapists, Occupational Health Therapists, Social Workers etc as appropriate</p> <p>*11. Your response: What is your definition of the term 'healthcare professional'? Presuming that the intention of this exercise is to reduce costs then the presumption has to be that the 'healthcare professional' will not be a medical practitioner and a stranger to the claimant. They will not have the individual knowledge or experience to make a decision. Whatever happens, NOT Atos.</p> <p>*Some disabilities make it difficult to communicate what the problems are or to understand what is being asked</p> <p>*12. Your response: What is the point of going to the expense and distress of reviewing life awards for conditions that are permanent or progressive.</p> <p>*13. Your response: The level of fraud for DLA is extremely low. Less than 1%. This is not a problem. One of the biggest problems is people who would qualify, not claiming.</p> <p>*14. Your response: Only if it is provided by people independent from DWP</p> <p>*15. Your response: One of the biggest problems is getting people who would qualify to apply. There should be no element of compulsion but more emphasis on getting the information out to these people and help should it be required.</p> <p>*16. Your response: with great difficulty. Service providers are difficult to identify and slow/reluctant to make provision.</p> <p>*A one-off payment would not take into account progressive needs or replacement requirements</p> <p>*17. Your response: Legislation and parental input – the fact that they are children</p> <p>*18. Your response: avoid duplication, bureaucracy and expense - it is bullying, distressing and depressing to go through assessment again and again dwelling on what you cannot do</p> <p>*19. Your response: an increase in duplication, bureaucracy and expense - it is bullying, distressing and depressing to go through assessment again and again dwelling on what you cannot do</p> <p>*20. Your response: I think this is a matter for consultation in</p> |

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| | | <p>its' own right</p> <p>*21. Your response: these proposals are fear inducing, discriminatory and amateur. People will have to resort to taking out discrimination cases against it if introduced as proposed. Wheelchairs in Whitehall?</p> <p>*22. Your response: What consultation? I have responded because it is currently the only thing open to me. The way it has been presented is that the result is predetermined.</p> <p>*The document is intellectually and academically incoherent. There has been insufficient time allowed and not enough expert research undertaken. Driven by inappropriate political and economic forces. Disaster Lies Ahead.</p> |
| EM821 | 18/02/2011 | <p>1. Your response:2. Your response:3. Your response:</p> <p>*4. Your response: Two rates may be insufficient to reflect the diverse range of disabilities</p> <p>*5. Your response: To consider those in care homes as akin to someone in hospital is to underestimate their needs. Those in hospital are less likely to be able to be taken out because of medical needs. Those in care homes do not necessarily have acute medical problems that a hospital patient would have. Instead their problems relate more to social and living problems. Being taken out is an important part of their well being. If the mobility element is withdrawn it will undermine this and treat many of the more physically disabled like patients in a Victorian psychiatric hospital and lead to institutional behaviour. Being able to go out into society and interact with other people is therefore an important factor in their well being and the mobility element of the DLA is the catalyst which enables this to happen.</p> <p>*If the mobility element is withdrawn from all those in care at the same time it will also undermine Motability and the work it does in making vehicles, in particular ones which require adaptations, available under a lease or HP arrangement. The reason for this is that where a vehicle is provided and the entitlement to the mobility payment ceases the vehicle is returned to Motability. If this happens to a significant number of vehicles in a short period of time there will be a sudden reduction in their cash flow and the value of the vehicles returned will reduce because there is a limited second hand market for vehicles which have been adapted. The Government will have two options. One to financially support Motability. The other is to stagger the change by allowing current agreements and arrangements to continue until the current lease or agreement comes to an end. This would then allow the time for the market to adapt to the change.</p> <p>*6. Your response:7. Your response:8. Your response:9. Your response:</p> <p>*10. Your response:11. Your response:12. Your response:13. Your response:*14. Your response:15. Your response:16. Your response:17. Your response:</p> |

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| | | <p>*18. Your response:19. Your response:20. Your response:21. Your response: *22. Your response:</p> |
| EM822 | 18/02/2011 | <p>1. People with mental health problems still suffer from experiencing stigma, although there has been a lot of work done to try and combat this, especially by mental health charities and the media.</p> <p>*I suffer from a mobility problem, which means I can only cope with walking into town to carry out my domestic activities, on days when I feel relatively well. I am hoping in the future, that this will get better, but apart from having an escort with me, I don't know how this situation could be improved. I would really like to visit Cardiff or go on holiday, but I know I cannot cope with this at the moment.</p> <p>*I believe DLA has given me the best means to have some quality of life. It means that I appear like any other person on the street, as I am able to afford good quality clothing and sensible shoes and go to the hairdresser etc.</p> <p>*Sometimes I feel so ill, I lack motivation to do anything at all, and this make me feel further depressed, which can be a downward spiral, which I struggle very hard to overcome.</p> <p>*2. I am very worried about it changing. When I was first on DLA, I found it very hard to adjust to as I was not in employment, which caused me terrible anxiety. I have got used to this over the years, and although it still causes me problems, at least at some times I have some peace of mind these days and I can occasionally enjoy my life. I have been able to do some voluntary work occasionally and what still keeps me motivated is that I will return to full-time work.</p> <p>*The emphasis on being able to return to work, whilst on DLA is very important to me and I hope this doesn't change.</p> <p>*I think the personal care and mobility component should remain the same. I think there should still be a higher rate, as I still have problems at night time.</p> <p>*3. Disabled people find it especially hard to suffer money problems. If you are fit and well, coping with having limited money can be regarded as a creative challenge.</p> <p>*4. I would need to know more about the two rates for each component to be able to comment on this. At the moment I am on higher rate personal care and lower rate mobility and I am very happy with this assessment. I still have recurring problems at night time, and I hope allowances can be made for this.</p> <p>*5. I wouldn't be able to comment on this, as I know only about experiencing a mental health problem, which I think does not mean an automatic entitlement and is based on the needs and circumstances of the individual applying.</p> <p>*6. I cannot really comment on prioritising support for others least able to live full and active lives as I only know about my own experience. I know, in my own situation, with support that I can live a more full and active life.</p> |

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| | | <p>*I believe, in my own case, the activities that are most essential for everyday life, are: intellectual stimulation, a healthy diet, interaction with family and friends, aims and goals for the future and going outside of the house.</p> <p>*7. I believe DLA has adequately supported in the past with a variable and fluctuating condition. Continuous assessment or health checks, in my situation, could really aggravate my situation. But if this is required under the new system, I will try my best to comply, but I hope that I may improve to gain employment. If I were employed, it may be difficult for me to take time off work to see medical professionals.</p> <p>*8. I would regard a BT Telephone and a Computer on the internet to be aids that support me with my disability.</p> <p>*9. I had no problems with my past claim form. I have designed questionnaires myself, and to me, the form was very well designed.</p> <p>*Information I think should be provided at Jobcentres, in the local library and on the internet.</p> <p>*10. I believe my GP would be the best person to provide supporting evidence. I have the facility offered of a Community Psychiatric Nurse and she also would also provide very good supporting evidence.</p> <p>*11. Over the years, it has become an increasingly harder task for me to see a medical professional. This Christmas, I was suicidal for most of the seasonal period with worry about seeing my consultant psychiatrist. I find no problem with talking to the Samaritans, MIND or MDF over the phone. I would hope, in the future, that medical assessments should be carried out over the phone. When I have a physical health problem, I usually contact NHS Direct first over the phone before contacting my GP.</p> <p>*12. I would hope that reviews are kept to a minimum as is the case with DLA. I have developed a system with my consultant psychiatrist where I write a report, documenting what I think is my current situation, as I find meeting up with my psychiatrist can be intimidating, and writing my out my own diagnosis gives her more information to review my situation.</p> <p>*I think it can be very important to have an advocate available for support if reviews are regarded as necessary.</p> <p>*13. A written report by myself occasionally on-line would suit me. I have found that using my computer everyday has become a very important part of my life.</p> <p>*14. I used to have access to welfare advice through my local MIND group, but with present cutbacks I am do not think this service will be provided in Abergavenny. The help of an advocate at times has been very useful to me.</p> <p>*Information about employment of carers would be useful. In addition, help and guidance with the relationship with a carer would be useful.</p> <p>*I know that the appeals procedure under DLA has been useful</p> |

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| | | <p>to some.</p> <p>*15. At times my local jobcentre has been very helpful with accessing benefits. I believe there is some scope to provide more welfare benefits advice to people.</p> <p>*16. If I were to learn to drive, help with purchasing a car might be useful. A BT telephone for me is essential, as is access to a computer at home. I also have a radio, which helps pass the time away, when I am particularly depressed.</p> <p>*I do not have a television, but for others this might be an important one-off cost to give some kind of personal recreation during the daytime.</p> <p>*17. I do not have sufficient knowledge to comment on this.</p> <p>*18. I have had a lot of support from Adult Continuing Education in Abergavenny, which has contributed considerably to improving the quality of my life. DLA entitles me to Severe Disability Allowance. I have also been supported by Gwent Association of Voluntary Organisations in gaining advocacy training and obtaining voluntary work.</p> <p>*19. I would assume this would mean loss of income to disabled people, which would have a deleterious effect on their physical and mental health.</p> <p>*20. On-line assessment for me would be useful. I have also found it very useful to call the DLA contact centre occasionally. Disability Working Tax Credit might be an option for me for the future, and I would hope that information would be shared so that if I applied it would not be a time-consuming process. I assume that information is shared with incapacity benefit and income support, so that there are not duplicated assessments.</p> <p>*21. I would hope that people with mental health problems would have the appropriate support necessary to making their claim for benefits. I know for me, that it can make me very unwell coping with assessments, but I have always found that the DLA has been very supportive and understanding.</p> <p>*22. I would hope that the results of this consultation would be made public. I am very worried about reports in the Daily Mail, and I would hope that a definitive policy be made public on the DWP website. I hope very much, that if changes were made, that these changes would take effect for a very long time (as did DLA). I am very worried that the benefit may periodically change, which would cause me and others a lot of worry.</p> <p>*I also feel, that in order to help people live independently in their own homes, that some kind of telephone help could be provided to be of assistance with this. I find it very hard to cope with things like utility bills and also repair and maintenance of my home. If some agency were provided to help with this, this would improve my quality of life considerably. Consumer Direct Contact Centre have been very helpful in the past with this. I also believe that internet shopping is also very useful for people suffering with disabilities.</p> |

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| EM823 | 18/02/2011 | <p>1. a) Inaccessible venues b) Lack of disabled car parking in suitable places- c) On occasions where fit people stand eg. stand up buffet, disabled people who are in the minority, and sometimes there is only one sit down and are ignored and isolated</p> <p>*2. a) It should be available to everyone who is in need of it</p> <p>*3. a) Domestic help including ironing b) Help in gardening c) Equipment to help get up stairs</p> <p>*d) Cost of a vehicle which supply's - high seats, automatic transmission</p> <p>*4. a) Should be clear if explained properly.</p> <p>*5. a) Based on needs of the individual</p> <p>*6. a) To be able to get out and about b) To be able to work to earn a living c) To be able to make a cup of tea and cook light meals</p> <p>*7. a) Allow the claimant with professional help to plead his/her case</p> <p>*8. a) No. Any aids and adaptations need to help a disabled person is an 'extra cost' and therefore should be supplied by DLA /PIP:</p> <p>*9. a) Select a cross section of claimants who could work with appropriate professionals to produce more appropriate leaflets.</p> <p>*10. a) Demonstration by the claimant to health care professional*b) Carer</p> <p>*11. a) The claimant should have the option of having an appropriate professional advisor to act on her/his behalf</p> <p>*12. a) Evidence needed to set the frequency of reviews would come from medical history of people having had that impairment coupled with the history of the claimant</p> <p>*13. a) Emphasise the requirement b) Send reminders at regular intervals by post c) Do spot checks</p> <p>*14. a) The criteria for the awards*b) Yes as part of the benefit claiming process</p> <p>*15. Your response:</p> <p>*16. a) PIP should be available to pay for these items</p> <p>*17. a) I am not qualified to say</p> <p>*18. a) Not very helpful.</p> <p>*b) Direct an appropriate agency to inform claimants of these facilities</p> <p>*19. a) Duplication of work*</p> <p>20. a) i am not qualified to say</p> <p>*21. Your response:</p> <p>*22. a) Disabled people have different levels of disabilities, and need different levels of help. Rather than preclude current beneficiaries from receiving any benefit at all. could there be two levels of benefit of PIP so that all disabled people could receive a level of help suitable for his/her disability</p> |
| EM824 | 18/02/2011 | <p>1. As a disabled person following an RTA in [REDACTED] resulting in a spinal cord injury leaving me paralysed from the neck down when I was [REDACTED] yrs old I am very aware of the numerous</p> |

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| | | <p>barriers that I face on a daily basis in trying to maintain my independence. This starts as soon as I wake up each day when I must wait for the arrival of carers to help me dress and get out of bed, have breakfast, drinks and make me comfortable in my power assisted wh/ch.</p> <p>*My life and how it is lived and the goals I have achieved have depended on both the involvement of other people, access to funding and through the introduction of the Disability Discrimination Act which gave me rights as well as responsibilities.</p> <p>*My DLA Mobility Component goes towards a wheelchair accessible vehicle through Motability which I would NEVER have been able to afford if it had not been available to me. My care component goes towards contributions to the provision of my care, and direct payments, my cleaner and my gardener. It does not begin to touch the additional costs of heating, power, clothing, wh/ch maintenance, petrol.</p> <p>*I do not live in a big city therefore there is limited access to public transport and what there is, is not wh/ch accessible. To use taxis to travel by is prohibitively expensive. I live in a village which currently has a library which I use extensively unfortunately this now being closed in April. *To lead an independent, full and active life you need accessible transport, accessible housing, accessible buildings/ built environment, accessible leisure and community facilities. Unfortunately as my library and parks in my local area are all due to be closed I will be in the same situation as the many and have full access to nothing.</p> <p>*2. I have been paralysed since [REDACTED] when I was [REDACTED] yrs old. There is no cure. Things do not get better in fact things start to deteriorate due to the ageing process and yet I understand that I am to be reassessed for DLA. I do not see how this helps ease the funding crisis for a 'health professional' who will no nothing about my condition come to reassess me.</p> <p>*3. Medical costs Although I am exempt from prescription charges I do incur other healthcare associated costs such as vitamin supplements, dressings, pain killers and non-NHS funded treatments such as chiropody, physiotherapy, reflexology, special shoes, cushions and foam wedges.</p> <p>*Care costs I do make a contribution to my Local Authority Care packages to enable me to live independently. I am sure that this will increase as I am aware that my Local Authority is about to reduce its budget considerably.</p> <p>*I also have additional costs as I have an assistance dog and I have to pay for his food, insurance and veterinary care as well as paying a personal assistant to help me go shopping etc....</p> <p>*Domestic costs I have assistance to do the following tasks:</p> <ul style="list-style-type: none"> *• Cleaning• Shopping• additional laundry as a result of incontinence• gardening *• decorating• repairs and maintenance• delivery costs for food, |

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| | | <p>clothing and equipment.</p> <p>*I also paid for all the adaptations to my bungalow. The kitchen had to be completely changed as did the bathroom and all the doors had to be widened and ramps/ slopes made to remove all steps.</p> <p>*Fuel costs As a tetraplegic my household fuel bills are higher than normal as a result of the following:• Electricity: I need to charge my wheelchair every night as well as my overhead electric ceiling hoist</p> <p>* Gas: my heating costs are high as I feel the cold and this winter has been particularly bad. (Those with Spinal Cord Injury are advised to heat their homes one degree higher than non-disabled people as a result of their immobility and the loss of the body's ability to regulate temperature)</p> <p>* I experience higher vehicle fuel costs as I have a large vehicle as it has to be fully wh/ch accessible and I tend to travel only short journeys rather than longer ones</p> <p>* Increased water and electricity bills to cover the additional laundry costs brought about by double incontinence.</p> <p>*Disability related equipment • powered wheelchair• communication aids - a computer + Dragon software• mugs, trays and eating utensils• hoists• shower and bath equipment• pressure cushions and mattresses plus spare covers</p> <p>* cost of hire purchase, repairs, spare parts, service agreements and maintenance• Clothing from disabled clothing companies• Special shoes and socks due to adaema/ swelling of feet and legs</p> <p>*Mobility costs Mobility aid costs• Powered and manual wheelchairs• Maintenance and insurance costs</p> <p>*Vehicle costs:• Extensive adaptations including hand controls and switches to enable me to drive</p> <p>* Lifts / removal of seats etc for those who remain in their chairs during travel</p> <p>* Larger vehicles such as people carriers for people who must remain in their wheelchair during transit</p> <p>* Automatic transition• Maintenance and breakdown charges</p> <p>*4. As I have complex support needs I have always received the higher rate of both components. I therefore do not have any comments to make on this.</p> <p>*5. As I have been paralysed from the neck down since [REDACTED] and have always had entitlement to these benefits I do not understand my I or people with similar complex levels of disability need to be reassessed. My condition has not changed for the better in fact I am now getting worse due to the added complications of the aging process and as a result of many operations that I have undergone in the past. It seems like a waste of time and resources.</p> <p>*6. My DLA is essential to me to be able to live. That is to be able to get up in the morning and go to bed at night. To have a bath and to live in a property that I can keep clean and with a</p> |

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| | | <p>garden that is kept tidy. Without DLA I would have to live in an institution but as there are so few, if any, capable of caring for a person with my level of SCI I have no idea who would fund the additional costs of this.</p> <p>*7. I cannot comment on this as my condition is not variable or fluctuating</p> <p>*8. This question really sets off alarm bells for me. Using a powered wh/ch is not like using a pair of glasses, it does not cure my disability. I still need assistance to get in it or get out of it. I still need help getting dressed and undressed I still need help to go to the toilet.</p> <p>*• My powered wheelchair has limited battery life and cannot go up curbs and does get stuck if the ground is not suitable.</p> <p>*• In the recent snow storms I was not able to get out of the house let alone up the drive powered chair or not. The pavements were very icy and of course were not gritted. I had to go on to the roads when it was possible to go out which was very frightening and very dirty.</p> <p>*• As a wheelchair user I cannot carry heavy or bulky shopping and would not be able to either travel with it or negotiate it onto public transport even if it were available which it isn't..</p> <p>*• Every part of my life requires me to use either a piece of equipment or utilize something that has been adapted. Everything has an additional cost attached to it and life in many ways has improved since the 1960s but it hasn't meant that my disability is any less or my need for DLA gone away.</p> <p>*9. I do not feel able to respond to this question</p> <p>*10. It is important that if assessments are undertaken by a Government appointed healthcare professional, evidence can be supplied from other healthcare specialists particularly my Spinal Cord Injury consultant.</p> <p>*11. I find this question very worrying. Throughout my life as a person with SCI my experience has always been that the only people who understand my condition is myself, an SCI consultant or another SCI person. If I have had to deal with another health care professional, including my GP, they all accept they have not got a clue and rely on me to know what I need from them. Failure to do so has always resulted in complications and a lot of additional medical intervention when this has not happened.</p> <p>*12. Your response: As I have said throughout this consultation my condition is what it is. I am paralysed from the neck down for [REDACTED] years I see no purpose in having lots of reviews, unless there is going to be the availability and access to additional services as my condition deteriorates through the aging process.</p> <p>*13. Spinal Cord Injury is a stable and permanent neurological condition for which there is no cure. Consequently, any changes in my needs will be as a result of further debilitation caused by age and the punishing lifestyle of living</p> |

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| | | <p>independently with a disability. As such it is important that the Government suitably conveys the message that PIPs are an evolving benefit that will offer additional support as a recipient's condition deteriorates.</p> <p>*14. Access to support and information from services provided by and for disabled people and their organisations</p> <p>*15. Your response:</p> <p>*16. As I have been disabled for the majority of my life my equipment and adaptations has been provided through a variety of sources depending on my situation at the time – Social Services, Local Authorities, Access to Work, Charities; grants and personal funding. As I get older and I have now had to give up work as well as the governments new proposals I have no idea what the future will bring and how I will replace, repair or buy new equipment as the need arises. As alterations to a kitchen, buying an electric wheelchair or installing a lift or overhead hoist may cost thousands of pounds and, as no aid or adaptation lasts forever, it will have to be replaced and maintained on a regular basis. As such it is absolutely essential that a disabled person can retain capital for a future major expense. It is vital that those with the highest reliance on equipment and adaptations receive both higher awards and extra supplements to enable them to buy the expensive equipment they need to live a properly independent life. Similarly, it is essential that the capital level of the means test for obtaining free personal care is raised substantially, or that disabled people are able to ring fence a proportion of their savings which will not be considered in such tests, so that they can make the necessary savings without being penalised through their care provision.</p> <p>*17. No comment</p> <p>*18. Having DLA acts as proof of disability for accessing many things such as wheelchair seating at a concert, blue badge, railway card, car tax and council tax. I hope that these reforms are not going to affect this as they are essential and would complicate life so much if taken away.</p> <p>*19. As above 0 I would then have to go and waste a GPs time and pay for a letter to be written, causing more nuisance and cost</p> <p>*20. Your response: I don't feel qualified to respond</p> <p>*21. These proposals are very concerning. There appears to be a complete lack of awareness of what having a significant disability means and what independence means for someone with complex support needs.</p> <p>*Things may have changed for the better in many ways since [REDACTED] but IU still have my impairment; I have independence because of receiving DLA and related services without them I am helpless and this needs taking in to account when developing policy.</p> <p>*22. Your response:</p> |

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| EM825 | 18/02/2011 | <p>1. Your response:</p> <p>*2. People receiving DLA whilst living in hospitals or residential care homes should continue to receive the benefit. Removing the payment, whilst it may be covered by local authority funds, removes a degree of independence from these people. Local authority payments may not allow people in care homes to specify what they wish to spend the benefit on and also may not be able to cover the specific travel requirements which some people have. In addition to this, I am concern that local authorities may struggle to meet these commitments given their current economic challenges.</p> <p>*3. Your response: 4. Your response: 5. Your response: 6. Your response:</p> <p>*7. I would urge the DWP to consider carefully its assessment of claimants with fluctuating conditions. Clearly multiple assessments would be costly and stressful for individuals and may still not coincide with a claimant's relapse. Assessments of claimants in with fluctuating conditions can only be done by taking into account input from both the person with the condition, perhaps close family members or carers as well as from the person's GP or other qualified medical practitioners which the person is in regular contact with.</p> <p>*Furthermore, all assessment should take into account, not just fluctuating symptoms but also hidden symptoms such as fatigue that might can be hugely debilitating but also difficult to objectively assess.</p> <p>*8. Your response:9. Your response:10. Your response:11. Your response:</p> <p>*12. Continual reassessment of people with deteriorating conditions would be humiliating, insensitive and cause unnecessary distress, Furthermore unnecessary costs would also be incurred. Continued reassessment of patients with conditions that will not improve or will deteriorate should not be part of these reforms.</p> <p>*Due consideration should be given in reviews to disabled people with fluctuating conditions such as MS. A person may appear well on the assessment day but have severed reduced mobility the following day. Hidden symptoms such as fatigue also need to be considered. Advice from personal GPs should be heavily relied upon for assessing such cases.</p> <p>*13. Your response: 14. Your response: 15. Your response: 16. Your response:</p> <p>*17. Your response: 18. Your response: 19. Your response: 20. Your response:</p> <p>*21. Your response:</p> <p>*22. I believe these reforms should attempt to more accurately match the payments of DLA to the impact of the impairment disable people have. I believe overpayments due to improved conditions and any potential fraud should be corrected. However I believe assessments should be carried out fairly,</p> |

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| | | and accurately by medical professionals, in conjunction with evidence from the claimants' families, carers, employers, GPs and of course from the claimants themselves. The assessments should in no way be driven by targets such as reducing the expenditure or caseloads by 20%. |
| EM826 | 18/02/2011 | <p>This is what you say in your "consultation"-</p> <ul style="list-style-type: none"> * The majority of people receiving DLA are aged 16 to 64. This reflects the DLA rules whereby all recipients have to be aged under 65 on application, but may retain an award of DLA beyond 65 provided conditions of entitlement continue to be met. It is proposed that these arrangements will continue under the new benefit. This is justified as we recognise that many people who have become disabled earlier in life have had fewer opportunities to work or save for later life. * Now in the bill, you say that PIP will cease at (age 65). You have misled everyone who has responded to your consultation as they will have assumed that the arrangements would continue under PIP. |
| EM827 | 18/02/2011 | <p>Disability Living Allowance-Consultation Questions - My answers.</p> <ul style="list-style-type: none"> * 1. Not enough awareness that disabled people can contribute to and have a full working life. * 2. Yes: It should be assessed by medically qualified staff. Assessments should continue to be made based on the periods when a person is least able to cope. The person getting the grant should be able to decide his/her own spending priorities. * 3. Different disabilities create different problems; costs and needs vary. Extra expense could be on: house cleaning, house maintenance, gardening. I need disabled adaptations for my car. A small grant might be given by "Mobility" if you get a new car through them but it does not cover the full cost. No grant is available if you fit *adaptions to your own car. The last adoptions I needed cost £ 2200 this being the second set needed as my conditioned worsened. I am required to have an assessment when renewing my driving license or if I need nrw adaptations if my condition worsens. * 4. The current explanations seem satisfactory - does there being two or more levels of award make any difference? Two rates might not provide enough scope for the giving of an award if one level is low and the other high - disabilities vary considerably so a middle level so a scale that reflects this is important. *5. Yes: some disabilities should have an automatic response to entitlement. What is meant by "needs and circumstances"? There should be no means testing nor should it be adjusted if a claimant is helped by *family or friends. A mobility allowance should not be remove- the cost of equipping a car can be considerable; simply because |

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| | | <p>a person might be in a care home does not mean that some other person might wish to</p> <ul style="list-style-type: none"> *take them out over and above the care home's transport services. *6. By making a grant you are acknowledging a need and this needs to be quickly implemented. A disabled persons activities are the same as a normal person; each individual will have different needs. You cannot *prioritise one need over another. *7. The award should be based on those periods when a person is most disabled. *8. No it should not take into account aids or adaptions used. *9. The current process seems to be clear. *10. A fully qualified medical opinion should be enough. *11. An individual's ability to clearly outline their problems will vary;you need to ensure that a less articulate person is not disadvantaged. *12. Medical evidence should be used- a simple yes or no as to whether a condition has improved or not should be enough. This should be provided by a qualified person e.g. the person's own G.P. *13. It is already stated that failure to inform the department of changes may result in loss of benefit. *14. Ensure disabled people are informed of their rights and keep the method of claiming simple i.e. a doctors report should suffice. *15. If a person has a disability then their doctor should know of it - require a surgery to submit a claim on their behalf. *16. A- By spending money B- Yes there should be the option to use Personal Independence Payment to meet a one-off cost. *17. This is not an area I have knowledge of. *18. Apart from being given a grant to improve the heating of my home I *have little knowledge about other services. *19. They would, presumably, miss out on services available to them. *20. I cannot advise on this. *21. I cannot comment on this. *22. No |
| EM828 | 18/02/2011 | <p>Please find attached my response to the consultation on DLA reform. I am responding as an individual and as a recipient of DLA. All expressed thoughts and ideas are my own. And you have my permission to reproduce any part of this document or the full document. Regards:</p> <ul style="list-style-type: none"> *1. : As a totally blind person I have to approach daily situations differently to my sighted peers, weather this be using a taxi as opposed to a bus for a rout to a less familiar place or using aids in the kitchen to help me cook and take care of myself. Ware I am able to be independent I will always strive to be. This |

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| | | <p>has impacts on my finances. E.G taxis are more expensive than buses, talking microwave ovens and other kitchen aids can also be rather costly. Not to mention computer hard ware and software such as screen reading software to help me access the internet to use online banking and order grocery shopping to hardware such as scanners to enable me to read post and other printed information. To maintain an up to date licensed version of JAWS the screen reader I use costs in the area of £80 per year, not to mention the initial out lay of around £800 for the software alone. Scanners and software to use those can also be expensive. Some assistive technology is prohibitively expensive, E.G sat alight navigation. They are available for blind people to aide mobility on less familiar ground but the cheapest at the lower and not so useful end of the market is around £260. Ones that are more likely to give a visually impaired person good and useful information are around the £900 mark. The hardest barriers to deal with are the ones that follow the social model of disability. The attitudes of people, companies or organisations and some local and national government departments that one may have to deal with on a daily basis. Problems include but are in no way limited to: Not providing information in accessible formats such as brail or email. Not accepting correspondence in an accessible format such as email. Not accepting serten transport needs such as provision of a taxi.</p> <p>*2. : Keeping the idea of DLA being paid to the disabled person to use as they feel best suits there needs would be the best way to keep the benefit. My own experiences with disabled students allowance DSA was that I ended up with allot of things I didn't need particularly, no training on equipment I didn't know how to use and I was left in a situation that meant I had to fight for things I had not been granted to me under the assessment process that I really did need to enable me to undertake my degree course. If the government was going to end up pushing aides on to disabled people that they thought were required this would be a very good money wasting exercise in my view, and there for render this consultation and reform process redundant.</p> <p>*3. : The extra costs we face are those of constant use of public transport networks particularly train travel. Ever rising fairs and if a disable person has the disabled person's rail card there is only a reduction of a third of the total price. In a lot of cases for socializing and shopping it can be necessary to use a taxi, this also gets very expensive.</p> <p>*Aside from travel cost the costs as I have mentioned above in relation to technology that can assist with daily tasks and also human help ware applicable. My rates of benefit don't really cover these costs as it stands however, they do provide a sort of subsidy witch does bring some of these technologies and assistance with in a closer reach.</p> |

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| | | <p>*However, that said it does require a huge level of watchfulness on how much is spent to keep the house hold heated powered and all other bills paid as well as myself fed and clothed.</p> <p>*Ad in that once technology is purchased and in place maintenance costs or costs of repairs can also be expensive.</p> <p>*4. : A three tear system I feel would be more useful as there are many levels of ability with in disability maybe a base rate and set of premiums or extra amounts could be bort in but if you wanted to keep it as easy and simple to understand and easy for decision makers to applied appropriate bandings then a three tear system as the current DLA system is would be more sensible.</p> <p>*Two rates could mean as I have said that people end up in a situation where they have a disability clearly but they don't feel with in the lower tear. Yes a three tear system may broaden the amount of people who can make a claim but it's important to provide support to all disabled people to a level that provides them with the ability to help them as much as possible. Consistency would be very important however many tears the system ends up with.</p> <p>*5. : If there is clearly a disability present then benefit should be awarded. If circumstances aren't going to change such as in the case of a terminal patient as you have sighted, then the award should be given.</p> <p>*If there is any kind of doubt as to the length of the situation then the person should be subject to more frequent review. When I lost my sight, there was no way I was ever going to regain what sight I had lost, if I would have had to have waited for up to 6months be for making any clamed things would have been very difficult. This time at the beginning of a severe disability can be one of the most stressful and expensive times for a person to get to grips with. Support must be provided there for. Six months is a very long time to wait when you need equipment or human support.</p> <p>*6. Your response: Being able to live independently to the best of my ability is very important to me. Weather I choose to use technology in the ways I have stated above or weather I want to use human assistance should be up to me to decide. Being able to take care of my own house hold with dignity and privacy awarded to other citizens is very important to me. Being able to get out to meet people attend functions or events that are not spersiphicaly for disabled people ware transport is provided is very important to. Feeling trapped within your own home is not a nice feeling. This could then lead to other problems. It would be nice to not have to worry too much if I go to meat a friend weather then I can afford to eat every day the following week. Also it would be useful for government departments such as the DWP to be able to take information from claimants over the phone as it is not always possible to provide information in written form threw a letter. Email or phone access would be a</p> |

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| | | <p>fantastic step forward. Computers have opened up the communications world for many people with many different disabilities. I am able to organize my shopping deliveries bank transfers over the phone why not adjustments to benefits.</p> <p>*7. : For many people I would think there circumstances don't infact change very often. Mine certainly have been the same now for a number of years. Ware clearly there is not going to be any change an indefinite award should be given with the proviso that the claimant informs DWP of any change that may come up. I do accept that some instances such as strokes may be needed to be treated differently, for example more frequent review. But I think that reviewing every one systematically would yes create much needed jobs possibly, but waste more money, money that the government wants to save.</p> <p>*8. : It's very important to remember that aides are just that, aides. There to help, often funded by the disable person them self. So it's important to point out to the person what they maybe in titled to get, but not to reduce the amount of money they are awarded because they have aides that make them independent.</p> <p>*One off payments or grants for very expensive pieces of equipment might be beneficial.</p> <p>*9. : Make shore that government officers have a good working knowledge of the claim form and the system imposed, it's important to provide good training far to often have I heard about people who ask for help filling in a form and end up educating the person meant to be assisting them. Give clear guide lines and pointers on the form to aid the persons understanding of the questions. Help charitable organizations to understand and then pass on information to their members or clients to assist with claims.</p> <p>*10. : The claimant needs to be able to state their problems and medical conditions with supporting evidence from eater a GP or there specialist consultant. We have a wonderful NHS so let's use it. It seems stupid to pay out for independent companies to undertake assessments of people's disabilities when mostly they have their own specialist who is familiar with their situation and the effect that that has on their life.</p> <p>*11. : The difficulties of a face to face meeting with a health care professional maybe that they are not completely familiar with the disability in question. Even an eye specialist may not be totally familiar with the problems encountered by a blind person on a day by day basis, so, if face to face meetings need to take place, the health care professional should listen to what is being said by the claimant. Not just form an idea all of their own and rite that on the form. Certain situations it might be advisable to use rehabilitation workers or occupational therapists to assist.</p> <p>*That said as I have stated the claimants specialist should be able to provide a grate deal of information and these face to</p> |

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| | | <p>face visits may not be required.</p> <p>*This would intern save allot of stress and anxiety on the part of the claimant.</p> <p>*I don't think there are circumstances that could be deemed as inappropriate as long as care is taken to listen to the claimant and as I said above understand what the problems are and not rush to form ideas with little back ground knowledge behind them.</p> <p>*12. Your response: As I have stated above, if it's very clear that someone with no vision for example is never going to regain their sight, then I feel an indefinite award should be made. In situations where there is a lightly hood of changes being frequent such as a stroke victim then more frequent updates will be required based on their recovery progress.</p> <p>*The DWP needs to be more proactive though I think in asking for updated information and providing examples of changes deemed important to the benefit in question.</p> <p>*It's important to remember that some changes that may seem very significant to an assessor may not seem significant to someone living with the disability every day.</p> <p>*The evidence provided about the person's disability could be used to set the frequency of reviews if there condition is stable and there has been no change in a long time and there is no change that can be predicted then less frequent updates should be the way to go.</p> <p>*13. Your response: Make contact with the department easier. Allow claimants to call and advise the department about changes, enable communications by email as well as post. A lot of disabled people find it hard to get out posting letters if they can write them. Again computers could make this process a lot easier.</p> <p>*As I have said provide examples of changes that would be important to pass on information about to the claimant.</p> <p>*14. Your response: A spersiphic adviser to assist with the form filling and a well maintained central portal for information about various disabilities and the claiming process that could be maintained by the DWP but that charities could have access to to help clients and members fill in claim forms.</p> <p>*15. Your response: It's important not to back applicants or claimants down an alleyway to a particular situation where they feel pressured to ask for or seek spersiphic advice or items as part of the PIP or DLA. They should be able to make their own life style choices.</p> <p>*16. Your response: Currently from my own point of view I fund aids with the money I get from DLA and other benefits.</p> <p>*The option should be there to help with one off cost items such as a GPS unit for a blind person. This could to a guide dog user provide a fantastic wealth of other information that by the nature the way guiding by a dog works they might otherwise miss out on. For example counting door ways to shops or entrances to</p> |

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| | | <p>houses. With a Cain the line of a building can be followed. With a dog, the dog take the rout that is widest and best for guiding so door ways can be missed.</p> <p>*One off payments should be an option also for things like power chairs and any particularly expensive aid or if a need arises ware by the claimant needs to replace a piece of equipment they rely on and doesn't have the funds to do so immediately.</p> <p>*17. Your response: Changes should be monitored more closely with children and more support given to parents with filling in the application forms, as parents with disabled children often struggle with understanding the forms as they are also getting used to the facts of the disability there child has.</p> <p>*18. Your response: Receiving DLA or PIP should enable pass porting features such as the current assistance with digital switch over.</p> <p>*It could include also ware appropriate the Eshoo of a blue badge parking permit, assistance with heating over particularly cold spells, assistance with any future energy efficiency legislation, and entitlement to subsidised or free travel on public transport ware appropriate.</p> <p>*19. Your response: Reseat of DLA is used in some cases to give automatic entitlement to certain support or extra benefits or schemes. This should continue as the more departments communicate the easier time the claimant has the less stress they are under the better quality of life they will have.</p> <p>*20. Your response: With consent from the claimant all information that can be shared should be shared. This will enable local councils to provide information about the claimant to departments such as housing and council tax, refuse collection (so they are able to provide assisted collection) and also provide in my own case things like correspondence in my preferred format weather that is brail audio or email. This would intern help departments to keep in touch with claimants and make departments more approachable.</p> <p>*21. Your response: As the benefit will be payable to anyone with a disability deemed bad enough to warrant it, I don't see that there are really any equality issues. If the claimant is disabled then there ethnicity isn't of paramount importance.</p> <p>*22. Your response: I don't agree with allot of the claims made about DLA. I still do believe it is fit for purpose.</p> <p>*There has been talk of it stopping people wanting to go out and get jobs; actually I think it's quite the opposite. I know people who have been able to go and get a job purely because DLA has been there to help support there extra requirements as a disable person.</p> <p>*Education has been more the problem over the benefit.</p> <p>*If people knew about it, and what its purpose is and had a better understanding of it I think it would be maintainable.</p> <p>*The increase in claimants of DLA is down to better public</p> |

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| | | <p>awareness. And a benefit that has a frord rate of less than one percent then can't need the extent of reform your proposal for PIP lays out.</p> <p>*My concern with PIP is that the people on the bottom end of the scale will on introduction of PIP fall off it, and suffer from doing so.</p> <p>*The government needs to look at this with extreme caution.</p> <p>*I for one feel a little victimised with all the cuts, and I can't help wondering if disabled people are just an easy target, but I don't want to sound too much like a news paper.</p> <p>*Whatever happens with PIP if indeed it goes ahead it must stay as a non means tested benefit.</p> |
| EM829 | 18/02/2011 | <p>This opportunity to respond is welcomed and the majority of my comments have been made in the section following question 22</p> <p>*1. Your response:2. Your response:3. Your response:4. Your response:</p> <p>*5. Your response: Some health conditions should trigger automatic entitlement. However, It is acknowledged that some conditions present fewer obvious disabilities for are more disabling and vice versa. Physicians with appropriate specialisms and continued CFD should be employed on a case by case basis.</p> <p>*6. Your response: It is recommended that this this question is addressed to the individual. For the majority of people this would be the support to participate in activities which others take for granted but even this assumptions should not be taken for granted.</p> <p>*7. Your response: Periodic review as clinical experience indicates</p> <p>*8. Your response:</p> <p>*9. Your response: See below</p> <p>*10. Your response: See below</p> <p>*11. Your response: It is recommended that the generic term "healthcare professional" be replaced by specifically qualified physician with appropriate clinical experience, despite the additional cost.</p> <p>*12. Your response:13. Your response:14. Your response:15. Your response:</p> <p>*16. Your response:</p> <p>*It is recommended that individuals can make their own choice and have greater knowledge of their own condition and how it can best be supported.</p> <p>*17. Your response:18. Your response:19. Your response:20. Your response:</p> <p>*21. Your response:</p> <p>*22. Your response: I am submitting this response to the proposals on Disability Living Allowance (DLA) Reform as someone working in facilitating integrated NHS and social services joint working, information dissemination to service users, statutory bodies and voluntary sector organisations.</p> |

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| | | <p>Previously I worked in the fields of learning disability, mental health and autism. I have worked with people whilst they made claims for DLA and supported one client through an appeal hearing.</p> <p>*I am also responding as the mother of a son in receipt of DLA with Asperger's Syndrome, an autistic spectrum disability (ASD).</p> <p>*DLA awards can allowed people with disabilities to support themselves in ways, which can sometimes, address some of the disadvantage they live with through their long-term conditions - which I agree should be a criteria for awards. The Personal Independent Payment (PIP), as anticipated in the document, is not a convincing vehicle to provide the flexibility, which despite its limitations, DLA has the potential to provide. I believe the following points to be of great importance;</p> <ul style="list-style-type: none"> *• DLA has been the only benefit of this type which fully recognises the applicant as an independent person c.f. incapacity benefit which for example, will not be received by individuals whose partner/spouse is earning over a certain amount. *• Long-term conditions and limiting illness have far greater prevalence in areas of social deprivation and consequently would disproportionately hit less economically advantaged individuals and communities. Evidence can be easily found in numerous source e.g. National Public Health statistics. *• DLA has been to only benefit of this kind which has the potential to provide additional income to enable the purchase of support, services or experiences which enable people with conditions, which are not necessarily physical, which can add to well-being and avoidance of more costly interventions including secondary or primary care treatment. I refer to mental health problems, learning disability and ASD. <p>*1.1 DLA is the most constructive financial allowance and a means of recognising the disadvantage of disability which an individual experiences, whilst also acknowledging their abilities. It is agree that this principle need to be perpetuates if we are not to gain substantial numbers of extra benefit claimants fixed on perceptions of disability.</p> <p>*1.14 With the substantial references throughout this document the consultation makes it clear that governmental plans deplore the cost of this benefit. It is my suggestion that vastly improved provision in the assessment of individuals seeking this benefit could save significant amounts. However, of greater significance is the lack of recognition that unemployment or a desire to avoid legitimate employment is inextricably linked to the life-long or long-term disabling results of disease, physical damage or abnormality, or pathological genetic variance.</p> <p>*1.1 It is my perception that there is an underlying problem of applicant's understanding of benefits in general and DLA in particular. This however is perpetuated, not by some failings</p> |

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| | | <p>solely on their part, but by assessors as well</p> <ul style="list-style-type: none"> *• the lack of clarity and guidance to inform claimants on the intent of the process *• assessment process indicate a lack of trust by assessors in specialist practitioner's diagnosis *• intimidation perceived by claimants by judgmental attitudes are comments which are commonly reported *• assessments are carried out by assessors without sufficient condition specific clinical experience. I am particularly perturbed by the lack of specialism displayed in assessing ASD and mental health conditions *• assessors make judgments without taking into account the claimants legitimate choice to choose a course of treatment which suits them e.g. taking a particular medication or indeed any medication. This this distinct from instances where the condition itself influences the individual's decision making processes *• the current applications form, gives no recognition of disability which is caused either by mental health problems or ASD. <p>*It is acknowledged that this document recognizes that the assessment process needs substantial improvement. It should be remembered that patients undergoing examination and interrogation about their condition from medical practitioners normally feel supported by advice and treatment at its conclusion. An assessment process which recognizes the distress and deterioration that can result from the emotional stress this process causes at present, would be welcomed. And I would further recommend that changes in the process are fully explained to the public with emphasis placed on the recognition that ability does not exclude receipt of the new benefit, rather that receipt of additional funds is provided to expand opportunities. *Evidence that contributes to the assessment process should be admissible from carers and other significant people in the individual's life. Many people are unable or unwilling to accurately or constructively describe their condition and they can also fail the appreciate its impact on their lives compared with a "normal" life experience. It should also be acknowledge that many "health care professionals" bring their own unprofessional opinions when they have little contact with their client e.g. In many instances the care or outreach worker can be more informative than a CPN. Also many patients do not inform their GPs adequately of their condition, their response or compliance with medication etc.</p> <p>*It is inevitable that the numbers of people with limiting conditions will increase through better diagnosis, which despite improved medication and clinical interventions, will be offset, not just by people living-longer but also younger people not dying as often. As a nation we have to bite the bullet on this. It is well known, and certainly within my professional experience,</p> |

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| | | <p>that people with physical ill health, learning disability and ASD have a greater frequency of poor mental health. Benefits should not just aim to address independent living, indeed living in isolation is, for the majority, positively harmful and produces deteriorating conditions. Money is a requirement for joining-in with society and accessing activities which keep keep people in-touch, engaged and contributing.</p> <p>*It should be acknowledged that the DLA assessment are currently negative experiences for applicants. Whatever awards are made the opportunity should be taken to give advise regarding development of ability, perhaps in conjunction with occupational therapists.</p> <p>*Improved effective sharing of information should be developed, the change would benefit all areas of treatment and care. Initiatives such as Unified Assessment have been significant and expensive failures. Communication - input, information and guidance needs to reach all parties involved with the interest of patients.</p> <p>*It should be noted that in the whole of this consultation document there is one reference to "mental" in the context of severe mentally impaired (Annex 1) and no reference at all the autistic conditions. Neither is learning disability referred to, but there is a reference to learning difficulty, which professionals will understand, is a significantly less disabling condition.</p> <p>*The document's definition of the "medical model of disability" is selective and in this form would generally be accepted by those who are also committed to the "social model". In consideration of reform of DLA, the Government should acknowledge that society has not eliminated discrimination which appears to be in better health than many DLA applicants.</p> <p>*My son gained a university place but after qualifying has had one long-term placement through a disability charity, since which he has been placed twice by agencies. These placements lasted no longer than six months. Despite hundred of permanent job applications he has had two interviews, one of which, with a government department was successful but withdrawn 11 months later because of an "embargo on recruitment". He was never given a starting date. I had informal advice from ACAS not to disclose his disability but he knows that his Asperger's Syndrome, although requiring no material adaptations, will be recognized from his unconventional behaviour.</p> <p>*I do not believe his is avoiding employment; he has a life-long disabling condition and is therefore disadvantaged, vulnerable, and at this time and probably forever 'untreatable'. It is my belief that no assessment can measure the degree of disadvantage his has to contend with daily, or payment which can prevent the depression and despair he experiences but I have been grateful that DLA was there enabled me to buy the educational support and social experience that made just</p> |

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| | | <p>enough difference to get him into university and believe, at least until after he qualified, that he could be a contributing and valued member of society.</p> <p>*To summarize, perhaps a replacement for DLA should seek to introduce greater equality of living experience. And no replacement should impinge on individual's choice.</p> |
| EM830 | 18/02/2011 | <p>1. Your response: isolating them from the rest of society, preventing access to work and day to day activities</p> <p>*2. Your response: There should be "for life" awards</p> <p>*3. Your response: transport costs and costs relating to the purchase of services to allow disabled people to remain independent such as care services.</p> <p>*4. Your response:</p> <p>*5. Your response: all terminal illness or progressive illness should be considered as not being able to be improved. It is foolish to reassess people whose condition is not going to improve as this is only going to cause additional distress.</p> <p>*6. Your response: there should be recognition that just because someone is disabled does not mean that they do not contribute to society. Allowing someone the finance to allow them to work (mobility component) or go shopping or to even social events with support are just as valuable as eating and going to the toilet.</p> <p>*7. Your response: The existing assessment forces people to focus on the negative it would be most helpful to have sections dealing with both how are you on best and worst days.</p> <p>*8. Your response: No, aids and adaptations can break, why should a person's disability be judged in relation to how their wheelchair functions?</p> <p>*9. Your response: Make it a clear process, minimise the paperwork and save money by doing without additional medicals when after all isn't a GP meant to know their own patients needs the best.</p> <p>*10. Your response: A person's GP, carer or other professional involved with them</p> <p>*11. Your response: Ensure the individual has the correct support before any interviews particularly if the individual has a learning disability or other significant problem</p> <p>*12. Your response: there perhaps could be a review every three years but instead of having the individual fill in forms perhaps there could be more contact with the person's GP who could provide this information if there is any scope for improvement in a person's condition.</p> <p>*13. Your response: I have concerns about this as it sounds as if people not reporting changes would be penalised in some way, remember we are talking about some of the most vulnerable people in our society who struggle with daily living as it is, to expect them to remember on top of this to advise the DWP of changes and if they forget to punish them is unfair. People who are on this benefit can have deficits in memory, cognitive</p> |

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| | | <p>impairments or be just too exhausted. *14. Your response: there does need to be clearer understanding of what areas of support the benefit will cover</p> <p>*15. Your response: I'm not quite sure what is meant by this.</p> <p>*16. Your response: Many disabled people I know already use their DLA to fund aids and adaptations, mobility scooters for example, I'm not sure a one off cost option would be helpful as many of the companies have already adapted to this means of providing assistance.</p> <p>*17. Your response: children are fragile and should not be subjected to intense medical examinations, again trust the opinions of those who know the children well rather than assume that parents are trying to lie, use GP's and other professionals and trust their opinion.</p> <p>*18. Your response: Increasingly with service cuts people are having to use their DLA to fund basic care needs, a minority of some disabled people need to be reminded that the benefit is for this purpose.</p> <p>*19. Your response: people would not be able to access basic services and supports</p> <p>*20. Your response:21. Your response:</p> <p>*22. Your response: I am concerned about the whole proposed change to DLA, as the benefit that has the least suspicion of fraud it feels that the proposals target the most vulnerable groups in society unfairly. To force severely disabled and vulnerable people to undergo reviews in the hope of saving a few pennies is disgusting. I have heard of several people now who have become so fearful of the possibility of them losing their benefit that they have planned their suicide. For a so called caring society this is unacceptable. There has also been a "trial by media" with people claiming disability benefits being called scroungers and benefit cheats and not one government voice saying otherwise</p> |
| EM831 | 17/02/2011 | <p>Dear Sir / Madam, I've attempted to email my response to the DLA consultation, but have received a notice saying delivery of the email has failed. Below is the body of the email sent:</p> <p>*1. There isn't enough paper in the world to fully answer this question! From a personal perspective, I have faced physical barriers – poor building design, noisy environments, bad lighting all prevent me doing things on a regular basis. For example I avoid eating in restaurants because often noise levels prevent me from hearing and understanding speech – even sitting across a small table from my partner, whose speech I am very familiar with, I struggle to converse with him in restaurants. I face attitudinal barriers as someone with hidden impairments. I don't look like I need a seat on public transport, I don't look like I need people to consider my communication support needs. Things from within the body can also act as barriers. It is very hard to engage with society when one lives with chronic pain or fatigue. These things are</p> |

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| | | <p>hard to mitigate for. There is no adjustment that can be made in my workplace for days when my brain simply won't unfog, and looking at a screen makes me feel dizzy and sick.</p> <p>*I would add that a 9 week consultation period, that occurred with Christmas and New Year in the middle of it is particularly unfair, particularly given the people that most need to engage with the consultation are those that may need extra time and support to analyse and respond to such an important and complex matter.</p> <p>*2. Yes. Three rates of DLA Care component recognises differing degrees of need with more subtlety than two rates would.</p> <p>*3. I can't speak for all disabled people. We have massively variant needs, and each of us finds our own ways to work around difficulties, and implement different coping strategies. I can't quantify exactly what costs are impairment related, and what costs I would incur if I wasn't disabled. I have tried to work out a few costs though, as illustration.</p> <p>*I use crutches to extend the distance I can walk. This is a fantastic tool that enables me to enjoy life outside my home. However, I still have to buy replacement ferrules every few months (shock absorbing ferrules that stop my wrists and shoulders becoming damaged cost about £25 per pair). I estimate this cost at £50 a year. These are not provided by the NHS, this is paid for out of my DLA. I wear padded gloves to further protect the nerves and bones in my hands, the padding becomes worn and flattened through use and loses its efficacy. Cost £12 a year. A small cost that I think is an interesting one is if I decide to get a cup of coffee whilst I'm out, I have to sit down to drink that coffee. I can't walk and carry coffee at the same time as both my hands are using my crutches. I need to sit at a table or it's reasonably likely I'll drop or knock the coffee over. This means I need to drink in, which costs me more than taking away - around 40p extra, which if I'm having coffee out three times a week, every week, equals £62.40 a year.</p> <p>*Stopping off in a café also means I can rest. Sometimes this is a necessity rather than a nicety. Sitting in a calm corner means I can recover if I am in a state of sensory overload. I wear trousers out very quickly, and a result of my Dyspraxia is that I struggle to repair clothes neatly enough for them still to be presentable. This means I end up buying new trousers a few times a year. I estimate I spend £40 more per year than I would were I not Dyspraxic.</p> <p>*I have bought a good quality can opener I find it easy to use. £12.00 I wear sturdy, supportive, lightweight walking shoes. I get through a pair at least every year. £60 per year. I use a graphics tablet rather than a mouse. £100</p> <p>*I eat good quality, fresh food to stay healthy. I have limited energy levels, and become extremely tired very easily if I do not eat well. I can't work full time. My job pays me enough to live</p> |

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| | | <p>on, however being limited to three days work a week means my impairment is costing me in the region of £6000 a year in lost earnings! DLA means I can afford to work part time, and still have my basic needs met.</p> <p>*4. I do not believe two levels will be nuanced enough to accurately meet different people's level of need. I am seriously concerned that people that *just* miss the criteria for higher rate support will not be supported adequately through lower rate support. Currently, middle rate care DLA means this is not such a problem.</p> <p>*5. Yes, I believe there are some conditions that without doubt increase people's cost of living so financial support should be automatically provided to those people.</p> <p>*I would include conditions such as Motor Neurone Disease, Multiple Sclerosis, Muscular Dystrophy in this list.</p> <p>*6. Essential activities are surely those that sustain life – feeding, toileting, sleeping, bathing, exercising. People should have the choice over how those needs are met, and how best they can be supported. What one person considers a full and active life may be considered idle by another person, and too much to cope with by a third person!</p> <p>*7. Simply accept that many conditions fluctuate. The human body is a wonderful complex thing, it isn't a machine and doesn't behave identically constantly. And often, when the appropriate support is put in place, people's conditions are much improved – which is the point of the support! The best thing you could do would be to listen to the people that are being assessed.</p> <p>*8. No, assessment shouldn't take aids and adaptations into account because those aids and adaptations aren't always available. For example, I know a man who has his flat set up with rails around his toilet, perching stool in his kitchen, front room arranged so everything is in easy reach, cupboards well organised and everything positioned low down, telephone that he can hear well. In his flat, he isn't disabled by his environment, and he needs no obvious support. As soon as he goes outdoors he encounters physical barriers, and needs to ask for help, for example, taking things off supermarket shelves, sitting at bus stops to rest. If he goes to his voluntary job he has to ask for help preparing his lunch because he can't open the microwave door where he works. He can't lift their kettle safely. He can't always find a mug somewhere he can reach it. Also, aids and adaptations continue to need maintenance, and continue to cause additional cost – Wheelchair users will still need to spend extra money on things like gloves, inner tubes, tyres, see my example with crutches given above, people that use assistive technology like speech synthesizers will need batteries, software upgrades. Systems fail, aids break. They need to be bought again, or repaired. In the interim while the aid or adaptation is unavailable the person may incur much higher costs than expected – to pay for</p> |

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| | | <p>shopping to be delivered, or to buy take-aways, or get taxis where normally someone could get the bus.</p> <p>*9. Your response:</p> <p>*10. Currently a range of people can be, and are asked to provide information. Many disabled people that have lived with their conditions for a long time are not “ill” and are not under the care of a consultant or specialist. In this type of situation I would suggest the individual is listened to, and documentary evidence is provided simply to confirm that the individual has the condition / conditions named. People that live with long term health problems are more likely to have a professional relationship with a GP, and possibly consultants or specialists. In this case, it would be appropriate to ask for information from one of these sources.</p> <p>*11. - The discussion must take place somewhere where the person being assessed is comfortable, and where their access requirements are absolutely met without question.- Someone applying for support is not on trial, and they are not guilty of anything. - People must be free to be accompanied in any meetings.</p> <p>*12. People with long term conditions shouldn't be subject to frequent review. Someone with Dyspraxia is never going to stop being Dyspraxic. Someone with Cerebral Palsy is never going to stop having Cerebral Palsy. To repeatedly reassess causes unnecessary stress, and will incur costs that are not necessary. I could see a five-yearly basic renewal for people with long-term conditions being reasonable. With short term conditions that may improve, two yearly review may be reasonable. But if it becomes clear after, for example, three reviews that the individual's needs haven't changed, they should be considered to have a long-term condition.</p> <p>*13. Your response:14. Your response:15. Your response:16. Your response:17. Your response:18. Your response:19. Your response:20. Your response:21. Your response:</p> <p>*22. Is there anything else you would like to tell us about the proposals in this public consultation?</p> <p>*My additional comments are below, taken from a letter sent to Ms Miller. Sections in italics are from an earlier response her office sent to me.</p> <p>**As I have said, we are currently in the process of developing the detail of the new assessment with the help of a group of independant specialists. While I therefore cannot give details at this time of how the assessment will affect ██████, I can assure you that it will not only take into account physical impairments but also mental, intellectual and cognitive ones."</p> <p>*I am glad to hear that mental, intellectual and cognitive impairment will be considered alongside physical impairment. I sincerely hope you also account for the reasonably common situation where someone has multiple relatively minor impairments that collectively work to make an individual</p> |

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| | | <p>moderately (or severely) impaired.</p> <p>*For example, a friend of mine has High Functioning Autism alongside Hypermobility Syndrome. Alone, each condition could be manageable (he is not severely Autistic, and his HMS is bad, but appropriate aids would give him some relief), but combined he suffers extreme fatigue which greatly reduces his cognitive ability meaning he goes into cognitive overload / Autistic meltdown on a regular basis. This further exhausts him, and makes his co-ordination worse meaning he experiences more joint dislocations than he would otherwise. (His wrists dislocate multiple times a day, shoulders daily, knees multiple times a week, hips similarly!).</p> <p>*Because he has to take high doses of anti-inflammatories and opiate-based painkillers to manage the pain from the multiple and frequent dislocations he experiences he is further impaired by the sedating side-effects of the painkillers.</p> <p>*I would be very interested to know who is in your group of independant specialists, and what qualifies them to be called specialists. Are you consulting with disabled people outside of this consultation?</p> <p>**"I was pleased to read that Disability Living Allowance enables ████████ to work. Currently the employment rate of Disability Living Allowance recipients is very low, I hope that out reform of Disability Living Allowance, alongside other current benefit reforms such as the Universal Credit and new Work Proramme will enable other disabled people to work and enjoy all the advantages that an active working life can bring."</p> <p>*The employment rate of DLA recipients being low is not the fault of the benefit! Being disabled make finding suitable, regular employment challenging, and instigating punitive measures to "encourage" people into work will only increase stress for those who are least able to deal with the pressure.</p> <p>*The document quoted in the DLA consultation document (Disability Living Allowance and work: Exploratory research and evidence review, 2010, DWP Research Report No. 648" (RR No.648).) later states "the main factor affecting the employment rates of disabled people is their disability or health condition" and "a larger than average proportion of DLA recipients also appears to be affected by the specific types of impairment that carry the greatest employment disadvantage for disabled people"</p> <p>*Surely it isn't a huge leap of logic to surmise that the types of impairment that result in needing the levels of care or mobility assistance are those impairments that make it very difficult to find suitable work?</p> <p>*Many conditions cause fatigue either directly, or as a side-effect of medication. Whilst someone may be capable of coherant thought and carrying out complex tasks when they are not fatigued, this may only account for half the week, and it can be impossible to predict which days are going to be good, and</p> |

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| | | <p>which bad. How is an employer to make reasonable adjustments for people with this kind of issue?</p> <p>*I know that disabled people can work - I work in an office with a higher than usual proportion of disabled people. But I also know that there's a big difference between someone's theoretical ability to work, and they're ability to find a suitable job where all necessary adjustments can be made.</p> <p>**I appreciate that there are many reasons why the number of people claiming Disability Living Allowance is increasing, but we need to get expenditure on a sustainable footing.</p> <p>*Over the last decade spending on Disability Living Allowance has risen dramatically. In just eight years the numbers claiming Disability Living Allowance has risen from around 2.5 million to nearly 3.2 million - an increase of 30 per cent."</p> <p>*Sadly, human beings on an individual level don't conform to economic demand. If there are 3.2 million people that need the type of assistance DLA provides, there are 3.2 million people that need support. There won't suddenly be fewer disabled people around just because there are fewer in receipt of a benefit, but there will suddenly be fewer disabled people enabled to live their lives. There will be more disabled people living below the poverty line, suffering poorer health because they're having to choose between paying for decent food or heating, suffering with exacerbated conditions because they can't access the support they need, because they're having to choose between some help around the house or paying for specialist physiotherapy.</p> <p>**The inherited fiscal legacy has forced the Government to make some tough decisions about how we target resources - the Budget deficit is costing this country £43 billion a year in interest payments alone. The Government has tried to make fair choices and to protect those who are most in need."</p> <p>*I suppose subsidising car drivers by delaying a rise in fuel duty, not closing loopholes in the tax system that allow companies to legally avoid paying billions in tax, continuing giving Winter Fuel Payments to all people over 65 regardless of their income or need were all just too tough compared to making cuts that will seriously affect the lives of disabled people, who are already the most financially and socially disadvantaged group in the country.</p> <p>*I am proud to live in a country where I can (and do) pay taxes to support people that are out of work, sick and disabled, on low incomes, or out of work. I would far rather pay and risk a tiny, tiny proportion of fraudulent DLA claims going unnoticed than see the kind of changes that are being proposed by your government, and will see people that can least afford to lose out living in genuine hardship, and suffer increased ill health and decreased independence as a result.</p> |
| EM832 | 18/02/2011 | Hello I understand that today is the last day for submissions for consultation about the replacement of DLA with PIP I enclose |

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| | | <p>2 forms. The first gives answers to questions 1-21 on your form, the second is designed as an answer to your question 22, which invites other comments. What I have written there is rather longer, but I do hope someone will read it, as I took many hours over several days to write it.</p> <p>*1. : healthy physically disabled: physical barriers. Mentally disabled: prejudice and medical problems. Chronically sick disabled: medical problems most important, physical barriers worse for those who are weakened by disease.</p> <p>*2. : recognition of differing levels of need. Role of GP & consultant input – recognition that nature of disease/impairment affects functioning in ways that may not be obvious to “disability analyst” with no experience of rare or multiple conditions. Not having everything reduced to computer program.</p> <p>*3. : adaptation of home, specialist disability equipment, help from other people. Note help not just needed for personal care (e.g. washing) but for all things the bed or chair-ridden can’t do e.g. turning off radiator, close curtains, pick up dropped book. Travel costs, incl car/power chair or scooter plus unexpected extras – cost of extra night in a hotel because journey to family wedding too tiring for one day, or needs to be broken multiple times. Mental health issues different, children different again.</p> <p>*4. : my guess? In practice people who used to get the bottom level of care will now get nothing. Having only one would mean that the bar would be set even higher and many people who really needed it would not get any help. Two rates not too complicated for people who can manage to fill in the forms – if you understand the principals behind DLA, then coping with the idea of “levels” is not hard for most disabled people or WRO to understand. People who only know that people who are disabled get money, and haven’t yet worked out the difference between DLA and ESA, are not going to stop to learn that DLA can go to those in work, or that there are two kinds of DLA, and that getting it doesn’t mean you get lots of easy money and a “free car” because you’ve got a fictional back back. And they certainly aren’t going to bother understanding different levels of payment. *Who will find it easier to understand? Ministers perhaps? Disability Analysts?</p> <p>*5. : Yes, particularly for childhood conditions, severe permanent disabilities (e.g. deaf-blind), anyone who has a degenerative condition should need assessing once to establish baselines and then again only if they want to claim higher levels of need. Terminally ill as now, but with 12 months not 6 – it can take weeks to get care set up even after the money is established. (Friend dying of cancer – it took six months to get her a wheelchair, which arrived the day after she died.)</p> <p>*6. : The obvious – getting and eating food & drink, toileting, basic hygiene, dressing. The less obvious also important for many – something to do (even if just watching the television)</p> |

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| | | <p>and basic social contact. It need not be in person, the internet serves many who can't manage face to face contact. For many disabled people, especially the housebound, a laptop and an internet connection can be their main source of health information, their means of basic administration (bill paying, finding telephone numbers, filling in forms for the DWP!) and the only point of contact with others who share their condition. For other people someone touching them – holding a hand perhaps – in some way other than as a lump of flesh to be washed and fed can make the difference between feeling alive and just being “not dead yet”.</p> <p>*7. : Use experts. Consultants usually know how well or otherwise a patient is, they've seen that condition often enough. Get some of the disability “analysts” trained in dealing with e.g. multiple sclerosis or arthritis or cancer.</p> <p>*Make sure that your computer program can cope with fluctuations over months, but also over days. It is frustrating to be asked, “Can you get the toilet on your own?” when the answer is “Easily in the morning, more slowly after lunch and by 5 o'clock I really need help if I'm to avoid loss of bladder control or the risk of falling, or both. Then some person or program decides to reduce that to “Yes” or “No”. And since the first bit was “Easily”, they enter “Yes”. If the claimant says, “No,” then the analyst decides they don't believe that the person always needs help and enters “Yes” anyway.</p> <p>*8. : It's reasonable to take into account some aids, but it can cut both ways. Someone who might be expected to get and manage a wheelchair may need an adapted car – but if they are on sticks, then they can manage.</p> <p>*Not having an obvious aid does not mean that people should just go and get one.</p> <p>*Consider why someone has not got a particular aid. For example, someone I knew needed the help of walking sticks, which would have made her more mobile. But she was too far gone in dementia to remember to use them and just dropped them or dragged them behind her. Or someone who could get round their own home with less risk and fatigue in an electric wheelchair – but reliance on a wheelchair would have excluded them from the sun room they loved, but was up two steps. Or tell someone to use a commode, when sitting with the smell of their own faeces until help arrived would make them acutely miserable. Or a teenager for whom a hearing aid represents social death – they don't mind not be able to hear what's happening, but fear being left out because hearing aids are “SO uncool”.</p> <p>*These things matter, when you talk about “full and active lives.”</p> <p>*9. : The form: Reduce the number of figures required e.g. “How many times a day?” or “How many minutes does it take you?” Re-think how you assess with people whose condition</p> |

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| | | <p>fluctuates (see above). I would suggest that you assess someone by what they can do when they are “fairly tired” – as any help needed for a substantial part of the day might just as well have to be budgeted for all the day. Remember this when they are asked for a medical!</p> <p>*As for improving information. Well, first tell your minister that DLA is not “a barrier to work”. Provide lots of “worked examples” (presumably fictional, but there might be real people willing to feature). Start with people who have some disabilities but need very little help and go on to those who need the highest level of care.</p> <p>*10. : How would you want your ability to wipe your own bum assessed? Did you know that being able to wipe your bum on the toilet is not a guarantee that you can wash your bum in the shower – seated or standing? Employ people who are disabled, or who have been carers and ask them to assess the forms and if necessary the interviews and see if they find the case convincing. Look at what the GP and the consultant says.</p> <p>*If you want to train people to be analysts, train them to carry out a sensitive examination, not to fill in a computer form in such a way as to minimise the chances of any award being made.</p> <p>*11. : There could be real benefits if the health care professional were independent, experienced in the conditions of the person they were assessing, properly chosen, trained, given time and not targets. Make sure that they can understand colloquial English – so they don’t mistake “pottering” for “doing pottery” – at the moment the person applying for ESA needs to be trained in how to speak to a “disability analyst”, and control their language very carefully, checking at every stage that they have been understood.</p> <p>*People with mental health issues may need assessing under different conditions to those appropriate for someone physically disabled, but otherwise healthy. Any assessment of someone who is taking heavy doses of mind-affecting drugs (e.g. painkillers, anti-psychotics, anti-convulsants) should be conducted with the expectation that the claimant may not be able to answer the questions sensibly or accurately.</p> <p>*12. : Accept that the process is never going to give perfect results, and that financially you’re better off accepting that you will overpay some people whilst not needing the administrative and legal burdens of reviewing everyone frequently. On initial assessment divide people into categories – (a) temporary or “might get better” (e.g. some mental health issues, some cancer, serious injury) (b) likely to fluctuate markedly but never recover entirely (e.g. some mental health issues, ME/CFS) (c) fixed disability (e.g. blindness, loss of a limb) (d) degenerative conditions (e.g. primary progressive MS, motor neurone disease, cystic fibrosis) (e) terminal within 9-12 months.</p> |

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| | | <p>*Then decide on an appropriate level of review for each category. Perhaps: (a) you review annually, (b) every two years for the first six years, and then every five years if their condition is not in fact fluctuating on a month-by-month basis (c) only if they develop additional needs, (d) review by asking their GP if their condition has changed markedly for better or worse and (e) only if they are still claiming after 2 years. This approach saves assessing each person individually, as many will be fairly obviously in one or other category. If they have multiple problems, assign them to the category of their worst problem e.g. MS, bedsores, depression – category (d), unless they're terminal. Treat children differently.</p> <p>*13. : See answer to Q 12 above, make review processes more appropriate. Plus make it less risky and daunting to go through the process – at the moment if you feel a bit better you can report it and spend the next 9 months trying to tell someone that you are “a bit better” and not “no longer in need of any help”. Then have to go through the whole process again when, perhaps, the cancer returns 18 months later. At the moment the whole process is so adversarial that even the honest would hesitate to put themselves through it. For some conditions, accept the word of the GP that the recipient is better/worse/the same.</p> <p>*14. : They need independent advice – not something where they expect to have the answers reported back to the DWP. Advice before they claim, and help with filling in the form would have advantages all round. Claimants would know how best to present their case, and DWP would get forms which had been filled in properly and with the appropriate level of detail.</p> <p>*15. : No. Compulsion would simply make people more determined to stay clear. What you need is the assumption that they will want to access advice, and a clear route to that advice provided. But you need an opt out for those who don't want it. Only exception might be for help with language issues, where it is in the interests of those doing the assessing, as well as the claimant, that the information should be accurate.</p> <p>*16. : Do you mean that there should be an option to make a one-off payment in place of a regular one? If so, NO. This will turn into a form of benefit cut, as decision makers would be encouraged to employ this method of getting people “off the books.” However, an arrangement like that use for Motability vehicles could have real advantages for someone whose greatest need is a through-the-floor lift, or an adapted bathroom.</p> <p>*17. Your response: When there is a disabled child, you have a whole family with needs – the parents need help to manage the child whilst also parenting any other children. For example, at the moment a Motability vehicle is there for the benefit of the disabled person. This could mean that a family with 3 children, one of whom is disabled, would have to have two cars, even if</p> |

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| | | <p>there is only one driver – because taking another child to a sleepover is not obviously to the benefit of the child receiving DLA Mobility HR. However, a family where one child has “a car of their own” and the others don’t is going to lead to a lot of resentment. You can pull a blue badge out of the glove box when it’s needed, but you can’t take a car in and out of Motability. *18. : It seems to me that this works quite well, though having to produce your “letter of entitlement” can be awkward – perhaps you could send people a credit card sized card with “in receipt of ...” so that it could be flashed at people. *19. : It would make things very much more difficult, and not just for the person in receipt of PIP. Imagine: everyone who currently holds a blue badge because they get HR DLA (M) has to go for an interview for a blue badge every 3 years. The local council would find themselves swamped, as might the GPs who, as well as being the administrative service of the NHS, would have to fill in more forms for each Blue Badge application. And that’s just one “passport benefit”.</p> <p>*20. : Sharing information only works when the IT works. Do you think that the record of government IT schemes is such as to make “information sharing” in the DWP a sensible idea? Ask someone about the progress of the NHS IT mega-project. Those who need to have “information” about benefits, disability services and health reporting would include GPs, consultants, support services, local social services, local housing services, the DWP, the children’s department, the department of employment, the Treasury, the tax man, hospitals, care homes, quite possibly the police, not to mention any private company (ATOS, EDS, private insurers) who might run any services for the government or the local council. Oh yes, and the banks! And each one of them would put together a team to make a good case that they should be included and given access to the data. How are you going to stop that meaning that everyone has access to information about anyone?</p> <p>*21. Your response: There are so many issues in this question. There is the question of language, and the fact that you can’t make word-for-word translations. Consider the matter of different modesty codes. There is a huge problem of people whose mental health, or mental developmental, problems makes it difficult or impossible for them to fill in forms, or even acknowledge that someone else has to fill in forms. How will you deal with observant Muslims during Ramadan, when fasting may make it inappropriate to ask them to attend medicals or answer detailed questions?</p> <p>*Question 22 answered in a separate document.</p> <p>*22. I’m submitting this as a separate document, since it’s a more descriptive answer. If you don’t take any notice of the rest, please try to understand this: This is about the chronically sick. The fashionable theory about disability is that it is a social construct, that people with a wheelchair should no more be</p> |

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| | | <p>discriminated against than people over six and half feet tall. Sure there are things the very tall find tricky – like going round houses with low ceilings, or trying to find shoes that fit – but on the whole society is getting round to making long beds and shirts with long arms. So, the social theory of disability goes, it is mostly the failure of society to make everywhere accessible by ramps that holds back the disabled, not the facts about their bodies. How true that is of the blind, the paraplegic or those with cerebral palsy is not the issue.</p> <p>*The issue here is that for those who are disabled by any form of chronic sickness, the “social model” is not applicable. It is certainly easier for us to manage when there are ramps, or lifts that are big enough for a wheelchair and someone to push it. Having a downstairs toilet in any house we visit makes life easier. But what is principally the matter with us is medical, not social. In the past is often pointed out that the disabled can be healthy, fit and intelligent. The sick may be disabled – indeed amongst the chronically sick many have secondary disabilities – but first and foremost they are sick.</p> <p>*Sickness brings many problems in its wake, but there are two which those who wrote the current ESA, and the future PIP test seem to consider minor or secondary, but they are not. Those two are pain and fatigue. At present I have only the known facts about the WCA test to hand, but I know that the new test for PIP will be closely modelled on it. So it is largely to the philosophy and implementation of the WCA that I wish to address myself.</p> <p>*The WCA descriptors talk about “discomfort”, which is in theory recognised as a reason why someone cannot do something as much or as quickly. Specifically, it seems, when a task increases your level of pain, then you may get some points for that in the WCA, as a legitimate reason for not being able to do that task, but this only begins to tackle problem of pain. Many amongst the chronically sick are permanently in pain. If a normally healthy person goes to work and is seen to be in considerable pain, they will probably be told to take analgesics, or to go home to bed. Yet substantial permanent everyday levels of physical pain are regarded as no reason not to work when it comes to the WCA.</p> <p>*Pain is not just a minor inconvenience, something you can remove with a couple of aspirin. For those who have severe rheumatoid arthritis there is no known really effective pain relief, short of drugging them into a coma.</p> <p>*Pain seriously affects every action you take. You measure everything by how much it will hurt, and that calculation slows you down. Pain avoidance means that you need slightly higher chairs, so your knees are less stressed when you stand up. Pain avoidance can mean making sure that you do not get into arguments, because that brings on migraine. Pain makes you less good at almost everything, from breathing to picking up a</p> |

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| | | <p>piece of paper to giving a toddler a hug.</p> <p>*Pain, all by itself, can make you inaccurate in your judgement of distance or your control of machinery. Even ignoring pain has its cost. Those trying to over-ride their pain are usually find that they are either more short-tempered or more prone to tears or dogged by depression. *Pain-killers are only a partial answer. For some people the pain relievers have side effects, from drowsiness, to irritability through to problems with eating or depression. Many medicines carry warnings, “may cause drowsiness, if affected do not use machinery.” Those taking medication which blurs their judgement also find that they can’t read a set of figures accurately, or type without making many errors. They may also find that pouring boiling water becomes more hazardous, navigating the turn in the stairs takes more concentration – just when concentration is hard to find.</p> <p>*Pain also affects your social skills – you get less tolerant and more likely to lose concentration and have to ask people to repeat things. You get a sudden twinge and forget to ask someone’s name, or cry out distressing someone and distracting every one from the business in hand.</p> <p>*Pain is also, unfortunately, very difficult to measure or establish by any objective test. If someone says that a task pains them, then they could be exaggerating, or even faking it – there are only a few ways to be sure that something hurts someone, and they only apply to some forms of pain. The current models of “illness behaviour” exclude pain as any reliable element in assessing someone’s degrees of need. This has been extended to the point where pain, which cannot be measured, is regularly discounted as a factor – someone who says that something hurts can simply be written of as a whiner or a hypochondriac. In reality most of them will be in pain and not being able to prove it with a pain-meter does not make it go away.</p> <p>*The new tests (and a re-writing of the old ones) needs to recognise that pain is not only something that may be caused by a particular action, but may be a sort of “background noise”, something that reduces everyday ability or effectiveness in more or less any task. Permanent pain, and permanent pain-killers, “top slice” the ability to do anything.</p> <p>*Fatigue is the other big issue. Most people understand pain, and some think that they understand fatigue, but as soon as they say, “Well I’m exhausted at the end of a long day,” those who have chronic fatigue know that there’s an understanding deficit. There are others trying to address this problem, but the more you try to describe how it feels the more people, who think they already know, class you as a whinger.</p> <p>*So I’m going to address one of the side issues of fatigue, which the DWP thinks that it has considered, but – in my opinion – has not. One of the features of fatigue is that it places a major role in the fluctuation of diseases like multiple</p> |

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| | | <p>sclerosis. This is the “good day, bad day” phenomenon which turns up frequently in the discussion of how well testing on a single day can tell you about other days. The standard answer is to fill in the form, and explain at the interview what things are like on an average day.</p> <p>*This is not necessarily helpful, as one observer remarked “someone may report being able to get up from a fall 8 times out of 10. But what matters is the 2 times they cannot manage without help.”</p> <p>*Even more damaging, however, is the myth of the “average day.”*The point here is that the form, the disability analyst and probably the decision maker at the DWP have been given no good understanding of a major problem. Some people here call it the “spoons theory”, I refer to it as “the energy economy.”</p> <p>*When you have an illness which results in a major fatigue problem, then your whole approach to any task changes. You have entered a zone where the energy economy applies. You have three factors which govern your behaviour: your resources, your outgoings and your overdraft. *Your resources reflect how much energy you have for the day. This is not a “level” at which you can function all day, it’s a supply which will be depleted. Any task you do takes away some of your energy – washing or showering, making breakfast and eating it. Getting dressed, feeding a child, walking them to school – all take up some of your limited supply of energy just as spending money reduces what you have in the bank. Some people are rich and can do all of these things without running out of energy – some could not dream of doing anything as exhausting as having a shower and drying themselves without lying down for an hour afterwards. *Every task through the day takes more of your energy supplies. Sometimes you can get some back with a nap. Occasionally there’s a crisis, or a special occasion, and you have to use your “overdraft”. This is when a supply of adrenaline keeps you going through a dinner party, or looking after a sick child. The problem with overdrafts is not only do you have to pay them back by doing a lot less the next day, there’s interest and it may take you two or three days doing hardly anything to get over one evening of indulgence.</p> <p>*This is why people with ME/CFS so hate the question, “What can you do on an average day?” The correct answer is, “well it all depends on whether I’m paying off an overdraft, saving for an expenditure to come, or just keeping some reserves.”</p> <p>Perhaps during the day the person goes to the toilet all by themselves, but as soon as their partner comes home from work they get help to stand up from a chair. This isn’t an attack of laziness, or a display of “learned helplessness”; it’s a careful use of resources – when you can get help easily, you use it. That means that you can have a bath in the evening. If you’d still been hauling yourself out of a chair then you wouldn’t have the energy left by bedtime to wash yourself – even with help.</p> |

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| | | <p>*On a macro scale this can mean giving up grocery shopping to join a family party once a month. On a micro scale it means always asking someone else to bend down and pick things up when they are there, so that you have the energy to do it when they are not there.</p> <p>*Some of the time I hear people saying that they should not have to help support people just so that they can go to parties. Few of them, however, will say that anyone who is disabled should not do anything except what is necessary for the maintenance of their bodies. Most disabled people need to have social contact, and some recreation. The chronically sick and fatigued can only do that with help – not just the help getting there and back, but help “saving up” enough energy to take on the project at all.</p> <p>*Consider the case of the person who has enough energy to decide which video they want to watch, to get up from a chair and locate the shelf it’s on, reach it down, get the disc out from a multi-disk package, turn on the dvd player and the tv, locate the remote controls for both devices and get back into the chair. This is all fine, but not if the process has left them too tired to enjoy the video afterwards, so they sit in a chair feeling exhausted for an hour instead. So, *Q; “Can you reach down a dvd from a shelf at head height?”</p> <p>*A: “Yes, but not if I want to watch it afterwards.</p> <p>*Any “functional analysis” will then show that the person can reach above their head – but will not show the consequences of that act. Nor, of course, will it show that the tiredness from earlier in the day means that reaching above the head is likely to bring on a dangerous bout of vertigo and a possible fall. (This applies equally to work and daily living)</p> <p>*I realise that taking these two factors – pain and fatigue – into account would expand, not reduce the number of people qualifying for benefits, which runs counter to the point of the exercise. But some acknowledgement that the pain and fatigue which form such a large part of the daily difficulties of the chronically sick are recognised by benefits initially targeted at the disabled would be most welcome. Please give these questions some serious attention.</p> |
| EM833 | 18/02/2011 | <p>1. LACK OF RESOURCES AND APPROPRIATE SUPPORT TO ENABLE ACCESS TO COMMUNITY ACTIVITIES – ESPECIALLY FOR THOSE WITH COMPLEX NEEDS AND BEHAVIOURS THAT CHALLENGE. FOR THOSE WHO CAN ACCESS THE COMMUNITY, THE LACK OF UNDERSTANDING FROM OTHERS CAN BE A HUGE BARRIER TO THEM BEING PART OF THAT COMMUNITY.</p> <p>*2. LIFE AWARDS TO THOSE WHO DEFINATELY WILL NOT GET BETTER E.G. PEOPLE BORN WITH CONDITIONS LIKE AUTISM – IF THEY REACH ADULTHOOD AND HAVE RECEIVED EVERY ASSISSTANCE AVAILABLE AND STILL NEED HIGH LEVELS OF SUPPORT, IT SHOULD BE</p> |

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| | | <p>ACCEPTED THAT THEY WILL REMAIN THE SAME. LIFELONG CONDITIONS THAT HAVE NO CURE MEAN JUST THAT.</p> <p>*MOTABILITY SHOULD REMAIN AS IT ENABLES MANY PEOPLE ACCESS THEIR COMMUNITY WHERE IF IT WAS NOT THERE THEY WOULD NOT BE ABLE TO GET OUT SAFELY.</p> <p>*3. HAVING TO ACCESS ACTIVITIES AT QUIET TIMES FOR THOSE WITH AUTISM – WHO DON'T LIKE CROWDS/NOISE. EXTRA COSTS FOR HOLIDAYS TO ENABLE APPROPRIATE SUPPORT, THIS HELPS FAMILY HAVE SOME SORT OF MORMALITY IN THEIR LIVES, ESPECAILLY FOR SIBLINGS IN THE FAMILY. IF A DISABLED PERSON NEEDS HELP TO ACCESS THE COMMUNITY AND PROMOTE SOME LEVELS OF INDEPONDANCE, THEY NEED TO PAY FOR THAT HELP – OTHERWISE THE MAJORITY OF RESPONSIBILITY IS PUT ON FAMILIES – WHY SHOULD YOUNG PEOPLE HAVE TO GO TO ACTIVITIES WITH THEIR PARENTS WHEN THEIR PEERS WOULD NOT.</p> <p>*4. HAVING THE SAME LEVELS AS NOW WOULD NOT CHANGE HOW THE BENEFIT IS ADMINISTERED – IT WOULD HELP IF YOU HAD INPUT FROM PEOPLE WHO UNDERSTAND WHAT IT IS LIKE TO LIVE WITH THESE CONDITIONS OR THEIR CARERS – NOT EVERY DISABLED PERSON WANTS TO MONEY GRAB – THEY WANT TO LIVE A NORMAL LIFE... IT WOULD BE MORE HELPFUL FOR THOSE MAKING THE DECISIONS TO UNDERSTAND DAILY LIFE NOT JUST READING IT ON A PIECE OF PAPER!!</p> <p>*5. SOME CONDITIONS SHOULD BE EXEMPT IF IT IS CLEAR THERE WILL NOT BE ANY CHANGE – HOW CAN ASSESSMENT SAVE MONEY WHEN YOU DO IT ANNUALLY FOR THE SAKE OF IT – ONLY TO BE TOLD THE SAME THING EVERY TIME AND STATE THE OBVIOUS, THAT THE INDIVIDUAL WILL NEVER IMPROVE!!</p> <p>*6. FOR THOSE WHO EXPERIENCE ANXIETY AND STRESS AND WHO HAVE BEHAVIOURS THAT CHALLENGE BECAUSE OF THEIR CONDITION E.G. AUTISM. THEY MAY NEED SUPPORT TO HELP THEM REMAIN SAFE AND BE SAFE AROUND OTHERS – THEY SHOULD STILL BE ABLE TO ACCESS THEIR COMMUNITY BUT NEED 24 HOUR SUPPORT TO DO THIS – THIS IS NOT THEIR FAULT AND THEY SHOULD NOT BE PENALISED BECAUSE OF IT. BEING SAFE, LIVING A NORMAL LIFE – EVEN IF SUPPORT IS NEEDED, SHOULD BE AN ESSENTIAL PART OF LIFE.</p> <p>*7. : BY ASKING THE CONSULTANTS WHO SPECIALISE IN THE CONDITION – AND ALSO THOSE WHO LIVE WITH IT.</p> <p>*8. : THE ASSESSMENT MAY TAKE INTO ACCOUNT THE AIDS BUT ONLY IN RESPECT OF THE HELP IT GIVES, PEOPLE SHOULD NOT THEN ASSUME THAT BECAUSE THE PERSON HAS AIDS THEIR CONDITION IS BETTER –</p> |

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| | | <p>BECAUSE A BLIND PERSON HAS A STICK AS AN AID DOES NOT THEN MEAN THEY CAN SEE. WITH AUTISM ALL THE STRATEGIES AVAILABLE CAN BE IN PLACE BUT THAT DOES NOT MEAN THAT PERSON WILL NOT REACT IN THE SAME WAY ON 2 SEPERATE OCCASIONS.</p> <p>*9. : TREAT THE INDIVIDUALS AS PEOPLE. MAKE ANY INFO SIMPLE AND STRAIGHT FORWARD – DON'T USE JARGON OR BIG WORDS – THE EASIER THE LANGUAGE THE EASIER TO UNDERSTAND. DON'T REPEAT QUESTIONS AND BE REALISTIC IN WHAT YOU'RE ASKING FOR.</p> <p>*10. : THE FAMILY AND PEOPLE WH KNOW THE INDIVIDUAL BEST ARE IN THE BEST POSITION TO GIVE EVIDENCE – NO-ONE CAN KNOW WHAT IT'S LIKE TO SUPPORT SOMEONE WITH A DISABLILITY UNLESS THEY DO IT NON-STOP 24HRS A DAY 7 DAYS A WEEK – IT IS DIFFERENT LIVING WITH IT THAN JUST SEEING SOMEONE FOR A SHORT TIME AND MAKING AN ASSUMPTION.</p> <p>*11. : PEOPLE WITH AUTISM AND THOSE WITH MENTAL HEALTH ISSUES CAN SUFFER EXTREME AMOUNTS OF STRESS/ANXIETY – HAVING TO THINK ABOUT FACING SOMEONE STRANGE, WHEN IT IS DIFFICULT JUST TO GET THEM OUT OF THE HOUSE WILL CAUSE HUGE AMOUNTS OF PROBLEMS FOR INDIVIDUALS AND THOSE HAVE TO DEAL WITH THE STRESS BECAUSE OF IT E.G. FAMILY CARERS. HAVING A FACE-TO-FACE MEETING DEPENDS ON THE PERSPECTIVE OF THAT INDIVIDUAL AND THE ASSUMPTIONS THEY MAKE ABOUT INDIVIDUALS AND THEIR CONDITIONS.</p> <p>*12. : IF SOMEONE IS BORN WITH A CONDITION THEN IF THEY REACH ADULTHOOD IT SHOULD BE OBVIOUS IF THAT PERSON WILL IMPROVE. IF THERE IS NO CURE AND EVERYTHING POSSIBLE HAS BEEN DONE WHY WASTE MONEY ON GOING THROUGH THE MOTION TO PROVE THAT EVERY YEAR. THERE ABSOLUTELY SHOULD BE DIFFERENT TYPES OF REVIEW DEPENDING ON THE CONDITION – FOR THOSE WITH ANXIETY IT WILL NEED TO BE DONE BY SOMEONE WITH EXTREME AMOUNTS OF SKILL OR THAT COULD RESULT IN MORE HARM BEING DONE AS A RESULT. USING JUST ANYONE COULD HAVE A DETRIMENTAL AFFECT ON THE INDIVIDUAL IF THAT PERSON HAS NO IDEA HOW TO COMMUNICATE WITH THOSE WITH DIFFICULTIES OF COMPREHENSION E.G. LEARNING DIFFICULTIES, AUTISM ETC.</p> <p>*13. : GENUINE CASES WILL ALWAYS BE HONEST, WHY WOULD WE WANT OUR FAMILY MEMBERS TO BE DISABLED – IF I COULD GIVE MY RIGHT ARM TO HAVE MY FAMILY MEMBERS LIVE EACH DAY HAPPY, STRESS AND PAIN FREE – DON'T YOU THINK I WOULD? EVERY FAMILY</p> |

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| | | <p>I KNOW FEELS THE SAME – WE DON'T CLAIM BECAUSE WE CAN, WE CLAIM BECAUSE WE CAN'T SURVIVE WITHOUT IT. SOME OF US HAVE NO PENSIONS THROUGH CARING, NO HOUSE OF OUR OWN AND NO JOB – BUT I WOULD STILL SAY IF THEIR CONDITIONS IMPROVED. FOR THOSE PEOPLE CLAIMING TO BOOST THEIR INCOME – I DON'T THINK YOU CAN MAKE THEM INFORM YOU.</p> <p>*14. Your response: ELIGIBILITY/HOW TO CLAIM/HOW TO APPEAL BE OPEN AND HONEST</p> <p>*15. Your response:</p> <p>*16. Your response: THEY HAVE TO FUND IT THEMSELVES IF IT IS NOT ACCESSIBLE FROM STATUTORY SERVICES – THERE SHOULD BE AN OPTION TO USE ANY MONEY AVAILABLE TO A DISABLED PERSON, TO IMPROVE THEIR QUALITY OF LIFE. HOWEVER WITH THE REMOVAL OF ILF AND SO MANY CUTS – LIFE WILL BECOME SO DIFFICULT FOR GENUINE DISABLED PEOPLE.</p> <p>*17. : MOST OF THE INFORMATION WILL PROBABLY BE GIVEN BY THE FAMILY – ALSO CHILDREN (AND ADULTS ESPECIALLY WITH A LEARNING DISABILITY, WILL ANSWER HOW THEY THINK YOU WANT THEM TO) THE PERSON DOING THE INTERVIEW WILL NEED TO BE SKILLED IN BEING ABLE TO GET THE CORRECT INFO FROM THEM. EXCELLENT COMMUNICATION SKILLS WILL BE NEEDED TO ASSESS ANY INDIVIDUAL WITH A LEARNING DISABILITY</p> <p>*18. : DLA DOES HAVE BENEFITS AT HELPING ACCESS TO OTHER SERVICES AND SHOULD BE GIVEN BY ALL PROFESSIONAL INVOLVED WITH THE PROCESS.</p> <p>*19. : THEY WOULD THEN NOT BE ABLE TO LIVE LIFE TO THE FULL AS THEY WOULD NOT HAVE THE FUNDS AVAILABLE – I DON'T MEAN LIVING THE HIGH LIFE, I MEAN EVERY DAY ACTIVITIES THAT WE ALL TAKE FOR GRANTED. GOING TO THE SHOPS, MEETING FRIENDS ETC.</p> <p>*THE LACK OF FUNDS WOULD FALL BACK TO THE FAMILIES, FOR THOSE WHO HAVE THEM, THIS MAY THEN LEAD TO CARERS REFUSING TO INPUT THEIR HELP – IF TOO MUCH PRESSURE IS PUT ON THEM – THIS COULD THEN LEAD TO MORE RESOURCES NEEDING TO BE FOUND TO SUPPORT THAT PERSON. MOST IMPORTANTLY – THE INDIVIDUAL COULD BECOME ISOLATED, DEPRESSED OR WORSE!!</p> <p>*20. : ESA AND DLA COULD BE COMBINED – IF A PERSON IS DEEMED NOT ABLE TO ACCESS WORK AND NEEDS HIGH LEVELS OF SUPPORT OR CANNOT BE LEFT ALONE DUE TO SAFETY ISSUES – SURELY THIS INFORMATION COULD BE USED TO INFORM BOTH PROCESSES</p> <p>*21. Your response:</p> <p>*22. : THE GOVERNMENT HAS SWORN TO HELP FAMILY</p> |

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| | | <p>CARERS – ALL THESE PROPOSALS COULD HAVE A DETRIMENTAL IMPACT ON THOSE VERY PEOPLE – I CARE FOR 3 FAMILY MEMBERS, ALL WITH HIGH LEVEL NEEDS. IF MORE STRAIN IS PUT ON ME TO SUPPORT EACH OF THEM THROUGH THE PROCESS, DEAL WITH THE FALLOUT THAT THE ASSESSMENTS CAUSE AND THEN HAVE TO SUPPORT THEM FINANCIALLY AS WELL – I AND MANY OTHERS MAY WELL GIVE UP AND TURN THE RESPONSIBILITY OVER - THEN HOW WOULD THAT SAVE MONEY???? I REALISE THE SYSTEM NEEDS LOOKING AT BUT IT SEEMS THAT THOSE WITH PROBLEMS THAT ARE OPTIONAL/CHANGEABLE ARE ASSESSED IN THE SAME WAY AS MY SONS, WHO WERE BORN WITH THEIR CONDITIONS – AND HAVE NO CHOICE!!! SOME INDIVIDUALS ALSO KNOW HOW TO WORK THE SYSTEM AND THEN SHARE THE INFO WITH THEIR MATES TO ALLOW THEM TO DO THE SAME. INSTEAD OF TARGETTING THOSE WITH CONDITIONS THAT ARE LIABLE TO CHANGE – YOU ARE TARGETTING THOSE GENUINE CASES WHO DESPERATELY NEED THE BENEFITS TO SURVIVE. HAVE YOU TRIED INVOLVING CARERS IN THE PROPOSED CHANGES – ASK THE EXPERTS WHAT THE ANSWERS SHOULD BE?</p> |
| EM834 | 18/02/2011 | <p>I am writing here with comments on the consultation on Disability Living Allowance, related to a selection of the questions asked. It is a matter of some concern that the government should have announced its conclusions and legislative proposals before the consultation closed, and it brings the integrity of the process into question.</p> <p>*1. This very general question prompts some concerns about the way in which the new Personal Independence Payment has been is being thought of. Financial payments cannot, in their nature, do whatever is necessary to lead to people living independent, full and active lives. The aims of the PIP have to be much more modest: to compensate people for extra expenses when they are suffering from certain types of long term disability. Financial payments can make a constructive contribution to independence provided that they are regular, predictable and accessible. They will not do so if they are unpredictable, heavily dependent on professional discretion or otherwise difficult to access.</p> <p>*2. It seems, from the introduction of the Welfare Reform Bill before the conclusion of this consultation, that this has already been decided. DLA has lost its focus. The component elements were initially intended to cover care needs and mobility needs. People over working age currently account for one-third of the costs of the benefit.</p> <p>*DLA has been used increasingly by people suffering from mental illness - most of the recent increase in claims is attributable to psychiatric conditions. It will be particularly</p> |

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| | | <p>important to clarify the position of people with mental illnesses. These conditions were not within the purview of DLA as initially conceived, but nothing in the consultation paper or the design of the Personal Independence Payment seems to exclude them. If that is correct, the needs of people with organic psychoses such as depression or schizophrenia could become one of the primary routes for qualifying for the benefit.</p> <p>*4. The boundaries of disability are rarely clear; wherever there is a differentiation in rates, it will prompt confusion. There has been a tendency for governments to assume that where error arises, it must reflect either a failure of claimants failure to be frank and open about their circumstances, or some fault in the administrative process. Often it is neither. There is no obvious distinction between the circumstances of people identified as having disabilities at the lower rate from those on middle or higher rates, while the distinction between unsuccessful applicants and those on the lower rate has been 'blurred'. People find it difficult to describe their circumstances, and impossible to place their needs in a scale relative to others. They do not understand why their condition is assessed as severe or less severe, and it is not reasonable to expect them to do so.</p> <p>*The proposed reforms reduce the number of rates, but more importantly they make the process more dependent on professional and individual assessment. This will not reduce uncertainty; it will increase it.</p> <p>*5. Claims that are based on the needs of the individual are complex and difficult to administer with fairness. The more automatic and explicit the rules become, the clearer and fairer they will be.</p> <p>*7. This is one of the most critical issues. Conditions like multiple sclerosis or arthritis do not have a consistent effect on functional capacity over time and cannot sensibly be responded to as if they did. In the case of MS, the nature of the disability may itself change - the condition can lead to impairment of vision at one time, dexterity or mobility at another, sustained exertion at a third, and so on. Varying the benefit according to conditions also carries the danger that the benefit will be unpredictable. The direction of movement should consequently be towards greater automaticity, not less. The benefits assessment should offer fixed awards for specific conditions for set periods.</p> <p>*8. This would create problems. First, it raises the possibility that people with the same impairments in similar situations will have different assessments for benefit. Second, it would penalise some people for managing their disability in different ways.</p> <p>*10. It is not generally possible to make a clear, consistent, undisputable assessment of people's abilities. There is some evidence that professionals who are trained to understand and</p> |

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| | | <p>perceive people's needs will recognise more issues than others, and a test that depends on the judgment of professionals rather than the application of defined rules cannot be expected to be wholly reliable between testers.</p> <p>*If the government is determined to persist with professional assessment, the assessment of functional capacity is primarily within the province and competence of occupational therapists rather than medical doctors.</p> <p>*11. Are there any circumstances in which it may be inappropriate to require a face-to-face meeting with a healthcare professional – either in an individual's own home or another location? *This promises to be a complex, individuated assessment. It will be expensive, administratively complex and highly dependent on the tester. This is the opposite of what the government ought to be doing.</p> <p>*13. The view of the benefit currently being conveyed is that it will be personalised, responsive to individual needs and responsive to changes in circumstances. That approach may be appropriate to the provision of personal support for disability - people want help with bathing or dressing to be sensitive to changes in their needs - but it is misplaced when it is applied to financial benefits. People want and need a degree of stability and predictability in their incomes; frequent changes in financial entitlement are a curse, especially for people on low incomes. They will create uncertainty and they will undermine independence. If the aim is to promote independence, the awards given should be for identified conditions for set periods of time.</p> <p>*19. There is a critical issue here for carers, whose access to benefits is determined by the entitlements of the person with disabilities. In the same way as people with disabilities, carers need benefits to be stable, predictable and accessible.</p> <p>*22. The consultation misrepresents DLA as an out of work benefit. It is not, and muddying the waters in this way does no-one any service.</p> <p>*The Personal Independence Payment should not be represented as a benefit supporting the needs of people with disabilities. It is clear that many important needs are not going to be met by the new benefit: for example, the time limits in paragraph 18 will exclude many people recovering from a stroke. Nor should it be represented as a personalised benefit that responds sensitively to changing needs; it cannot do this effectively, and it should not try. Either presentation would lead to confusion and resentment when the benefit failed to deliver what seemed to be promised. The PIP should rather be presented, in much less ambitious terms, as a form of social protection - a limited form of insurance provided against some undesirable eventualities. That would allow for a benefit that is simpler, clear and fairer.</p> |

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| EM835 | 18/02/2011 | <p>Dear DWP, my comments as a stroke survivor:</p> <ul style="list-style-type: none"> *1. 1. continuation or worsening of the disabling condition *2. lack of clarity and accountability in advice given by DWP staff, leading to a lack of trust. *3. uncertainty over continuance of improvement in disabling condition and likelihood a necessary return to benefit would result in lower benefit - worsened, because of the recent withdrawal of option to try work for a year and return to same benefit if job did not work out. *2. *3. Heating - many disabling conditions result in the individual feeling the cold more than the normal. This includes many stroke survivors whose affected side often feels colder. All incur higher heating costs. *Aids to allow necessary activities including mobility, kitchen, and bathroom aids and fixtures. This is important as reduced funding to local authorities will result in a poorer service locally. *Food. Where a condition results in an inability to prepare food on a consistent basis, the extra cost of pre-prepared meals is significant. *4. A points system score is as easily divided into the current 11 divisions as into the proposed lower number. The difficulty is getting the points awarded to reflect need. *A disadvantage is less flexibility in covering the range of disability and the extra expense incurred. In the current environment, it is difficult to imagine claimants will be 'levelled up', so the proposed change would result in a reduction of benefit for most who receive it and none for those who fall off the bottom rates. *5. Following stroke, there is a huge range of intensity and variety of symptoms of disability. Individual assessment would provide the most accurate measure of need. *6. Sleep, cleanliness, buying/ preparing/cooking food. *7. Take the word of the claimant. To claim it is possible to be objective and fair is a myth. *Post stroke, I suffer tiredness which affects both my physical and mental abilities. If I do too much, my left side physical ability degrades to the point where my hand is clasped in a tight fist and my arm, leg and foot are similarly spastic. Mentally. I become over emotional, neurotic, over sensitive to the point where normally pleasurable experiences, such as music, become intolerable. *I have learnt over many years when I have reached my limit and need to rest. How you measure that is beyond me. *8. All used aids should be taken into account *Yes. If the claimant does not use an aid, s/he and their doctor should be asked why. If there is no good reason, the claimant should be expected to try it. *9. Ensure the CAB and other agencies who supply benefit advice and help in completing forms are funded so they can |

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| | | <p>continue to provide the service.</p> <p>*As with DLA, the statement PIPs are to cover extra costs resulting from disability and is paid whether the recipient is in work or not should clear up any confusion.</p> <p>*10. My post stroke history goes back 46 years; my benefit history 16 years. I know that my medical notes have been weeded and do not now include all relevant information. As my condition is chronic, generally settled, if gradually declining, I rarely consult my GP, so there is little current activity record. My experience of the DWP is that, by intent or accident, they do not keep records. It should be a DWP responsibility to keep records which would at least cover the situation when the benefit was first granted.</p> <p>*11. All those identified by the CAB in relation to the WCA, in their report 'Not Working', including*short interviews which do not allow time to explain complex symptoms</p> <p>*drop down answers on the computer*misinterpretation of claimant's explanation</p> <p>*failure routinely to provide a print out of the data entered</p> <p>*The Stroke Association website contains details of a claimant who, in November 2010, attended a WCA. The doctor stopped the assessment because the claimant was too distressed as it was too soon after his stroke. The need for an assessment should be decided by consultation with claimant's doctors.</p> <p>*12. The claimant's doctors should be consulted to identify the likelihood of improvement (or deterioration).</p> <p>*13. I do not accept the new system will be simpler. The DWP does not seem to find difficulty in prosecuting claimants who are seen to be cheating the system. What needs to change?</p> <p>*14. Documents in simple English and written advice from DWP staff who can be held accountable for it.</p> <p>*15. Best done by providing good, accountable advice and support.</p> <p>*16. Yes. Flexibility makes life easier.</p> <p>*17.</p> <p>*18.</p> <p>*19.</p> <p>*20. Why not make one assessment and grant all relevant benefits.</p> <p>*21.</p> <p>*22. 1. I was concerned at the short time given for responses. The following emails refer. Mr Pugh accepted my argument but made no change to closing date. As well as the consultation document itself being a considerable document, there are hundreds of pages in referenced documents, which provide background to some controversial statements - see 2 below.</p> <p>*The easiest conclusion to make is that this consultation is a sop to cover decisions already made.</p> <p>*2. There are 4 reasons given for change:</p> <p>*1. too many people get DLA; 2. claimants do not understand</p> |

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| | | <p>its purpose or that it is paid whether working or not; 3 different rates difficult to understand and administer; 4 claimants believe it to be an out of work benefit.</p> <p>*In relation to points 22.2.2 and 4, reference 5 at para 16 of the consultation is based on a very small sample for which I could find no evidence of statistical relevance of any of its conclusions, it contains considerable evidence that if there is such a problem of understanding, it exists within the DWP. As the PIP is a direct replacement of DLA, the same problems will persist. In an interview on the BBC's World at One on 7 Feb, the feature of universal credit that it is paid whether claimant is in work or not was described as a benefit. Is it proposed to introduce to the new benefit a known problem or is the suggestion it is a reason for change hollow.</p> <p>*Points 22.2.1 and 3 demonstrate a determination to exclude some claimants from this benefit and for the rest (as argued at point 4 above) to reduce the payments they receive. The Stroke Association report 'UK stroke survivors needs survey' carried out by King's College London staff concluded stroke survivors already live in relative poverty. These proposals will worsen their position.</p> <p>*In her forward to the consultation, the minister states that 'We have been absolutely clear that our welfare reform plans are designed to protect people in the most vulnerable situations, including disabled people. We are committed to a sustainable and fair system that allows people to work when they can and provides unconditional support to those who are unable to work.' It is difficult to see how the proposals match this promise.</p> <p>*Emails:*Subject: RE: Public Consultation Disability Living Allowance Reform</p> <p>*Dear Mr Pugh,*I am writing to you as the DWP Consultation Co-ordinator to express concern at the time proposed for consultation on this reform.</p> <p>*The DWP document seeking consultation states a minimum of 12 weeks is normally allowed. In this case 10 weeks have been allowed (Dec 6 to Feb 14).</p> <p>*The document is lengthy (40 pages) and potential respondents will need time to read and absorb the proposals before commenting.</p> <p>*The document has been issued in the weeks leading up to the busy Christmas holiday, when respondents (both working and none-working) will have less time for assessing the document in this period.</p> <p>*I am not aware of any announcement by the government to warn interested parties of publication of the proposal and the need to begin assessing it. Luckily, I was notified by a sharp eyed fellow stroke survivor.</p> <p>*Those affected by these proposals may well have been affected by several recent announcements of changes to benefits. While the government may well have individual teams</p> |

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| | | <p>working on these proposals simultaneously, the potential recipients of the benefits are having to address one change after another. Many will not have the stamina to match the government's output - particularly if they are ill.</p> <p>*The authors of the reform proposal suggest the normal 12 week minimum is not necessary because they are consulting on general principles only.</p> <p>*While seeking general principles, the paper is very detailed and it is important that individuals are given a proper amount of time to read, digest and comment upon the general principles. Subsequent detail will be built upon the foundations of general principle resulting from this consultation. I submit that the closing date should be extended to 14 March to take account of these factors and to allow effective consultation. Yours sincerely, [REDACTED]</p> <p><i>*Thank you for this message. This formal consultation is only part of our consultation activity on this issue. We had consulted extensively with disability organisations prior to its publication, and our Minister has given a commitment to further consult on detailed proposals arising from it. Whilst understanding your points, I am satisfied that in the circumstances described, the formal consultation period is reasonable. In terms of publicity for this, we arranged a press release and press briefing, and national press coverage was achieved. Roger Pugh DWP Communications</i></p> |
| EM836 | 18/02/2011 | <p>1. The main problems preventing Registered Blind/ Partially Sighted people from participating in society are Mobility and Access. Blind and Visually Impaired people can't drive! Accessible public transport is a must. Ability to afford taxis for unfamiliar routes is vital. The Government's rejection of EU rules forcing bus operators to have busses with audible next stop announcements and talking bus stops is dreadful. Buses in London already have this but not in the rest of the country.</p> <p>*Access is also a requirement and lack of access is a major barrier. Getting printed information in alternative formats has improved with the DDA. There is still one omission in legislation, namely digital accessibility. Cash machines are still not accessible to totally blind people. Newer ones have earphone jacks, but they don't work! They just relay the same beeps that you get when you use the cash machine normally. The earphone jacks should allow one to plug in earphones and hear the screen being read by a built in screen reader. Still no magnification option on cash machines, and no high contrast option. The displays while better on most cash machines are variable. Some have black or coloured text on white backgrounds and others have light text on a dark background that is far better. The new VISA debit cards are dreadful. The word "DEBIT" is in very dark type on a dark background and this is true for all banks I think. It certainly is for First Direct and for Nat West. My bank says there is nothing they can do</p> |

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| | | <p>about this. Why the banks can't be forced to make the DEBIT word on these cards stand out is beyond me.</p> <p>*Rail ticket machines are inaccessible. I have yet to see any electronic kiosk that is accessible!</p> <p>*Jobcentre Plus job search machines are inaccessible! This is dreadful, since it puts more pressure on DEA's and is outrageous in that these are new technology and should have had access built in.</p> <p>*Consumer goods are still inaccessible. There are no accessible DAB digital radios. None of them have talking menus or information about what is on the radio that sighted people get on the display. The displays are variable at best and dreadful at worst. Some are a lot better than others. There is one accessible talking FreeView box. There is no cheap (normal priced) FreeView PVR. The cheapest option for this is around £600 odd.</p> <p>*Buying an accessible mobile phone is dreadful. Only Vodafone will subsidise Talks. (Although now I think they will pay for Mobile Access not Talks). When I looked into getting a new phone when my one stopped holding its charge after 10 years I found that I couldn't get a mobile with Zooms on it from Vodafone. All the other phone companies won't subsidise access software at all and worse you are on your own if you get a phone from them and the Access Software doesn't work. Getting out of a contract would be difficult if not impossible! It was also impossible to see phones in action with Access Software installed. The only place I was able to see a phone with Talks working was at the RNIB and then the staff didn't really know about it! I now have an accessible mobile phone that was very cheap, but is no longer made the Motorola F3.</p> <p>*Things are slowly getting better with the iPhone. One reason why the iPhone 4 and iPhone 3GS are so popular with blind people is I think that the buying experience is so much better in this country than for any other mobile! You can try one out at your local Apple Store with the built in VoiceOver screenreader and Zoom magnification.</p> <p>*Later versions of Android are good in that they have a screenreader available, but unfortunately this is downloadable from the Android Marketplace App Store! It is not on the phone to begin with. The screenreader is free which is good. You would still have to go into a mobile phone shop and ask for the screenreader to be installed - assuming the staff knew what to do! A recent edition of "In Touch" on BBC Radio 4 said don't expect help from mobile phone shops in the UK regarding access! This is disgusting! Why should mobile phone shops get away with not providing advice and help in accessible phones! Ofcom should make it a requirement that all mobile suppliers provide accessible phones for all their disabled customers at the same rates as ordinary customers and importantly take responsibility when things don't work out</p> |

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| | | <p>properly. Also Ofcom should force shops selling phones to provide advice and support to people getting accessible phones, and should have a selection of phones with Access Software on them ready for customers to try out! My experience of trying to buy an accessible mobile phone was dreadful and I don't want anyone else to have to go through this!</p> <p>*Computers need to have built-in access as well. Apple are trail blazers in this. Microsoft has come on some what. However its screen reader Narrator isn't nearly as good as VoiceOver for the mac.</p> <p>*The fact that the Government is set against forcing makers of manufactured goods have built in access makes no sense since this would decrease the costs to disabled people considerably since for a PC a commercial screenreader and magnifier combination costs around £1200. The Apple Mac has this built-in.</p> <p>*2. The benefit should have 3 rates of benefit. Removing the lower rate of mobility in PIPs is wrong. The benefit should still be focused on the extra costs of being disabled.</p> <p>*3. I have a cleaner every week that costs £6.50. I have had new glasses last year that use complex lenses that cost £121.30. I have also had to replace my Desktop CCTV that cost £2395. The previous one was 8 years old and costed a similar amount of money. A portable CCTV £400. White sticks £8.95. I also tend to eat out during the day as cooking is difficult. I also use taxis for unfamiliar routes and if I am taking large bags to the railway station.</p> <p>*4. a. Having 2 levels of benefit isn't a good idea. It won't provide the same levels of support as those on the current low level of support for care (most Blind and Partially Sighted people) will drop off lower rate care if they are claiming it. I see minimal advantages to having 2 rates rather than 3. The assessment will be complicated anyway whatever happens!</p> <p>*b. The disadvantages of having 2 rates rather than 3 are that Blind/Partially Sighted people will drop off Lower Rate Care.</p> <p>*5. Yes as now! Getting rid of passporting will put people who have clearly demonstrable needs at further disadvantage, and will increase stress unnecessarily and also increase costs. Pasporting is a cost saving measure that means assessors don't need to check each and every condition, because some are clearly requiring benefit. Getting rid of pasporting has the effect of removing the hard won award of Middle Rate Mobility to Registered Severely</p> <p>*Sight Impaired/ Totally Blind individuals.</p> <p>*6. This is a cost cutting measure and all activities that disabled people find difficult or impossible should be taken into account is assessing the benefit. Following the Haliday case DLA can be paid for social needs as well as more basic needs. Trying to get rid of this is wrong! Disabled people are still going to be just as disabled at the end of this exercise as at the beginning. This</p> |

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| | | <p>is not an out of work benefit, you get is because you are disabled and there are costs to disability. This won't change. Disabled people are taking the brunt of the cuts.</p> <p>*7. By using evidence from the claimants GP or ophthalmologist , and having the assessment done by a qualified relevant healthcare professional. Not people in experienced in the condition of the person they are assessing as has happened on several occasions in the assessments for ESA. These are my first thoughts on this matter, this is a difficult problem and others will have ideas on this! Above all the assessor needs to be on the side of the disabled person and not trying to catch them out!</p> <p>*8. This is extremely difficult! There are two ways this can go. Either the assessor can say that "You have these aids therefore you are coping and don't need benefit" or they can use the aids as indications of need and use that as indications of requirement of benefit. If the former then taking aids into account is not a good idea! My first reaction when I read this was one of fear. a. My instinct is not to take them into account, and to try to assess the individual assuming no aids are available, and indicate what aids would be useful. This will help in the assessment of benefit.</p> <p>*b. If aids are being included they should be ones that are normally used by the disabled person concerned, e.g. Wheelchairs, crutches, CCTVs, Screen Magnification Software, Screen Readers, computers etc.</p> <p>*c. With aids the person already has the thing to consider is how were they obtained? if they were bought by the disabled person then they will need to be replaced when they ware out and this will again be borne by the disabled person. Benefit would be useful to put depreciation money aside for the day when they need to be replaced. For aids that would be useful, benefit would be useful to allow the disabled person to save for them. Both cases should be considered.</p> <p>*9. The claim form is difficult or impossible for blind or partially sighted people to fill in on their own.</p> <p>*a. The form should be available on line (Preferably with a web based form like normal web sites such as www.amazon.co.uk or www.play.com etc. and NOT a PDF that needs to be printed out and then filled in by hand and put in the post! Also the benefit should be applied form by phone as well. Note that not all blind and Partially Sighted people have access to the internet at home. The RNIB estimates that 77% of blind and Partially Sighted people don't have broadband internet at home. Note that with libraries closing the available accessible public internet terminals will be dropping. Not all libraries have accessible internet. Near where my sister lives Hassocks Library doesn't have accessible computers! The nearest it can come up with is a large print keyboard. Being able to fill in the form on your own is a double edged sword when it comes to</p> |

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| | | <p>DLA. I needed help filling it in and it was really helpful to have a benefits adviser to help me fill it in! If the Government wants to move to assessments for PIP applications then the form could be very much simplified and the main work done at the assessment. I have just gone on to the Directgov website and checked the DLA page, and there is no easy way to apply on line. The form was change in 2007 and there is still no web based on-line form! You have to printout and fill in the claim form. This is very bad practice! Blind people would have to get someone else to help them fill in the form. The website does state that people are available to help to fill in the form. Although it can be a double edged sword filling in the form on your own, not to have the option because of poor website design is in excusable since the DDA/Equality Act requires accessible information which includes forms!</p> <p>*b. The information should be available in alternative formats and on line. Alternative formats should include Large Print, Braille, audio and on line.*10. What is available and being used for DLA at present! For fluctuating conditions more weight should be placed on input from GP's etc. There certainly shouldn't be any more onerous demands for evidence! For those registered blind/partially sighted evidence for blind registration etc. should be used where appropriate particularly for the new middle rate mobility award for Severely Sight Impaired.</p> <p>*11. a. It would be more costly than having claimants fill in the forms themselves or with outside help in the case of Blind or Partially Sighted people. The other disadvantages are if the assessor doesn't understand the needs of visually impaired people then the wrong assessments can be made. This is happening in the case of ESA. The benefits are that the initial form can be much more simplified and the claimant would find the initial application much more friendly.</p> <p>*b. The case where Severely Visually Impaired people are applying for Middle Rate Mobility DLA having to have eye tests when they are in fact totally blind is inappropriate. Where there is clear passporting involved would possibly be inappropriate.</p> <p>*12. a. The frequency of review should depend on the condition of the claimant. if it is a stable condition, then the reviews should be less frequent than if the condition is changeable.</p> <p>*b. Yes! Blind/Visually Impaired people need assessments that take into account their disability! There are too many cases of people being wrongly assessed for ESA at the moment! There is a high rate of appeals for DLA at the moment as well.</p> <p>*13. By having a less cumbersome re-assessment process.</p> <p>*14. Advice about services available e.g. Home Help/ Cleaning services should be made available, also other services if suggested, then approved service providers in the local area</p> |

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| | | <p>should be made available, perhaps liaising with council social services where necessary.</p> <p>*15. This has to be avoided. If the local services are not up to scratch then forcing people to take services is not right. Having advice available at the assessment would alleviate the problem people not getting advice. However advice is still advice and can be ignored if required e.g. offered services are not suitable.</p> <p>*16. I currently fund nearly all my aids and equipment. I had a worrying appointment with Southampton Low Vision Aid Clinic recently. Their budget has been cut by 86%. I was going to have my monocular replaced as it was getting old and difficult to clean. I was told that they weren't providing these "High Power" aids anymore. I was told that there was an allowance possibly Attendance Allowance that could pay for them. DLA is the benefit for working age people and Attendance Allowance is the equivalent benefit for people of pension age. The idea of having to pay for LVA's out of DLA is appalling. There have always been provided by the NHS. LVA's are not a DLAable item in my opinion. If this is happening in Southampton is it happening anywhere else? There should be an option for PIP to meet one off costs. A lot of the aids that blind/partially sighted/severely sight impaired people need are expensive. Note that during the consultation and Southampton LVA clinic they said that they didn't stock the "More Complex" i.e. "High Power" aids because most people found that electronic magnifiers (portable CCTV's) were better. The NHS doesn't supply these. The NHS should be forced to supply basic LVA's.</p> <p>*17. I have no experience in this area, but generally the assessors should know what they are talking about, and should examine the claimant and not just look at a computer screen while doing the assessment. So if someone is blind they should concentrate on sight loss and should understand and be aware of the needs of visually impaired people. Administrative errors are unexceptable!</p> <p>*18. Passporting is vital! People on dialysis at home need passporting. Totally Blind/Severely Sight Impaired people need passporting to get Middle Rate Mobility.</p> <p>*19. I would make life far more stressful for people who could handle it the least. Getting rid of passporting is vindictive.</p> <p>*20. Information from blind/partially sighted registration should be used in the assessment for DLA for blind/partially sighted individuals. Input from GP's and ophthalmologists should also be used.</p> <p>*21. The cuts in benefit could adversely affect women, since they are the predominant careers in society and will have to take the short fall in benefits cuts and job losses. If the care components of the new PIP benefit are cut then there will be less home help support being purchased and this will have an effect of women's unemployment. These proposals will also</p> |

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| | | <p>adversely affect disabled people because the cuts will remove vital support. People won't stop being disabled because the benefit is cut! This isn't like making work pay, people don't have a choice as to whether to be come disabled, they can however TRY to find a job!</p> <p>*22. These benefit proposals are very bad for blind and partially sighted people in particular and disabled people in general. They are cuts driven. Disabled people are bearing the brunt of cuts, across government and local councils. I am not looking forward to being re-assessed for Incapacity Benefit or DLA. Getting rid of lower rate Care component is wrong! Trying to get rid of the hard won Middle rate Mobility for Blind/Severely Visually Impaired is also wrong, along with cutting Mobility Component for people in care homes. Combined with public transport cuts (mainly busses but also Taxi Cards) and Libraries (Tories have had it in for Libraries for 30 years) is dreadful. Getting rid of Libraries will get rid of accessible public internet for lots of Blind people.</p> |
| EM837 | 18/02/2011 | <p>1. Your response: The barriers are almost too numerous to list. I am a disabled person – an individual with a mobility impairment. I do not expect the earth and recognise that making certain things accessible to me will sometimes present a challenge and occasionally prove impossible. Despite a reasonable knowledge of my legal rights, strong communication skills, and a willingness to compromise, I remain regularly excluded from buildings, events and employment which could and should be made accessible to me at least according to the spirit of the various equality laws in this country. On some – but by no means all – of the occasions I have been excluded, I have had at least a theoretical right to take legal action against the people or organisations responsible. In practice, I could afford neither the time, energy or financial risk for what would've been very limited gain. For me, enforceable anti-discrimination laws which compel employers and organisations to take seriously their responsibility to treat disabled people equally is imperative.</p> <p>*2. Your response: Disability Living Allowance (or its equivalent) needs to be a payment which is flexible. By that, I mean there should be at least a chunk of the payment which comes without conditions and the recipient can choose how they spend, when they need. I have cerebral palsy. My walking is extremely limited and my stamina greatly reduced. My own impairment is unpredictable, my needs are unpredictable, and therefore the financial (and emotional and physical) cost of my impairment is often equally difficult to judge. Sometimes I will find my ability to walk is restricted, and need to pay for taxis if I am continue leading an independent and active life. Sometimes I will discover myself suddenly exhausted and completely unable to shop for food or do laundry. On those days I use my DLA to pay for food to be delivered or get my laundry service washed.</p> |

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| | | <p>My local authority can help me with none of these things because my needs are not consistent enough – I can sometimes do all of these things – but my DLA enables me to live independently without asking for additional help from central government or my local council. Last year, I paid more in tax than I received in DLA and I do not believe this would've been possible without my having a regular DLA payment which I was trusted to spend as I needed, when I needed.</p> <p>*3. Your response: Last year, the costs I incurred as a direct result of my impairment were significantly more than the total DLA payments I received. I am responding in a personal capacity and for me the costs were: the price of taxis due to inaccessible public transport and limited stamina, the cost of having my laundry service washed at least twice monthly, the costs of a cleaner to do my weekly housework because I have neither the physical capacity or the stamina, the cost of additional water because I have no choice but to bath daily (my impairment makes me extremely stiff; hot water provides necessary relief), and the cost of additional heating because I get very cold, very easily. In addition, I wear out a pair of shoes a month as a direct result of my impairment, and have to take unpaid time of work to attend medical appointments. (I am self-employed.) Beyond DLA, and unlike some other disabled people, I do not qualify for any assistance from my local council or central government with these needs.</p> <p>*Because of my stamina problems, I am unable to work for as many weeks in the year as my non-disabled colleagues. This requires considerable financial planning on my part and I consider the lower earnings a direct 'cost' of my impairment, though one not as obvious as the shoes, taxis, and so forth. Likewise, I live in private rented properties and cannot drive due to my impairment, so need to live within my walking distance of accessible public transport. Consequently, I pay significantly more in rent each month than my peers who earn similar amounts</p> <p>*4. Your response: How easily the new benefit is understood surely depends on how well it is explained. Clear communication is essential. At the moment, I receive the lower rate of the care component of DLA and the higher rate of mobility. I feel I might be entitled to the middle rate of the care component but I have not attempted to reapply because I realise my award can go down as well as up, I have had problems with applications being declined in the past, and I simply cannot afford to lose the payment I do get. A transparent and consistent application process where the most claimants receive the correct award first time is more important to me in terms of ensuring appropriate levels of support than any worries about varying rates. However, where rates do vary there will always be a risk for people – like myself – who fall into the grey area between two categories.</p> |

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| | | <p>*5. Your response: I feel all awards should be based on needs and circumstances. It's possible that people with certain impairments will automatically have those needs and circumstances, so automatic entitlement for those people should not be ruled out altogether. After all, assessing people unnecessarily is a waste of time and money. However, careful consideration should be given to which conditions might qualify as there are some anomalies in the current system.</p> <p>*6. Your response: For me, the key is flexibility. Rather than offering payments for specific activities or because of specific impairments, offering payments which enable the recipient to make clear choices about how best to use the money they receive, in conjunction with other services if necessary.</p> <p>*In a personal capacity, the essential activity is the ability to make independent decisions about how to live my life. The ability to work, the ability to be happy, the ability to access transport and go where I want and need to go, the ability to socialise with family and friends and make my own decisions about how to live my life.</p> <p>*7. Your response: I have an unpredictable, variable and fluctuating condition, and with that, unpredictable, varying and fluctuating needs, so this question is key for me. Although my impairment (cerebral palsy) is relatively common, the way it manifests itself in my case is relatively rare, and this, in combination with its variability, has led to difficulties with previous DLA assessments. I believe very strongly that in my case, it would've helped if a medical professional who knows me personally was involved in the assessment process, and that his opinion was taken into account before I went to appeal. (A stressful process for my family and an expensive one for the taxpayer.)</p> <p>*8. Your response: I am concerned by this question. I use various aids and adaptations, the most obvious being a specialised walking stick. I also use certain types of specialist technology. I am entitled to no support to fund these adaptations – my specialist wanted to try inserts in my shoes last year and I had to pay for a pair of shoes myself for him to experiment on – so I use my DLA to contribute toward the cost when I am able. I do not believe any aids or adaptations an individual has had to fund themselves should be taken into account.</p> <p>*I've also had experience of being given equipment which was supposed to, for example, help make it easier for me to prepare meals, but did not have the desired effect. If equipment IS going to be taken into account, it is therefore important that assessors take the time to find out if the disabled person does get as much benefit from the item as they are theoretical supposed to.</p> <p>*For that reason, I am highly sceptical about aids which an individual might 'easily obtain' being taken into account. For</p> |

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| | | <p>one thing, I have never been able to ‘easily obtain’ a single mobility aid or adaptation. Finding the right piece of equipment is a lengthy and complex process. For another, it is impossible to say what effect an aid or adaptation might have on an individual’s life until they have it and have got used to using it. I have had numerous false starts with equipment which was supposed to be life-changing for me but in fact were desperate failiures.</p> <p>*Likewise, managing long term chronic impairments is sometimes more art than science. I’m someone who chooses to walk with difficulty rather than use a wheelchair. A wheelchair might be an option for me one day, but for the moment, walking suits my life and is better for my health than wheeling. However, superficially it appears to many – even some non-specialist medics – that a wheelchair would increase my mobility. The expert medics who know me well support that decision. I would be worried that someone without that knowledge might decide I could ‘easily obtain’ a wheelchair and assess me as such, when wheelchair would have a detrimental impact on my life.</p> <p>*9. Your response: I have two English Literature degrees and find the current claim forms impossible. Two things would help. First, a shorter form asking fewer questions, but allowing longer answers. For me, the current Access to Work claim form and follow up process works well. You say who you are, what your impairment is, and what you believe your support needs are, after a handful of open-ended questions. You then speak to an individual adviser who discusses this with you, conducts an assessment if necessary, and makes a decision. It’s a much smoother process and does not require fitting very specific and individual needs into uniform boxes.</p> <p>*In terms of improving information, write this in plain English rather than jargon that sounds like a foreign language. Have helpline staff who are actually able to help, rather than repeat scripted lines. I once called the DLA helpline because I received two letters containing conflicting information about whether or not I needed to be re-assessed. I called the helpline for advice and the call taker simply read me the second letter very slowly. I explained I understood the letter but it conflicted with what I’d been told the previous week. She was unable to assist and the mystery took weeks to unravel. A helpline people can call and receive real information and constructive help would go a long way to promoting understanding.</p> <p>*10. Your response: As I said above, for people with complex conditions, rare conditions, or common conditions which present themselves in an unusual way, I believe the only way to assess people and get clear evidence is by involving an expert in that condition, usually one who knows the individual concerned.</p> <p>*11. Your response: When being assessed for benefits or</p> |

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| | | <p>services in the past, I have had difficulties with healthcare professionals who do not understand my impairment, or have limited time and are therefore unable to conduct a full assessment of my needs or listen to what I am telling them about the impact of my impairment on my everyday life. Once, my application for DLA was declined because the GP conducting the assessment wrote that he believed I would recover in 6 months. Since cerebral palsy is a lifelong condition, this is clearly an extraordinary and erroneous opinion, yet I had to go through an appeal process to overturn it. It later emerged that I was the first person with CP this particular GP had ever met. That is clearly inappropriate. I therefore believe individuals should be assessed by healthcare professionals with expertise in the impairment of the person they are assessing.</p> <p>*It would be inappropriate to reassess an individual only if they had already been assessed as having a lifelong condition which was static and would never improve.</p> <p>*12. Your response: I believe the frequency of reviews should be determined by the likelihood of an individual either recovering or worsening. It makes sense to focus resources for reviews on those people whose needs are most likely to alter.</p> <p>*13. Your response: Offer a variety of response methods: eg. Phone, text, email, post. Also be clear about what constitutes a change in circumstance. Almost all impairments fluctuate to some degree or other, like anybody's daily health. Therefore be clear about what changes you wish to know about and how long they should be in evidence before you'd expect an individual to report a change. Tailor those requirements to the individual if possible, because people's impairments vary so much.</p> <p>*14. Your response: Please be extremely clear about what you want to know. There is a great deal I could tell you about my impairment but only a small part of it is relevant to any given benefit application. Please be extremely clear about what evidence you would like us to provide in order to support our claim as at the moment what you want and how you want us to present the information can be tricky to establish, hence many unnecessarily rejected claims and avoidable appeals.</p> <p>*15. Your response: I am lucky enough to be adept at accessing the support I need to live a happy, functional life as a disabled person. It is my experience that I could access or be referred to any number of services, and have several different appointments every week if I wanted. My own experience suggests that while most of these appointments are well meant, many of them are circular and offer no practical benefit to my life. Over decades of experience, I have learnt to accept referrals to the service I feel are most useful, and decline the others, allowing me to get on with my professional and personal life.</p> |

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| | | <p>*My first concern with this proposal is that someone like me would end up being required to attend appointments I had declined through personal choice and for good reason, and I'd end up being compelled to attend them by the DWP rather than doing a day's work instead. That would be daft.</p> <p>*My second concern is that, as I said before managing long term chronic impairments is sometimes more art than science. I'm someone who chooses to walk with difficulty rather than use a wheelchair. Walking suits my life better than wheeling and the expert medics who know me well understand why and support that decision. It is complex, and a generic assessor without specialist knowledge of me or my impairment might misunderstand my reluctance to attend certain services as unwillingness to co-operate.</p> <p>*16. Your response: I fund my aids and adaptations through earned income, DLA and gifts from parents. I feel lucky to have earned income and parents who can afford to gift me money occasionally. I would be extremely happy if I had the option of using PIP to meet a one off cost, were there anything that expensive I needed.</p> <p>*17. Your response:</p> <p>*18. Your response: I do feel that DLA as a gateway benefit is problematic. There are some people who do not fit DLA criteria but are disabled. As a result, they cannot access other services that would be of benefit to them, and that does not feel fair. An improvement would be that unsuccessful access to DLA did not automatically bar certain other services, and vice versa.</p> <p>*19. Your response: I would worry about endless assessment – each benefit and service demanding it do its own assessment before you can access it.</p> <p>*20. Your response: I would be very happy for information to be shared among carefully selected department and individuals if it meant an end to endless time-consuming and distressing assessments. I would be very happy for certain elements of my medical records to be shared – with my consent – for the purpose of benefit assessment. For instance, a specialist physio recently did a comprehensive assessment of my impairment and its impact on my life, more thorough and accurate than any the DWP had ever done. Sharing this would increase the accuracy of DWP assessments of me and save time and money for me and everyone else involved. However, I would be concerned that if my physio recorded I had a few good days, or weeks, or months, this would lead to a halt in my benefit before the change was sustained or permanent, so information like this would have to be used with care.</p> <p>*21. Your response:</p> <p>*22. Your response: Much of the rhetoric is about people with the greatest need or most severely disabled. I am someone with moderate needs and moderate disability and in the words</p> |

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| | | <p>of my neurologist, I 'function very effectively' in the world. It happens that my moderate needs have a huge impact on my life, socially, professionally and financial. Presently DLA is the only support I get. Because my needs are not more severe, I am not entitled to anything else from the state, and I do not really expect that I should be</p> <p>*Currently I receive less than £300 a month in DLA payment. The real costs of my disability support needs are far greater than that. I pay more tax than I receive in DLA and I reckon I am pretty good value to the UK! I want the government to know that I am grateful for the money I receive, I invest it carefully to ensure I am able to live life to the maximum, and as a result I work almost full time, pay tax and have an active, happy social life. Without DLA, I am far from convinced I would be in a position to do any of that. Of course it is right that most of the limited resources for these payments are targeted at those with the greatest needs. No one would argue with that. All I'd ask is please do not assume that those with less severe needs can manage without assistance – in my experience, that is not the case.</p> <p>*Equally important, those of us with complex and variable needs often have difficulty accessing other sorts of support because our needs are inconsistent. DLA is brilliant for me because I am able to spend it on anything I deem appropriate to meet my support needs, at the precise moment I need that item or service. I realise that providing money without strings can be difficult for governments, but for someone in my position the flexibility is invaluable.</p> |
| EM838 | 18/02/2011 | <p>1. Public transport; rural bus services are still very poor and tend not to run in the evenings, necessitating the use of expensive taxis - or not going out.</p> <p>*Reasonable adjustments by employers for people with variable disabilities, such as medical conditions that frequently prevent someone working for short periods of time, such as a week. This is not necessarily something that private sector employers can or should be expected to address alone.</p> <p>*2. Assessment according to need, not diagnosis.</p> <p>*3. Transport, special diets, heating, special equipment.</p> <p>*4. Your response:</p> <p>*5. If some conditions have consistent outcomes in terms of level of disability, and little likelihood of improvement, it would not be cost-effective to assess individual circumstances due to the possibility of reducing entitlement and thus making savings. People with such conditions should be entitled to ask for benefit to be increased, however.</p> <p>*6. The activities most essential for everyday life will depend on what sort of lifestyle the individual wants to lead and the resources available to them. The support required could be determined by observing people with differing levels of disability through a typical day, and noting the problems they have, or by</p> |

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| | | <p>asking them to do a 'think-aloud' whilst carrying out everyday tasks. These are questions that could most appropriately be answered through a formal research project rather than a public consultation, since people are often so used to their disabilities they overlook factors that prevent them from leading what would be considered a normal life.</p> <p>*7. Ask applicants to keep a diary for a week or a month prior to assessment and use the record as an indicator of variability. Alternatively use time-sampling; the applicant records what they can/can't do or are/are not doing at regular intervals over a week or month. This is another potential research project, since it's quite likely that some conditions show consistent patterns of variability - people with chronic fatigue syndrome might be able to function normally for a brief period each day, or for two days a week, for example, but then spend the rest of their time having to recover from exertion.</p> <p>*8. The assessment should be looking at what financial support the person needs in order to be able to lead what most people would consider to be a normal life. If, with aids and adaptations, they can lead what most people would consider to be a normal life, the cost of the aids and adaptations that allow them to lead such a life needs to be taken into account.</p> <p>*Some aids and adaptations might be relatively inexpensive and in widespread use, such as spectacles, hearing aids and walking sticks and might be excluded from the assessment; others, such as wheelchairs, scooters, stairlifts and more specialised aids and adaptations might be more expensive and more difficult to obtain and therefore should be included in the assessment.</p> <p>*9. The claim form is difficult to fill in because the same disabilities need to be described from different perspectives. This makes the form very lengthy, requires a great deal of repetition and is akin to completing an exam paper, where one is constantly required to think about what the question means. In my son's case, relatively minor visual and auditory impairments have had a complex and significant effect on his ability to lead a normal life in many respects, but rather than explaining the core problems and listing the problems that arise from them, I had to provide the same information in multiple ways.</p> <p>*Other ways of eliciting information about disabilities would be to ask the person to describe the lifestyle they would like to have, and for a description of the lifestyle they do have. The account could then be scored in terms of disabilities. The account has to be backed up by an assessment of ability and doctor's comments, so would be verified.</p> <p>*Alternatively, a long list of the most commonly encountered disabilities and their degrees of severity could be listed and could then be scored by looking at a pattern of ticked boxes. The option of providing additional information could be</p> |

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| | | <p>provided.</p> <p>*Information about DLA is readily available, but is not always being accessed by people who need it. The most obvious solution would be to have a clearly-worded leaflet available in doctors' surgeries, and for doctors to encourage patients to give the leaflet to patients to whom it might be relevant.</p> <p>*10. The problem with 'ability' is that it is contextual. The person best placed to provide supporting evidence about ability is the disabled person themselves, but the reliability of their evidence is sometimes questionable.</p> <p>*Any benefit for people with a disability requires an assessment of the individual involved. The temptation for government is to minimise costs by providing assistance in terms of cash only after a 'quick and dirty' assessment. The risk is that aiming for short-term savings can result in higher long-term costs, as we have seen. Because the individual's specific disabilities and unique circumstances need to be examined anyway, what might be more cost-effective in the long-term, and of more benefit to disabled people, would be to set up local disability clinics, which could provide a team assessment from, say a GP, physiotherapist and clinical psychologist, and which could also offer advice and ongoing support from specialists, including other disabled people, on specific aids, adjustments to lifestyle, support organisations, work opportunities, benefits advice etc. Such clinics would also have benefits in terms of an aging population likely to encounter many of the problems experienced by people with disabilities.</p> <p>*Benefits would be awarded according to need. Anyone with a confirmed long-term disability, known to be unlikely to improve, and that incurred significant ongoing expenditure would not need frequent re-assessment and would get a higher rate of benefit. Someone with a variable disability that incurred few costs would get a lower rate, but might need to be re-assessed at regular intervals.</p> <p>*11. Disability is very wide-ranging. It is highly unlikely that 'a healthcare professional' is likely to have sufficient experience in every type of disability to carry out an accurate assessment, especially during a short examination. For many people, disabilities are very variable - they might be technically able to stand, sit, walk for 50m, put on their socks etc, but whether they can do so all day, every day in all circumstances likely to be encountered is another matter.</p> <p>*It could be informative to run pilot assessments comparing validity and reliability using 'a health professional', a GP, a physiotherapist, another disabled person, and a team to see what results emerge.</p> <p>*12. Some disabilities are known to be unlikely to improve and the extra expense involved in maintaining mobility, diet etc are predictable; people in this category could have infrequent reviews. Other disabilities can change and would require more</p> |

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| | | <p>frequent review.</p> <p>*13. Framing disability support in terms of cash only brings with it the risk of attracting fraudsters and the temptation not to report improvements in circumstances. Currently it is very difficult for disabled people to obtain aids, advice, support and information, including medical information, that might help them address their problems and improve their quality of life. In my experience DLA payments are often used in lieu of the practical support that the person actually needs and would benefit from accessing. It would be interesting to see if there are changes in the rate of under- and over- payments if support in kind is offered prior to a financial award. *14. As the parent of a child claiming DLA, I have found it very difficult to obtain relevant medical information, speech therapy, occupational therapy, advice on communication aids, mobility aids etc. In my experience the NHS currently operates a system of triage; patients with no medical problems are reassured, patients with serious or easily treatable medical conditions are treated, and everyone else, including patients with difficult-to-diagnose disorders and the disabled, are the walking wounded. With hindsight, I know that with the right information, and with timely intervention, my son's disabilities would have been considerably less than they have been to date. With appropriate information and interventions I have no doubt that the bill for DLA would be lowered. Unfortunately, the management of public sector services through budgets means that there are groups of people who fall between several stools; no service wants to be burdened with spending money on them. Disabled people are one such group. Disability needs to be addressed through a whole-system approach. In spite of much rhetoric about joined-up thinking, piecemeal strategies have remained the norm.</p> <p>*15. If advice and support were easily accessible, then more people would be likely to 'take action' and a 'requirement' for them to do so would not be needed. As an able-bodied, articulate person, I have found trying to access advice and support for my son extraordinarily difficult and so exhausting, frustrating and demoralising that my own health has suffered. It seems inappropriate to be talking of 'requiring' disabled people to access advice and support when systems issues make it so difficult to access advice and support that someone with no disabilities is tempted to give up in despair.</p> <p>*16. They often go without aids and adaptations because they can't afford them. Or relatives pay for them. Yes there should be a payment to meet a one-off cost.</p> <p>*17. Children's disabilities, by definition, are going to change. Sometimes the disability increases, because the developmental gap between a child and his or her peers widens. Sometimes the disability lessens as the child learns coping strategies. The need for more frequent assessment is an obvious outcome.</p> |

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| | | <p>*What has concerned me as my son has grown up is that as more professionals have understood the social model of disability, so fewer have an understanding of the physical origins of the disability itself. My son has relatively minor visual and auditory impairments that because of the way they have affected his development, between them have had a significant impact on his quality of life. But so far, it has proven impossible to get a thorough assessment of visual and auditory function, never mind treatment. Early assessment and intervention might have resulted in him not being seen as having a disability at all.</p> <p>*18. Your response:19. Your response:20. Your response:21. Your response:</p> <p>*22. Your response:</p> |
| EM839 | 18/02/2011 | <p>Please find our consultation response attached.</p> <p>*1. Illness affects lives as well as disability Difficulties with transport and getting about Cognitive difficulties *Speech and language problems Financial difficulties Access to required NHS services/medications Access to other help/services Prejudice against disability/illness</p> <p>*2. Being non work-related Being non means-tested Being linked to the Motability scheme</p> <p>*3. Help with personal care Transport/getting about Help around the home (cleaning, gardening etc)*Equipment for mobility and exercise Adaptations to the home</p> <p>*4. Two rates may make the benefit easier to administer, however it may mean that it cannot be targeted as specifically to a person's needs as DLA's three rates can be.</p> <p>*5. Some conditions are always debilitating from the outset and should receive an automatic entitlement. It is degrading to be made to jump through hoops to qualify for benefit when your needs are already obvious.</p> <p>*6. Local Authority disability registration records should be taken into account to be able to prioritise cases.</p> <p>*7. Advice from an applicant's GP and other health professionals must be taken into account for this.</p> <p>*8. Yes, as these can indicate the seriousness of a person's condition. However, an applicant should not be penalised if they choose not to use a particular aid which may be available to them.</p> <p>*9. The current application process is rather crass and does not address an applicant's individual needs. Being disabled/ill means that life can be very difficult and complex and the benefit application process really needs to address this. A one-fits-all approach to disability does not work.</p> <p>*10. An applicant's own health professionals e.g. GP, consultants, community matron, physiotherapist.</p> <p>*11. For applicants with complex conditions, the healthcare professional conducting the assessment must have an adequate knowledge of that condition. A basic GP will not do.</p> |

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| | | <p>If an applicant's own healthcare professionals provide advice that the applicant clearly meets the qualifying criteria, then an assessment should not be necessary.</p> <p>*12. Evidence provided by the applicant's own healthcare professionals should be used for this.</p> <p>*13. Your response:</p> <p>*14. Anyone applying for the benefit should be supplied with all applicable information otherwise the whole application exercise would be compromised.</p> <p>*15. Your response:16. Your response:17. Your response:18. Your response:</p> <p>*19. Your response:</p> <p>*20. Attending any sort of assessment can be physically/emotionally difficult for disabled/ill people so any duplication should be avoided where possible. An applicant can indicate which information they are content to be shared and they would then be aware if this would lead to the need for a further assessment.</p> <p>*21. Your response:</p> <p>*22. It is vitally important that those people with a genuine entitlement to the benefit are not denied it. The Government's priority should be to target the many people who receive benefit but have no real claim to it rather than those who are genuinely disabled/ill whose lives are difficult enough already.</p> |
| EM840 | 18/02/2011 | <p>1. • Lack of proper legal protection/advocacy • lack of money and jobs • bad attitude towards disabled people in society, in particular discrimination from employers • lack of good access, not enough accessible public transport • fear of crime/hate crime • redundancies and the recession.</p> <p>*2. Your response: GPs know the applicants and therefore should understand the issues faced by them. How can someone who doesn't know you assess you? Cars are a necessity to many, so Motability is vital. People living in care homes, etc., should still get the mobility component of the new benefit.</p> <p>*3. Your response: Transport, wheelchairs and other equipment, clothing, laundry, adaptation of cars/van conversion, employing personal assistants</p> <p>*4. Your response:</p> <p>*5. Your response: If your condition is unlikely to improve (or never to), at least significantly, this should be taken into account. Mental health should also be taken into account, and memory problems.</p> <p>*6. Your response: Work, seeing friends and family, visits to hospital/outpatients/podiatry/GP, collecting prescriptions, shopping, trips out (theatre, sporting events, etc.) attending places of worship.</p> <p>*7. Your response: Even fluctuating/variable conditions can be lifelong, so they should be treated as such; i.e. depression, bipolar disorder, etc.</p> |

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| | | <p>*8. Your response: Just because someone has, for example, a wheelchair or prosthetic limb, it doesn't mean that it is the equivalent of having fully functioning limbs. For example, it often takes more time and energy getting to places than it would for non-disabled people. Also, not all wheelchairs and scooters fit on public transport, and many of these rely on batteries which can go flat.</p> <p>*9. Any form should be simplified as far as possible and vetted by the Plain English Society. Easy read versions should be readily available.</p> <p>*10. Your response: This may vary from day to day, so it can be very difficult to assess ability. *GPs, district nurses, Occupational Therapists, Special Educational Needs Co-ordinators, teachers, relatives.</p> <p>*11. Your response: As mentioned before, how can someone you don't know possibly assess your condition? How can people be selected two will be compassionate and listen carefully and use common sense? Whoever does the assessments should not just be in it for the money – it needs to be a vocation for them. Some people get very flustered when being questioned by people, especially strangers, so they would not respond well to being interrogated.</p> <p>*Some people are very loath to talk to strangers – for example, some on the autistic spectrum. There are others who find communication difficult anyway, so another way may need to be found. There are some people who may present a danger to themselves or others.</p> <p>*Some people have chaotic lifestyles, which means that it may be hard to conduct a meeting with them as they may not remember, or they may not be in a fit state to be interviewed. They may not wish to be met at their own home.</p> <p>*12. Your response: It may prove difficult to schedule reviews for people with some fluctuating or varying conditions, including some mental health conditions. Some conditions are completely stable and never change and this needs to be reflected. However, some conditions deteriorate rapidly.</p> <p>* People have different communication needs, and some may need more time and patience when interviewed. Others may need to respond using technology such as PCs, communication grids/boards etc. and this takes more time as well.</p> <p>*Others still may need interpreters – i.e. Deaf or Deaf/blind people – or people to act as advocates.</p> <p>*13. Your response:</p> <p>*14. Your response:</p> <p>* 15. No. The system should be right in the first place. Advocacy organisations and the experiences in particular of Citizens' Advice Bureaux with regard to the pilots should be given particular weight. You cannot coerce people to get advice, and such advice may not in any case to be available. An objective of the policy should be to minimise the numbers of</p> |

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| | | <p>appeals and people who need encouragement to take action. Cart before horse.</p> <p>*16. Your response: 17. Your response: 18. Your response: *19. Greater impact on local authority budgets which are already under significant threat.*20. Your response: Medical records, with the consent of the disabled person.</p> <p>*21. Significant adverse impact on those whose disability impairs communication; they will be more likely to struggle to communicate the nature of their disability to those who do not know them and their condition.</p> <p>*There is an adverse impact in general terms.</p> <p>*22. The consultation has only run for 9 weeks, despite Government guidance suggesting that 12 weeks is appropriate, it also creates problems for people who have alternative communication needs.</p> |
| EM841 | 18/02/2011 | <p>Dear Sirs 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.</p> <p>*I wish to raise general points about the proposals, as well as a specific concern about proposal item 40 “whether or not we should take into account a child’s support needs if they are being met from public funds by another institution, such as a school”.</p> <p>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: <ul style="list-style-type: none"> *o Transport to appointments & parking; *o Specialist buggies for older children; *o Road safety equipment for older children; *• General Health and Safety – our children lack safety awareness: <ul style="list-style-type: none"> *o Road safety equipment for older children;; *o Locks, stair gates and similar for older children *o Night safety equipment for older children; *o 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, |

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| | | <p>highly disturbed nights going on up to 16 years of age, bed wetting, vomiting and night disturbance. This incurs additional costs such as:</p> <ul style="list-style-type: none"> *o Sleep Apnoea alarms – for breathing problems affecting sleep; *o Decongestants;*o Additional night laundry – up to 6, 7 times a night; *o Bed rails for longer than children of the same age; *o Greater breakages; *o 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; *o Shocks and scares can provoke cessation of breathing, this can involve admission to hospital; *• Additional laundry and cleaning costs: <ul style="list-style-type: none"> *o Greater electricity use; *o Greater washing machine use, more frequent replacement; *o Need to have more much bedding and clothing than for another child; *o Much greater use of baby wipes beyond the age of three; *• Special correspondence in relation to medical appointments, a child’s Statement of Special Educational Needs, or communication with schools: <ul style="list-style-type: none"> *o Incurs additional PC, printing and writing material costs; *• Specialist food and feeding equipment – since so many of our children are impacted by significant sensory issues and / or allergies; *• Specialist clothes, because of our children’s low muscle tone: <ul style="list-style-type: none"> *o Shoes; *o Body support corsets; *• 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: <ul style="list-style-type: none"> *o Specialist putty; *o Chewy Tubes; *o Computer programs; *o SLT resource books and materials; *o Adapted bikes; *o Adapted swimming kit; *o Trampolines; *o Specialist chairs / tables / pens / writing slant; *o Specialist classes such as music, dance, swimming needed as Occupational Therapy; *• Specialist training and courses for parents (and carers); *• Specialist childcare such as Little Angels, an agency employing staff specially trained to look after children with special needs; *• Additional holiday related costs: |

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| | | <p>*o 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>*o Higher rates of travel insurance, especially if heart condition;</p> <p>*o 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 outside of school. In addition, school holiday periods are not covered by provision in school, so that holiday respite or childcare would need to be by a paid trained specialist, or by specialist play centres manned by trained staff – there are already too few of the latter, and many are currently closing.</p> <p>*A further specific concern relates to the proposal to introduce eligibility for support only 6 months after diagnosis. In the case of Down Syndrome, diagnosis is at birth, while children with Down Syndrome typically require often intensive medical intervention within their first 6 months of life. This incurs significant additional costs. A three month delay in eligibility for financial support is already damaging, extending this to 6 months would represent further damage to families at their time of greatest vulnerability, and would additionally risk the long-term health of children.*I am 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. I 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. I 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, I have wider concerns about aspects of the proposed DLA reform, as follows:</p> <ul style="list-style-type: none"> *• Costs associated with Down Syndrome are not only about healthcare, but reflect a range of support and care needs, which must be taken into account; *• It is exceptionally rare for a person with Down Syndrome not to have expensive additional support needs as an adult; *• Finally, families with children with Down Syndrome are already placed under significant and measurably damaging financial pressure. Families of children with Down Syndrome |

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| | | <p>have been shown to suffer:</p> <ul style="list-style-type: none"> *• Reduced earnings – diminished by 1/3 with a child with disability; *• Greater incidence of marital break up and divorce; *• Negative impacts upon siblings, often necessitating additional sibling childcare, if a principal carer has to attend additional appointments. <p>*The consequences of taking away some of the already inadequate levels of DLA financial support, many of which will incur additional costs to the State, include:</p> <ul style="list-style-type: none"> *o Children with Down Syndrome becoming adults with less independence, needing more expensive care, since they will be more socially isolated and physically dependent; *o Greater financial stress upon families, in particular restricting the capacity of both parents to attain full time employment, thus reducing family earnings and tax and NI contribution; *o An increase in the numbers of children needing greater, and more expensive, institutional care; *o An increase in rates of separation and divorce among families of children with Down Syndrome. <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. Yours faithfully,</p> |
| EM842 | 18/02/2011 | <p>I am concerned that the move to examination by a health care professional will not allow due weight to other evidence. My mother had a stroke 10 years ago. She thinks she can do more than she can. This is part of the brain injury the memory is there - but the reality she she cannot write or understand new tasks.</p> <p>*Please ensure that other evidence is taken into account when deciding PIP, especially in cases of brain injury.</p> |
| EM843 | 18/02/2011 | <p>1. It depends on the disability. You can't even generalise about all people with the same disability. For example, for my son (who has autism), the barriers are within himself (he has no sense of danger, few social skills and violent, uncontrollable rages) and also within society (rigid rules, others' attitudes).</p> <p>*2. The rates at which DLA is paid. People build their lives around the money that they have coming in; reducing the amount of payment would result in financial problems, and people with disabilities already have enough problems.</p> <p>*Also, the willingness to listen to professional evidence from someone who knows the disabled person should be retained, although it is debatable whether that always happened under the current system (where a DWP-paid doctor who had never met my son made decisions about him that were contradicted entirely by my son's consultant, but it took a lengthy appeals process to reverse that decision). A system based purely on a visit to the disabled person, like my son, by someone who was not an expert in his very complex condition and who did not</p> |

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| | | <p>know him well enough to understand the difficulties that he faces would not be fit for purpose.</p> <p>*3. Again, this will vary from disability to disability and person to person. In my son's case, the extra costs incurred by his disability are multiple: he needs specialist 1:1 childcare as he is unable to access mainstream childcare for the hour after school that he needs caring for until I get home from work (I could, of course, leave my job, but that would cost the country money in other ways). He also needs specialist 1:1 support at any social activities. These two costs are unaffordable without his DLA. His DLA also goes towards the cost of making the house safe, providing specialist sensory equipment to keep him calm and replacing the items that he damages in an involuntary, violent, uncontrollable meltdown – which often occur daily.</p> <p>*4. Two rates would make the benefit easier to understand and administer; however, I worry about the people who fall between the two rates, who would probably end up on the lower rate when they would have previously qualified for the middle rate. I would, instead, prefer a move to three rates for both components, corresponding to the terminology of mild, moderate and severe needs. I don't agree that two rates would 'reflect the range of individual need' at all; it would do the opposite.</p> <p>*5. I think that the 'severely mentally impaired' entitlement should remain the same, as it is a clear definition which would have the same outcome for all those who would fall under that description, regardless of external factors. Aside from that, all claims should be based on the needs of the individual; however, there should be a recognition within the decision-making framework of the basic problems that all people with a certain disability will face, rather than every claimant having to prove how each and every aspect of their disability affects their life. For example, children with autism will all suffer from communication and interaction impairments and repetitive behaviours/ rigidity of thought. This should be a given as it is part of the diagnostic criteria. What should be considered on an individual basis is 1) what additional difficulties arise from the individual's presentation of that condition and 2) how those behaviours affect their daily lives.</p> <p>*6. The only good thing about the current form is that fact that it is not a checklist or a scoring sheet. It allows you to describe subtleties or intricacies about an individual's condition that are essential to help the DWP assessor understand the impact of the individual's condition.</p> <p>*The definition of a full and active life/ the activities most essential for everyday life are:</p> <p>*The ability to be able to get to places independently and safely</p> <p>*The ability to clean, feed and look after yourself safely, healthily and successfully</p> <p>*The ability to communicate with others successfully</p> |

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| | | <p>*The ability to make safe and rational choices</p> <p>*The ability to access social opportunities</p> <p>*The ability to access meaningful education, employment or other undertakings or activities</p> <p>*7. I don't know. I guess making the penalties severe enough to deter people from not reporting a change in circumstances would be one way, but the fraud rate is so low that this seems irrelevant. I would make the guidance clearer on calculating an 'average' week, month or year, to help give an overall picture.</p> <p>*8. Unsure. If assessments are individualised, this should be irrelevant.</p> <p>*9. The only good thing about the current form is that fact that it is not a checklist or a scoring sheet. It allows you to describe subtleties or intricacies about an individual's condition that are essential to help the DWP assessor understand the impact of the individual's condition. However, it is far too long and traumatic to fill in; I would prefer a move to a system where claimants could have a choice to rely more on professionals' evidence about the disability – I mean expert professionals who know them, not unknown assessors – rather than having to write everything out.</p> <p>*I'm unsure what the problem is with the current information available to people about who qualifies. I personally think that people know who qualifies and I also don't believe that A) many people think that they can't work on DLA or B) changing the benefit to a new name will make the people who were unclear clearer.</p> <p>*10. Professionals' evidence about the disability – I mean expert professionals who know them, not unknown assessors – is essential.</p> <p>*11. In my son's circumstances, this change to a face-to-face meeting would be extremely dangerous, upsetting and quite pointless. If someone came to our house, they would probably be attacked with furniture if my son was in aggressive mode, or else he would injure himself repeatedly if in withdrawn mode. He hates strangers and would not communicate with them anyway. It would also be impossible for anyone to appreciate the level and challenges of my son's disability without spending significant amounts of time with him. A meeting elsewhere would be similarly traumatic, for different reasons. Perhaps this assessment works for those with physical, concrete disabilities but not mental disabilities.</p> <p>*12. I agree that reviews should be carried out if a condition is likely to change. There are some conditions which are unlikely to change much and so it seems inefficient, as well as needlessly costly and stressful, to keep reviewing them. Initial assessments could ask professionals who know the disabled person for their prognosis, which could help determine length of awards.</p> <p>*13. I guess making the penalties severe enough to deter</p> |

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| | | <p>people from not reporting a change in circumstances would be one way, but the fraud rate is so low that this seems irrelevant.</p> <p>*14. What is out there that can be accessed without having to use DLA to pay for it. Yes, it would be helpful for the process to help signpost.</p> <p>*15. Unsure. You would need to avoid adding to problematic lives.</p> <p>*16. Unsure</p> <p>*17. I am appalled by the implication of this statement: “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” as it implies that a child who was already receiving the most help at school might see their DLA reduced. This would be extremely unfair, as the children with the most help at school are likely to be the most disabled and therefore with the highest level of need at home. I think that Statements of SEN should be considered a key part of evidence, as they are a legal document and therefore the information that they contain is already likely to have been checked, re-checked and fully verified. However, some areas issue more Statements than others, so having a Statement shouldn’t become a hoop to compulsorily jump through.</p> <p>*18. I know that it is a qualifying benefit for some things but don’t know much about this personally.</p> <p>*19. Many would lose out, financially and possibly in other ways too.</p> <p>*20. For children: Statements of SEN statutory assessments.*For children and adults: initial and core assessments by Social Services.</p> <p>*21. If your assessment process is a tick-box approach, geared more towards physical disability, you will be discriminating against those suffering from a less tangible disability.</p> <p>*22. Whatever you do must take into account the fact that DLA is not claimed fraudulently by many people. Evidence suggests that it is, in fact, under-claimed. Therefore, cutting expenditure by 20% already suggests that people will lose out unfairly.DLA is not easy to get as it is. If you make it harder, you will be denying disabled people the help that they need.</p> <p>*People (like me) buy their houses/ agree their rent/ plan their budgets around what they have. When I bought my house, I knew how much I earned and I knew how much DLA my son was getting. Neither seemed likely to change at the time, as my job is very secure and my son’s needs only worsen with time as the gap between him and his peers widens ever-further. It is therefore unfair to change the goalposts without consideration to the fact that my son losing his DLA would send our world into meltdown. Without that money, I would have to choose between selling the house to pay for what DLA had previously paid for, or stopping my son from accessing leisure and childcare safely and successfully. Both choices would result in</p> |

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| | | turmoil for my son. Whatever changes are made need to be made with that responsibility in mind. |
| EM844 | 18/02/2011 | <p>Dear Sir/Madam Please find below my response to some of the questions posed in your recent consultation around DLA and PIP. I have formed these responses following discussions with professionals in occupational therapy, re-ablement services and welfare benefits advice services. I have also spoken to the lead Councillor for Adult Social Care in the Bradford District, Cllr Amir Hussain, who is in agreement with the responses I have given below. I hope you find them useful when developing a fair and sustainable benefit to support some of the most vulnerable people in our society.</p> <p>*Incidentally, when I've looked at the figures for those claiming DLA in the my local authority area, what I've found is that the rate of new claimants from one year to the next since May 2010 receiving DLA has either dropped or stayed the same and the increase in the overall numbers of people currently receiving the benefit is for those who have been receiving the benefit for 5 years or more. The media releases put out seemed to suggest that hoards of people were queuing up to claim the benefit year on year, this just isn't the case.</p> <p>*Also, would someone in your office let the Prime Minister and Iain Duncan Smith MP know that people claiming DLA, and PIP in the future, can work and claim this benefit at the same time as it is not primarily a benefit for those who are unable to work through their condition. The media release issued around the Welfare Reform Bill yesterday suggests that both of them think the benefit is for those who are unable to work!*Please find my responses below:</p> <p>*2. Response: The qualifying period should stay the same or be reduced. The benefit is aimed at supporting people to maintain their daily lives. Without support, even three months is too long to expect people, who are facing additional costs due to their condition, to maintain their 'normal' lives. A delay of 6 six months could mean 'normal' daily living routines/activities were no longer an option. People should get some benefit immediately and then have a full assessment for the continuation of the benefit later, and increased benefit should be back dated in exceptional circumstances. The benefit should also be available for people who are temporarily affected by a condition, such as following stroke where it may take the individual some time to recover capabilities, as this would support them to maintain their normal lives. Once the temporary condition had resolved itself the benefit could be withdrawn.</p> <p>*These measures would provide support to people when they needed it and stop or slow down people's needs from escalating. People with degenerative conditions should not have to undergo a review to assess if they still need the benefit. They should only be reviewed with a view to increasing award to the higher level. Unless there are major advances in medical</p> |

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| | | <p>or support technology, people with a degenerative condition who are receiving the higher level awards should not be required to undergo a review. Those in receipt of the benefit should be reviewed more intensely to ensure the right level of support is being awarded. The current rates (3 for care and 2 for mobility) should also be maintained See response to question 4 below.</p> <p>*4. Response: No, effectively the lower rate for care would be removed meaning that people who currently get this support would no longer receive it. It is easy to understand at present 3 rates for care comprised of 2 rates covering care during the day and a higher rate covering night time care with 2 rates for mobility. This makes the benefit more flexible, than the proposals, to meet people's needs.</p> <p>*A consistent and objective assessment would make the benefit easier to understand and administer.</p> <p>*€ What, if any, disadvantages or problems could having two rates per component cause?*Response: The proposal would mean that people with lower care needs could be excluded from receiving the support and this would mean that they would also lose their passport to other entitlements.</p> <p>*8. Response: Yes, aids and adaptations used should be taken into account.</p> <p>*The assessment should be about function and not about the type of disability. In some instances aids and adaptations can enable people with a disability to function in the same way as people who are non-disabled.</p> <p>*The assessment should consider what a person can actually do and this would include with the use of any aids, equipment or adaptations and not on what the particular disability could prevent them from doing. There is a need to move from just considering 'deficit' to including consideration of 'assets'.</p> <p>*However, whilst aids, equipment and adaptations can be beneficial in supporting people to live their lives, their use should not mean that the individual is not assessed for the benefit nor that the individual is denied access to DLA or Personal Independence Payment. Using an aid etc. does not always remove the need for additional support. Whilst people may be able to get around using a wheelchair, the use of this equipment may also take a fair amount of energy leading to tiredness and there may be more need to have access to taxis and additional energy through increased intake of high calorific food stuffs.</p> <p>*Even when people can use equipment etc. to support their daily lives, consideration needs to be made for the timely replacement or upgrading of these items so that they can continue to benefit from this support.</p> <p>*Aids and adaptations may be available in the persons own home but would not support their life outside of their home. Access to any aids and adaptations to support the normal life of</p> |

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| | | <p>the individual in all circumstances needs to be considered when deciding eligibility and rates.</p> <p>*€ What aids and adaptations should be included?*Response: All aids, adaptations and equipment should be considered.</p> <p>*€ Should the assessment only take into account aids and adaptations where</p> <p>*the person already has them or should we consider those that the person might be eligible for and can easily obtain?</p> <p>*Response: Individuals should be assessed and advised about what aids, adaptations and equipment could promote their independence. This could be part of the overall assessment process for accessing Personal Independence Payments.</p> <p>*The assessment should consider the impact of aids etc. that could be beneficial to the individual whether they are using them at the time of the assessment or not.</p> <p>*A view to what aids, equipment or adaptations could be beneficial to an individual would need to be provided by a properly qualified person.</p> <p>*There must be an expectation that needs will be met in the most cost effective way possible.</p> <p>*9. Response: The application form needs to be supported with guided notes that explain the process and also what will be taken into account when determining eligibility and level of award. Questions need to be posed correctly to get the factual information from people about how they are managing to carry out daily tasks. Asking how someone does something rather than if they can, would give a better indication of any support required.</p> <p>*€ How can we improve information about the new benefit so that people are clear about what it is for and who is likely to qualify? Response: see above</p> <p>*Have consistent approach to making decisions and be able to communicate why the decision has been made in enough detail to the individual so that they can understand on what grounds the decision has been made.</p> <p>*Make it clear that DLA/PIP claimants can work and working will not affect their entitlement. *10. Response: Evidence from GPs. However, currently GPs can charge up to £90 to individuals for providing this evidence. Evidence should be provided in an equitable manner and at no charge to the individual. GPs also need support to enable them to provide the correct evidence to support the assessment process.</p> <p>*Evidence should be consistently presented and be objective and not subjective.</p> <p>*Evidence from the individual should be accepted. GPs can get it wrong e.g. finding people with terminal illnesses fit for work.</p> <p>*It would be dangerous to rely on evidence from consultants who do not see individuals often enough and also from GPs where the individual may not attend for regular appointments.</p> |

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| | | <p>*Although Occupational Therapists could provide valuable evidence to support an assessment of ability, the current waiting times to access OTs would mean that this was an unviable route.</p> <p>*Any medical assessments should be tailored to the benefit being applied for. Therefore it is not appropriate to use the medical assessment that deems someone to be ineligible for Employment Support Allowance to be used to determine that the person is also not entitled to DLA or PIP.</p> <p>*Where specialists are unable to give a firm future prognosis for recovery, DWP should award the benefit and reassess continuing eligibility in the future.</p> <p>*13. Response: Some people have fluctuating conditions and it would be difficult for them to identify that things have improved long term. At what point would there be an expectation for an individual to inform the DWP of an improvement?</p> <p>*The DWP need to be really clear about what constitutes a change in circumstances that will need to be notified. If there is just a vague requirement to notify any changes in circumstances this would likely lead to people worrying unduly about minor changes adversely affecting their income and a need to reassess where there was no real reason to do so.</p> <p>*Although being assessed can cause distress to an individual as it can impact on income, it would be better to have more regular assessments of ability to determine if the correct level of award was being made. This would have a cost implication on the DWP and maybe a reassessment every 2 to 3 years would be appropriate.</p> <p>*However, where someone was not receiving the higher rates they should be able to notify earlier and get re-assessed on this basis.</p> <p>*14. Response: People applying for PIP need a full welfare benefits assessment at the same time. Therefore they would need to be sign posted to this provision. If the Government is serious about ensuring that support is there for the most vulnerable, this would require more funding to the sector in order for this to happen.*Information should be available to applicants providing examples of what qualifies for support along with guided notes to help applicants fill in the form properly. Additionally, questions should be worded in order to get the best information from the applicants regarding their abilities and how they currently manage to carry out tasks etc.</p> <p>*15. Response: Any claim for PIP should not be held up whilst the individual is required to access other advice and support.</p> <p>*A component would be that if applying for PIP an individual would be given a full benefit check and help, from an impartial professional, to fill in the forms.</p> <p>*People are currently losing the right their right to claim DLA as</p> |

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| | | <p>DWP are using the same assessment to determine eligibility as they use to determine limited capability to work through ESA but DLA is not about a person's ability to work therefore this is the wrong assessment tool to use.</p> <p>*Claimants should not be stigmatised but should be supported to access the support they need and are entitled to.</p> <p>*16. Response: Currently there is no charge for equipment and it is not means tested. For major adaptations individuals can apply for a DFG (Disability Facilities Grant), this is means tested. In some instances the adaptations are provided by the RSL (Registered Social Landlord)</p> <p>*However, many individuals pay for aids and adaptations themselves out of their DLA such as vibrating alarm clocks, speaking software for computers etc.</p> <p>*There could be an option to use PIP to meet a one-off costs and this should be coupled to access to further funds for maintenance, repair, replacement and associated insurance costs.</p> <p>*18. Response: It has been very useful. If the lower rate of care is removed then people who won't qualify for PIP won't be pass ported to these other entitlements as there is no other route to them at present. Removal of the lower rate for care would adversely affect children with learning disabilities.</p> <p>*The DWP would need to look at how people who might not be eligible for PIP would be able to access these other entitlements. In doing this, they would need to consider any subsequent pressures on professionals carrying out additional assessments if these were required in the future and the affect on people's independence of having payments delayed further due to pressures in the process.</p> <p>*Pass porting works well at the moment. Passport to free prescriptions would improve the current arrangements.</p> <p>*19. Response: See above response to question 13.</p> <p>*System could face unmanageable pressure if assessments etc. were needed to confirm eligibility for currently pass ported entitlements. This could result in people not receiving the support they need when they need it. This could result in people having to access higher level services to meet their needs.</p> <p>*20. Response: Assessments need to be appropriate for the benefit being applied for. The combining of assessments could lead to people not being able to claim for the support they are entitled to.</p> <p>*The current arrangement when permission to share information must be obtained from the individual should remain.</p> <p>*The assessment needs to take account of how other assessments are currently weighted i.e. critical, substantial, moderate and low and any other provision being provided to the individual needs to be taken into account when assessing in relation to the effect this has on the individual's ability to</p> |

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| | | <p>function e.g. DFG.</p> <p>*22. The number of people claiming DLA should not be a reason for reforming it. If more people need support in their daily living, they need that support.</p> <p>*Conditions affect people differently and people should be assessed on their individual ability and not on what could be 'expected' to be the ability of an average person with the condition.</p> <p>*Support needs to be there when people need it, not six months down the line.</p> <p>*People with learning disabilities or mental health conditions find it difficult to claim due to their conditions. DWP needs to consider how it can improve processes to ensure this group of people can access the support that they are entitled to.</p> |
| EM845 | 18/02/2011 | Scanned image] |
| EM846 | 22/02/2011 | <p>I have received a notification from Your mailbox to say that my consultation response could not be received as the file was too large. I will try to send a compressed version, which I hope you will still accept, even though the deadline has passed, since it is your computer system that has been unable to handle the size of the folder. Please let me know if there is a problem with this.</p> <p>*1. • Being seen as a drain on society rather than economically active</p> <p>*2. • I think that separate components or benefits for care and mobility are needed</p> <p>*3. • Housing• Heating• Water (if metered)• Telephone• Clothing• Food</p> <p>*• Laundry• Household equipment and furniture• Transport• Attending social events</p> <p>*• Accessing work• Personal assistants/carers• Holidays• Home maintenance including cleaning• Garden maintenance</p> <p>*4. • It would be better if the two rates were more obviously related to levels of support needs/physical disability/mental disability. Currently, the two rates of mobility component actually cover different things. For example, currently, people think that if their walking ability is not quite as bad as 'virtually unable to walk' they should be entitled to the lower rate of the mobility component, whereas the lower rate is actually for people who require guidance and supervision.</p> <p>*• Having only two rates for the care component will create huge jumps in the level of benefit from nothing to a lower rate and from the lower rate to the higher rate. The three rates currently available at least mean that there are three steps. Ideally, there should be more of a sliding scale rather than different rates as this would better reflect the spectrum of people's needs.</p> <p>*5. • I think there are very few health conditions or impairments which affect people's ability to get around or care for themselves in a predictable way. Mostly the way people are</p> |

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| | | <p>affected varies considerably and is affected to some extent by lifestyle and mental capacity.</p> <p>*• However, if someone is totally blind, for example, there are anomalies in the current system. A blind person whose family does all of their household chores for them would only be entitled to the lowest rate of the care component whilst a blind person who performed all of their own household chores but needed frequent support in order to be able to do so would qualify for the middle rate. Yet you could argue that both require similar amounts of help but in different forms.</p> <p>*• I do think that certain conditions could be exempted from more detailed scrutiny and lead to an automatic entitlement to benefit, such as total blindness, profound deafness, amputations and health conditions resulting in a very short life expectancy.</p> <p>*6. If the first question is asking how we identify those people who require support, then we still need a combination of self-assessment plus independent evidence. However, it needs to be made clearer to applicants that they do need to provide evidence and they need to be encouraged not to guess at the extent of their difficulties as they currently do. I often see people complete the DLA forms to the effect that they can only walk five metres in ten minutes – clearly physically impossible and not helpful.</p> <p>*The independent evidence also needs to directly answer the relevant questions, perhaps on a pro forma that the applicants can give to their ‘referees’. Currently, there is too much ambiguity and decision-makers are left to infer meaning.</p> <p>*The second part of the question:• The first priority needs to be support which people require to maintain their health and safety, such as medical procedures, nutrition, hygiene, supervision and maintaining a satisfactory living environment. Currently, the support has to be intimate and personal but this overlooks the essential nature of some tasks that people require help with such as food shopping, cleaning and laundry. This would make more sense than the current basis of the care component, ‘bodily functions’• Then priority needs to be given to the support that people require to assist them in leading fulfilling, meaningful and productive lives i.e. to take part in family life and the wider community in a way that makes sense to them.</p> <p>*7. • There does need to be a minimum length of time that a condition has to exist before benefit can be awarded – currently 9 months. However, there needs to be a better system of being able to take account of conditions that medical experts believe will improve within the time limit but then do not. There needs to be a mechanism by which the decision can be deferred until after the 9 months has expired. •</p> <p>*8. The assessment should take into account aids and adaptations. I also feel that, as part of the process, if</p> |

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| | | <p>appropriate, people should be encouraged to have Occupational Therapy/physio assessment for aids and adaptations. Many people come to tribunals and tell us that they have not told their doctor about certain difficulties they are having or have been unaware that they could have an OT assessment. This could improve the quality of people's lives as well as being cost-effective in the long run even if it means an increase in the need for OT's and the provision of more expensive equipment.</p> <p>*9. • The on-line and paper versions of the forms need to be more similar than they currently are.* There needs to be a checklist for accompanying documentation etc. listing evidence that needs to be supplied, investigations and advice that have been sought, for example prescription print-out,</p> <p>*10. • Medical reports from GPs, consultants, physios, OTs, Community Nurses etc</p> <p>*• Social care assessments, such as Initial Assessments or Common Assessment Framework assessments for children and Care Management assessments, care plans or support plans for adults that have been agreed by social care professionals</p> <p>*11. • I don't think that the 'mechanised' medical assessments, which are used for the WCA format, are helpful. A discussion-type interview might be better but it does need to be coupled with a physical examination.</p> <p>*• Face-to-face interviews/examinations are not helpful for many people with mental health problems as they often find the situation very distressing and their difficulties are not easy to assess in a single interview.</p> <p>*• Similarly, such interviews may not always be appropriate for children with autistic spectrum conditions.</p> <p>*12. • I think that in renewal application forms it should be made clear to the claimant that, if the DWP are not going to look at the papers from the original award, they must describe their circumstances fully. This would help claimants realise that it is not enough to state 'nothing has changed', which often leads Decision Makers to conclude that they have no care or mobility needs as none have been stated on the renewal form.</p> <p>*• However, I think that the DWP should retain all the information for the life of a current claim and be able to refer to it for renewals/reviews. This could be done digitally to aid storage and retrieval.</p> <p>*• I think the current system of determining the length of DLA awards (and thus renewal/review intervals) works reasonably well.</p> <p>*• I think there are some people whose condition is unlikely to change for whom there would only be a need for them to declare periodically that nothing has changed. However, there are others who should be required to submit evidence of their continuing need for the benefit at appropriate intervals.</p> |

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| | | <p>*13. • They could be required to declare annually (at the time of the annual uplift) on a tick list that key changes have not occurred in the previous 12 months and that they will inform the DWP if such changes should occur in future. This would help to remind people of the changes which the DWP needs to be informed about.</p> <p>*14. • If the PIP is a 'passport benefit' for other things, such as a blue badge, it would be useful to inform people at the time the award is confirmed and on renewal/review.</p> <p>*• They could also be given information about how to apply for social care support and Occupational Therapy assessments to help with aids and adaptations.</p> <p>*15. Your response:</p> <p>*16. • I think the ability to use the benefit to lease a Motability vehicle etc should remain.*• Perhaps a similar scheme could be used to lease/buy equipment/adaptations</p> <p>*17. Your response:18. Your response:</p> <p>*19. • This would lead to an increase in the number of assessments people would have to have in order to access other benefits and services</p> <p>*20. Your response:21. Your response:</p> <p>*22. • A major benefit of DLA, both for children and adults, is the fact that the money can be used by the recipients in a way which best suits them. Unlike Personal Budgets, it does not have to be accounted for in minute detail, which would seriously detract from its usefulness. For example, a family with a disabled child has a myriad of extra expenses embedded in their general living costs, such as housing, transport, clothing, laundry, furnishings, telephones, child care, food, heating etc. The DLA can be used to help support all these extra costs without causing huge expenditure of effort in quantifying exactly what these extra costs are. The same can be said for adults in receipt of DLA and also older people in receipt of Attendance Allowance. Thus I do not feel that there should be any attempt to combine PIP and social care Personal Budgets. • There needs to be a closer look at the way in which Local Authorities treat DLA/PIP when assessing for charges. Many disabled people, who only have state benefits as income, are being charged substantially in excess of what they receive for care despite having all the other extra household expenses outlined above. If the government assesses that someone should receive a certain weekly amount to pay for their care needs, how can a Local Authority demand more than this?</p> |
| EM847 | 14/02/2011 | <p>An individual's response to the Public Consultation on the reform of Disability Living Allowance</p> <p>*This response has been written by an individual, who is both a disabled person and a carer of two disabled people,</p> <p>*Question 1 The twelve basic rights of a disabled person are: access to the environment, services, communication, advocacy, transport, information, housing, education, employment, health</p> |

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| | | <p>and healthcare services, social and leisure activities, income and benefits, equipment and telecare and self directed support and personal assistance.</p> <p>*Disabled people face the following barriers when they try to participate in society, and also live an independent life: - physical barriers and environmental barriers, poor information and communication, people's attitudes to the disabled person as well societal attitudes, organisational, institutional and administrative barriers. These barriers could be things like no step free access to buildings, information not accessible to the disabled person, inappropriate communication, the disabled person is seen as thick, stupid or a waste of space, the disabled person might be ignored and the carer may be talked to instead, the workplace, school or public building may not be accessible for the blind person, deaf person or someone who has a learning disability. There may be inaccessible transport, information is not given to the disabled person to allow them to make an informed choice, and there may be unequal access in the area of the law.</p> <p>*The disabled person may think that they cannot participate in society as they are a problem, they may perceive themselves as not having rights, and they may feel that they are unable do anything, but rather things are done to them or for them.</p> <p>*Question 2 DLA is currently being paid as a form of recognition that the disabled person has needs which may or may not be met in other ways it is up to the disabled person to spend it as they feel that they need to – this is an area where they can have some sort of control, freedom and independence. If this is taken away as is being suggested that this would be contrary to the stated aims of the government to increase a disabled person's right to control, freedom and independence. DLA is currently flexible in what it can be used for and this should continue. It can be used for heating, leisure activities or anything else that the disabled person wants to spend the money on. DLA is used towards the cost of maintenance of equipment, or replacement. DLA is also used to help towards the costs of higher utility bills. The disabled person is the best person to decide what to spend their DLA on, if they are capable of doing so, or be able to help decide how to spend the benefit on. It should not be for the DWP to decide what the money is spent on, as every disabled person is different, and their needs will be different.</p> <p>*Question 3The high costs that are faced by disabled people include:- medical bills, prescriptions, high water bills (due to a high level of laundry), heating bills – being at home more than a non disabled person, or needing to keep heating up due to impairments, special diets, having shopping delivered, maintaining a vehicle – which may be specially adapted for their needs, the cost of the internet – so that they continue to have community links, the high costs of a hotel room – if it needs to</p> |

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| | | <p>be especially adapted one, or they need to pay for their carer to stay with them, they may need to pay for an interpreter, or an assistance dog. The cost of travel for disabled people will be higher, as even if they can use community transport – they may not be able to access the accessible vehicles.</p> <p>*Disabled people may not be able to access public transport and so be reliant on either accessible vehicles – in the form of community transport, or taxis – which may or may not be able to take on the specific wheelchair used by the disabled person, or be reliant on being able to be driven by a carer or their personal assistant in their car if they are unable to drive themselves.</p> <p>*Disabled people also rely on taxis or being driven by other people if they are unable to drive themselves. They may not have very good levels of concentration, or co-ordination due to their disabilities. This is another area where transport can be expensive.</p> <p>*The disabled person may also need to pay for someone to do their housework, shopping and garden maintenance – this is a cost that non disabled people do not have to face. They are able to do these things. The disabled person may also need to have someone come in and do things such as change a light bulb, or other everyday activities which they cannot do.</p> <p>*Question 4 a) The advantage of having 3 rates of care, as is the case at the moment is that DLA can be paid to someone who may not be able to access any support from another service (i.e. social services). The 3 rates of DLA does show that everyone's needs are different, and that this is the best way to recognise the difference in need. With low rate care, you only need to show that you get a minimum of 7 hours care a week. This currently works out at £2.25 per hour. If that was going to be provided by social services – it may be decided that despite the disabled person needing 7 hours of care a week, it is more cost effective to have it all on the same day or only have 2 sessions of help. With having 3 rates of care, you are able to provide help to those who may not get help from social services and that some people who have needs, but are not deemed medium do at least get some care support. I do not think that just having 2 rates for the 2 components will make it any easier to understand or to administer. The problem at the moment is that there is not a campaign to ensure that there is a greater increase in take up, or that disabled people know of the existence of DLA. It would also be better to improve the existing scheme, rather than creating something completely new.</p> <p>*b) With the existing 3 rates of the components – it does guarantee a person can get some support. Whereas if there are only 2 rates, then a person may lose out not only in not getting this benefit, but also they may not get any support from social services – as they are deemed not disabled enough – with the tightening of eligibility criteria. Another thing to consider is that a</p> |

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| | | <p>disabled person may have needs that this benefit can meet – but they are deemed not disabled enough to meet the requirements for either rate of benefit.</p> <p>*Question 5” The existing automatic entitlements should remain in place. This is because someone who has a learning disability or who is blind or deaf or severe speech problem will have these problems for life. The costs associated with these impairments may also remain unchanged. The current automatic entitlements work at the moment in an efficient and effective way to allocate some resources. There is no way that it should be a points scoring exercise. People have disabilities, and need help and support to overcome not only these disabilities but also the barriers that are put up by society. DLA is paid in recognition that disabled people have needs, for which they may not receive help from other sources.</p> <p>*Question 6 “The new benefit must ensure there is some focus on people who have additional costs as this may be the only way in which they can get support. With the tightening of eligibility criteria for social services support, it will be harder for a disabled person to be able to access that area of support. The payment of DLA/PIP is in recognition and this should remain so, that the disabled person has needs which need to be met.</p> <p>*Activities which are most essential from everyday life include interaction and communication, getting around not only their house but also outside, being able to get dressed, feed oneself and look after personal care. These are needed regardless if a person works or not. If DLA is taken away from someone, who is deemed not to be disabled enough to merit social services help, then they may have to stop paying for someone to help them with getting dressed, getting around, interacting, joining social activities etc.</p> <p>*Question 7” The prospective test is going to be difficult with fluctuating conditions as it contains an element of predicting the future. It is also going to be a snap shot of what the disabled person is on that day. For example, a person with ME or MS might be feeling great on the day of the test, but the following day be not able to do anything. The new test will also find it difficult to determine how conditions like ME or MS have an impact on day to day living. There is another problem with the proposal in and that is it takes place over a short period of time. This is a particular problem with things such MS are progressive and this must be taken into account. *Question 8” If a disabled person needs any aids or adaptations, then these will be used to help them with everyday activities and also to attempt to overcome any disabilities. As I have said before, a person in a wheelchair – may still have difficulty in getting out to their day care centre, place of work, if they cannot access the accessible transport due the type of wheelchair that they have. A disabled person should be allowed to decide what aids and</p> |

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| | | <p>adaptations that may use, rather than be under pressure to use a particular aid or adaptation. Aids and adaptations is a very wide area, it could include medication, self help things such as therma wraps, or other things that can be bought. A disabled person may find that a particular aid or adaptation is useful, but another disabled person may not find that they are useful. A disabled person is still a disabled person whether they use aids or not. By using aids and adaptations, the disabled person is able to have some independence. Not all people with this who have the same condition will use the same aids and adaptations. A person in a wheelchair will still have mobility problems whether they are in their wheelchair or not. You may have someone with arthritis and needs a wheelchair but another person does not need a wheelchair. Just because someone doesn't need a wheelchair now, it does not mean that they will need it in sometime in the future. Therefore I think that the assessment should not take into account aids and adaptations if they're already in use or how the person may use them in the future. A disabled person is supposed to have choice, freedom and independence, and then they should have freedom in this area as well. With the disabled person being able to choose what aids and adaptations that they wish to use, it will save the government money – rather than money being spent on unnecessary aids and adaptations. By giving disabled people DLA/PIP – the government is using it to save money in the long run. Without this benefit, then the costs to the NHS and social services will be greater as the demand for the aids and adaptations increases. Also under the new form of NHS, there is going to be an increase in post code lottery – some disabled people may be able to get aids and adaptations on the NHS, whilst others will not. At least with DLA/PIP benefit the rates of benefit are the same across the board. It will be increasingly difficult to get aids and adaptations from social services due to the tightening of the eligibility criteria.</p> <p>*Question 9 “a) One of the ways in which you can make the process for applying the benefit easier is to make sure they were to be questions asked on the form are clear and easily understood. Another way would be to ensure that they don't ask repetitive questions when people have already answered questions earlier on in the form. The disabled person is an expert when it comes to their disability. The disabled person's carer is also the expert when it comes to describing how the disability impacts on the disabled person who is claiming the benefit if the disabled person is unable to complete the form by themselves. Another way would be to encourage the disabled person, or their carer, to go and get help from other sources – such as CAB, or other disabled people, so that they are answering the questions in a truthful way. The present form is better than what has been used in the past. This should continue. It is useful that there is space to fully describe what a</p> |

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| | | <p>disabled person means by how the disability affects their life.</p> <p>*b) One of the ways in which the disabled could be encouraged to claim the benefit is to stop talking about it as if it was an out of work benefit. It is at the moment paid to disabled people whether they are in work or not. The government could also ensure that there are a big publicity campaign encouraging disabled people to claim the benefit. There is a wide spread agreement that pensioners should be encouraged to claim what is rightly theirs, and this should be the case for disabled people. Information leaflets explaining the new benefit should be produced in the widest possible number of formats (easy read, Braille, large print, audio, in different ethnic languages etc.). Disabled people should be encouraged to contact the local organisations who can help them complete the forms. These organisations could be providing advocacy, information and advice for disabled people and their carers by disabled people and their carers.</p> <p>*Question 10” This is another question where the disabled person should have the freedom and choice to decide who is best able to provide any supporting evidence to back their claim for the benefit. It may or not be their GP, consultant, their carer, their support worker, or someone else who could provide evidence on how the disability affects the disabled person. The disabled person is the best placed person who can describe their disability, and they are the best person to decide who should be approached in asking for supporting evidence. If the disabled person is unable to decide this, due to say having a learning disability, then it should be the carer who decides this.</p> <p>*Question 11” The difficulty in having a face-to-face discussion with a healthcare professional is that they may not understand what the disabled person is saying. If the disabled person is deaf and is reliant on sign language, or they have a speech impairments, or they have a learning difficulty then they may not be able to communicate with the healthcare professional. These problems may be made worse if the disabled person is not allowed to have their carer or a representative in the room with them. A deaf person who relies on sign language must be allowed to provide their own interpreters otherwise a lot of time could be spent on the deaf person getting used to the interpreter and vice versa. This may result in them losing their entitlement to benefit.</p> <p>*The healthcare professional may not have any knowledge or expertise in the disability that the disabled person has. They may not understand that a person with a learning disability or a speech impairments needs to have plenty of time to think and to answer the questions. This again could result in a withdrawal of benefit, and a loss of entitlements to other benefits or services.*The professional may have a rather thick foreign accent which may make it difficult to them to be understood. The disabled person may be vulnerable due to their disabilities,</p> |

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| | | <p>and therefore it may not be appropriate for them to have a face-to-face meeting with a healthcare professional. This would be regardless of whether the meeting took place in their home or at another location.</p> <p>*Question 12” If there are to be periodic reviews, then they should be as now every three or five years. Some conditions do change over time, and the needs do perhaps change. However, if a person has been assessed as being entitled to benefit – for example high rate mobility due to being blind or deaf or they have a speech impairment or a earning disability, then these should not be reviewed periodically. Their needs will not have changed since the first time they were assessed. If they had a speech problem when they were a child they will always have a speech impairment. The costs that these people face will be the same, they may need to have an interpreter, or carry a hearing loop with them or have someone with them who can help them to interact with the society. However it will not make it very cost-effective for the government to insist that these people have to go through repeated assessments or reviews when there is a clear entitlement to benefits. A person who has arthritis or who has lost their limbs will not suddenly improve and no longer have arthritis or grow limbs. The stress and exertion caused by repeated assessments may make someone's condition worse. A person with chronic depression will not have their condition helped by the stress and worry that they may lose their benefit.</p> <p>*The reviews that are carried out at the moment are when the benefit is for a set period of time, for example for 3 or 5 years. This is set by the DWP, and is not dependent on the condition or impairment of the individual. It would be too expensive for the government to have different reviews for the different impairment/conditions. If someone has several impairments would they be expected to undergo several reviews to get their benefit? Just because a person is deemed not to be disabled enough to get the benefit on a particular day – does not seem to be fair. A person may be well on that day, but not great on other days – how would that be factored into the reviews or the assessment by the healthcare professional. Just like a person who has revised well for exams, but does badly, so a person who has to undergo a review – may not be showing a true reflection of what their life is really like.</p> <p>*Question 13” By expecting the disabled person constantly report changes to their conditions, then make the situation very onerous, stressful and burdensome. It would not just be disabled person would find a situation very stressful, it could also be the DWP staff. The DWP staff may end up spending more time on the phone noting any changes, rather than actually assessing a new application or a renewal application. It is adding another layer of bureaucracy when the government should be making it easier for disabled people to claim what is theirs. When should a person report a change, on a good day</p> |

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| | | <p>or on a bad day? If they are constantly reporting changes for fear of losing benefit then they may spend not enough time on trying to live an independent life. Changes may be very slowly, but there could be deterioration in their condition, as well as improvements. These variations are subjective and not objective.</p> <p>*If someone has a condition such as ME or MS, it may be difficult to work out if a change should be reported. The focus is being taken off the overall condition/impairments, and putting it on simple changes. With some conditions any changes may be gradual, and an individual may not necessarily realise that that they have had a change in their condition.</p> <p>*A disabled person should not be penalised for not informing the department about change in condition. The change is not always very significant. By my introducing the possibility of penalties, the DWP may have an extra level of bureaucracy which is costly in these financial tight times. There should be clear easy to understand guidance or what changes should be reported. In the past where changes in circumstances have not been reported, they have not been viewed as either fraud or error by the DWP. This should still be the case.</p> <p>*Question 14” It should again be up to the disabled person to decide whether they want to find out what types of information and advice that they may find useful. They may already be doing the right things in managing their condition. Each person is different, and so some people might find that their condition is managed in a certain way, whereas another disabled person may not find that useful in managing the same condition. There is no guarantee that the NHS or social services would be able to provide the information and advice that the disabled person has been referred to them for. They may decide that the disabled person is not entitled to that piece of advice, information, or aid and adaptation because they do not fit the criteria that these two bodies have when deciding who would get what piece of advice or information. Many disabled people already know what’s available and try to use this, but that does not stop them from being disabled. With the cutbacks in social care and possibly the NHS, the disabled person may not be able to get their the help that they need.</p> <p>*I do not think that the staff at the DWP are the best placed people who would be able to advice on what is available locally. They would have to know what was available in Surrey, Cornwall, Cumbria, London, Merseyside etc. Each place would have different things available. What is available in one part of the country may not be available elsewhere. The best people to be able to advice would be those who are in the locality already and are able to provide advice, support, information on what is available locally for disabled people and their carers.</p> <p>*I am not sure whether making this type of device and information as part of the benefit claiming process would be</p> |

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| | | <p>useful or helpful. I do not think that by making it a pre-requisite for getting benefit will actually help the disabled person to feel that they have freedom, control and independence. This government seems to want this on one hand, but by possibly insisting on it seems to be going in the opposite direction. Disabled people, it must be remembered, are not automatically guaranteed help from either the NHS or social services.</p> <p>*Question 15” A disabled person may not take any action to find out any advice and support, because they had not got the means in which to get hold of the advice. For example they may not be able to use the Internet, or the phone, or write, or be about to find out information in the library (if there are any libraries that can provide this information). They may be also members of minority communities which restrict usage outside agencies for help. It should be up to the disabled person whether to use the information given to them. The disabled person has the right to choose whether to take up the advice or access the information, after all a non disabled person is not compelled to do things so why should a disabled person? A disabled person must have the freedom to decide what they want to do or not do whether to take up advice or not. The DWP must ensure that disabled people have the freedom of choice and there should not be any compulsion to do something. A disabled person may not be able to act on a piece of advice due to their disability.</p> <p>*Question 16”DLA is paid in recognition that a disabled person has needs, and this is done after an assessment. Disabled people should continue to have, as they have currently, the right to decide what aids and adaptations they will use and what they will not. Each disabled person is different, so their use of aids and adaptations will also vary. Some disabled people do not use aids – for example a person with a learning disability – but they are not less disabled than a blind person who uses a white stick, or a guide dog. It should be up to the disabled person what aid they will need. They may get them from the government they get them from social services or the NHS or buy it from a shop. But it should be up to the disabled person to decide what aid they wish to have and where they might get it, or at least try to get it. The disabled person used to be able to have access to the Independent Living Fund.</p> <p>*DLA is also used to maintain and replace as necessary the aids and equipment. With the NHS failing to help disabled people and maintain equipment, it is necessary for the disabled person to be responsible for this. Aids and equipment are not bought once. They may be bought repeatedly, or repaired and certainly maintained. The consultation seems to be suggesting that the disabled person ability to get aids and adaptations is to move away from a non means tested way (DLA/PIP) to a means tested way – the NHS and social services. Both of these latter bodies will be tightening their eligibility criteria – so make</p> |

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| | | <p>it harder for the disabled person to get the aid that they need.</p> <p>*The disabled person should be allowed to decide what maintenance an aid needs, or if it needs replacing - and use the benefit accordingly. The NHS is failing to help disabled people in this area, so if the disabled person is reliant on them to provide help with maintaining it or replacing it – they may not get that help.</p> <p>*Question 17” Disabled children differ from disabled adults in the way that conditions affect them. If you have a newborn disabled child, it may be difficult to predict how that disability will change over the lifetime. For example, it used to be that a child with Down's syndrome was not expected to live very long. However nowadays a person with down syndrome can live till are 50. A child may not necessarily show that they have a disability until they have got older. A child with brain damage or autism, or learning disability may not display the fact that they have this problem until it is deemed that they are not meeting the expected milestones. A child’s disability does change over time, and so for some children, it is necessary to have regular reviews. A child should not be expected to have face to face assessments with a stranger – as they will not understand what is being said, or what is expected of them. If the child has a speech impairment or a learning disability – then it might be useful for their carer to be present to help them through the process. Are the healthcare professionals going to have enhanced CRBs? If not, then there is no way that they should be allowed to do a face to face assessment with a child with disabilities. A child should always have a competent adult with them during the assessments, as this will ensure that the child will not, or at least, does not lose their benefit.</p> <p>*Another difference when you are assessing a child, it that you are comparing a disabled child with a non disabled child, so a parent has to know what a non disabled child should be able to do when they are claiming for a disabled child.*It must be remembered that if a child has a severe speech and language impairment, then they will have this for the rest of their life. This does not go away as they get older. A child who is autistic, will always be autistic, a child who has cerebral palsy – will always have that. These disabilities will not disappear when the child gets to 11 or 18. These disabilities will continue to have a huge impact on their ability to be able to lead a full and independent life, which would be expected for a non disabled child. A child with speech impairment, or autism or cerebral palsy or a learning disability, would not be expected to go to higher education such as university. They will not be able to do the more skilled jobs. So their chances of social mobility are greatly restricted.</p> <p>*Question 18” DLA has been very useful to in being able to access to other services or entitlement. One of the main ones if you are a parent carer is that you are entitled to carer's benefit.</p> |

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| | | <p>This must be allowed to continue, as at the moment is the DWP can check if the carer is caring for someone who has the right level of care component. DLA has also been used to access things such as the blue badge, eligibility of schemes such as warm front, additional transport support such as rail cards and possibly via exemption from vehicle excise duty, and also fast tracking of support from councils such as is needed for adaptations to the home. When you have been assessed as needing DLA, then you can use this as proof of your disability. This proof is accepted not only by local government, but also by other organisations, and it can be used as way of the getting support from other organisations regardless of whether they are a government agency or not. The possibility of getting different types of support from things such as cinemas, leisure organisations etc needs to be advertised more widely.</p> <p>Sometimes you only know about some support or special offer if you are registered disabled by being told by another disabled person. By proving that you have DLA, you are able to show that you are disabled and have needs which need to be met.</p> <p>*The current 3 grades of premiums that are accessed by disabled people when it comes to other benefits such as housing benefit, council tax and income support, are there to recognise that there are different grades of disability, and therefore there are different grades of need. Complex needs are reflected in the complexity of benefit. When the new Universal Credit comes into being, then this needs to be considered. The changes that are up for consultation are for working age adults. However, if you are getting DLA at 65 – then you are entitled to it for life and can continue to get it into old age. This means that if you are currently getting lower rate care DLA – then you can continue to get it. With these proposals – cutting the lower rate DLA – would mean that a disabled person aged 67 – that used to get this rate – will lose it forever. How is the government going to sort that out I am unable to tell. By having universal credit – it is supposed to be for out of work benefits. But the elderly have done their work and need to be helped with costs. These costs are there regardless of ability to work or get around.</p> <p>*Question 19” If the new benefit does not this passport ability, then it might make it more difficult for a disabled person to prove that they are disabled, and entitled to some services/benefits. If disabled people are not able to use it as a passport or other benefits and services, then that would reinforce a feeling that disabled people and their families are at a disadvantage. Service providers need to be able to see that a disabled person is entitled to those services. Whilst it is true that some disabilities are easier to see that someone is entitled to some service or support, it may not be the case with other disabilities. For example, a blind person with a white stick or a guide dog -- everyone can see that they are entitled to any</p> |

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| | | <p>services that will help them overcome their site problem. However someone with a mental disability or a learning disability -- it may not be so clear to everyone that this person needs some sort of support or service. As I have said before, DLA is proof that you are disabled, and that you have needs that need to be met. This proof is accepted by non government agencies as proof of disability. This needs to continue.</p> <p>*Question 20" Each organisation is going to have its own criteria, and therefore you are not ever going to be in a position where one assessment fits all. The DLA criteria is different to that for social service involvement. Just because you get certain things from say your local council – i.e. a disabled bus pas, does not mean that you will get DLA. A statement of special educational needs, assessment is different to that for social service involvement. DLA is paid in recognition of needs regardless of whether those needs can be met elsewhere. It is a safety net for those who may not be deemed entitled to social care support. Whilst it would be lovely to have a one size fits all assessment, it is not just practical or possible.</p> <p>*Question 21" It appears that you have not properly thought through or done a proper equality impact assessment on carers – they have to prove that they are caring for someone who has either the correct level of DLA care (middle rate or high rate), or attendance allowance. Yes there are other criteria that they need to meet, but this is a crucial one as it allows the DWP to check that they are caring for those they say they are and that they are getting the appropriate level of DLA. Carers' Allowance is like DLA, can be paid whether the carer is in work or not. Yes they are only allowed to work a set number of hours and are not paid more than a set amount. *It is not exactly clear how these proposals are going to affect the elderly – who may get DLA for life if they claim it before they are 65. This needs to be seriously considered as they are going to be affected by the introduction of the Universal Credit.</p> <p>*Question 22" The consultation was not for the proper length of time, which meant that disabled people have been put at a disadvantage in being able to put forward their views. The questions have been slanted</p> |
| EM848 | 17/02/2011 | <p>██████████</p> <p>*I write this as an individual, as a mother of a 'disabled' son with an Autistic Spectrum Disorder, and as a human being who is deeply concerned about inhumane, and appalling way that the Government is treating and further stigmatizing 3.1 million people who have disabilities and physical and mental impairments. Using the social model of disability, unfortunately it is the Government who is the 'disabler'.</p> <p>*The Government's Approach to Reform - The New Benefit: Our Proposals, p. 11</p> <p>*Your proposal to replace Disability Living Allowance with 'Personal Independence Payment' is absolutely not necessary</p> |

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| | | <p>and your ideological stance of 'overcoming the barriers faced by disabled people to lead full and active lives' (DWP Consultation, 2010, p. 11, http://www.dwp.gov.uk/docs/dla-reform-consultation.pdf) is patronizing, discriminatory, and fraudulent. The Disability Living Allowance already provides for 'Care' and 'Mobility' rates based on an individual's needs for some 3.1 million people with disabilities (House of Commons Library, 'June Budget and Spending Review 2010: DLA and ESA Changes. 3 http://www.parliament.uk/briefingpapers/commons/lib/research/briefings/snsp-05749.pdf). The system has one of the lowest rates of fraud and error at 1.9%(ibid, p. 4) compared to Jobseekers at 4.4% or 5.7% for Income Support (ibid). In 2005, DWP's own estimate of fraud leading to overpayments for DLA was .5% (Disability Alliance, 2011, p. 7, citing DWP Fraud, Error and other Incorrectness in Disability Living Allowance, 2005 http://www.disabilityalliance.org/dlainterim.pdf).. The Government's 'transparent' reason for introducing this is their wish to 'make a savings worth 20% of expenditure', or in another words treating people disabled or otherwise as objects to be dumped on to JSA or ESA, then after a year where they face the highest unemployment to face destitution. In my own experience of being a mother with an adult son with an Autistic Spectrum Disorder, his claim for DLA was first rejected when he was only 11 years old despite being diagnosed by one of the world's most respected diagnostician, Dr. Lorna Wing. With regards to DLA presently, the fear and distress that is induced as a result of the repeated assessments--even if they are every 3 years--is demoralizing, but under a ESA type programme of Inquisition, the chance for official error is even greater as the WCA cannot properly evaluate people's disabilities by computerised input. But more than this it is not necessary if there is medical evidence submitted by the individual in support of their claim.</p> <p>"....Disabled people are rightly not prepared to accept being restricted from playing an active part in society" (DWP Public Consultation-DLA Reform, 2010, p. 11, http://www.dwp.gov.uk/docs/dla-reform-consultation.pdf) The Government's intention to cut 20% claims to DLA represent the greatest 'restriction' for people with disabilities to participate in Civic Society. Psychosocially, the whole process as it stands of applying for DLA is extremely stressful but utilizing real medical professionals to provide the information needed is fair, but instead 'objective' medical information is often ignored by Atos Officials it seems. Even people with disabilities may have life-long and complex 'condition' such as an Autistic Spectrum Disorder, nevertheless every 3 years a person may be assessed Unfortunately, because the DWP, in my opinion, cannot sway the GP's and medical professionals, instead they contract out ultimately biased 'health care professionals' who</p> |

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| | | <p>bring the whole system into disrepute. 'Changes in legislation' (ibid) won't reduce my son's difficulty with communication, with social interaction, with sensory problems, with needing social support and counseling because of co-morbid depression; nor will it erase Society's discrimination. According to the Hawkins (How to find work that works for people with Asperger syndrome, 2004, p. 12): "Estimates of underemployed or unemployed people with Asperger Syndrome soar well into the 80 percent range. Even those individuals who are formally educated with post-secondary degrees have low employment rates'. If the Government were serious about helping people into work, they would have Disability Advisors who actually understood the kind of social and communicative difficulties my son faces, but sadly at each Jobcentre there are not the resources, nor the good will to treat a person like my son with the respect he deserves. Further, if the Government was serious about helping people, rather than demeaning people, they would ensure that Assessment procedures would not attempt to pretend that there is somehow 'objective' evidence about what is an 'invisible disability' such as Autism or mental illness. Moreover, because the person with Autism is not always able to communicate their distress, a 20 minute ATOS Medical Assessment is a mockery of persons with intellectual disabilities.</p> <p>""The assessment will be objective, reflect the impact of the barriers disabled people may experience and make sure they are treated as individuals"" (DWP, 2010, p. 11). Numerous disability organizations including Professor Harrington's report has demonstrated that the ESA WCA is 'not fit for use'. Likewise the assessment procedures for DLA can never be 'objective' since the person(s) who are evaluating another human being have their own subjectivity to deal with, not helped by a bias of being contracted with DWP. It is 'deceptive' by the DWP to attempt to present the ATOS Medical Services as 'independent'; undoubtedly there is a conflict of interest. The Government is proposing a similar system which the risks subjecting people to a system similar to the Victorian Poor Law, deciding who will go into the metaphorical workhouse, who can break stones into pebbles, who are the 'deserving' or the 'undeserving'. *'Central to Personal Independence Payment will be a new, fairer, objective assessment, which will allow us to identify those who face which will allow us to identify those who face the greatest need, in a more consistent and transparent manner' (DWP, 2010, p. 11). Interesting, it is not necessary to 'identify' such people with cancer, people with MS, people with Autism, people with Rheumatoid Arthritis, people with back pain, people with depression, people with degenerative diseases, or people with brain tumours. They have already been identified. It is called diagnosis.... How is the Government to determine their pain, their humanity, their worthiness?</p> |

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| | | <p>Surely, it is for GP's, Consultants to decide through the objectivity of science and medicine, not some outsourced disability trained mid-wife. The Government is at fault, and it is the Government that is immoral and fraudulent speaking as it does in a Orwellian double speak and a forked tongue.</p> <p>*'We will ensure that the award continues to reflect the individual's changing needs over time by building in periodic reviews' (DWP, 2010, p. 11). It is hard not to be cynical. This is what the DLA already does. It is based on the individual, it is based on the changing needs of the person with the disability, and it is subject to review. I trust that the Government will build into your estimate for how much this all is going to cost chasing up people with lifelong disability such as people with amputated limbs, people with cancer where the Doctor's diagnosis doesn't fit easily into the DWP's 6-month timeframe. Another example, I know of of someone who has had bowel cancer where 12 inches of their rectum is removed; will the Government ask to check how his/her fecal incontinence has changed in the last 3 months, 6 months? Where will it stop?</p> <p>*'We will introduce a Bill that will set out the high-level legal framework underpinning the new benefit, with the detailed requirements set out in secondary legislation' (DWP, 2010, p. 11). Let us hope that the Government will be aware of its duties under the Equality Act 2010 such as 'The Equality Act maintains the duty to make reasonable adjustments, but it makes it more straightforward, because there is now a single trigger point for when adjustments have to be made. Reasonable adjustments have to be made to avoid a disabled person being put at a "substantial disadvantage" compared with non-disabled people' (Government's Equalities Office, 2011, np, http://www.equalities.gov.uk/equality_act_2010/faqs_on_the_equality_act_2010/disability.aspx). This legislation that is being proposed is fundamentally flawed, and this is the reason because it is discriminatory and creates 'substantial disadvantage' by unfairly treating people with disabilities as frauds and suspect. By forcing, yes coercing, sick and people with disabled people to attend assessments the Government is placing millions of people at risk of indirect discrimination and in its zealous pursuit of making economic cuts, it is forgetting the humane treatments of its citizens. The whole discourse surrounding this 'Reform' disguises the real intention, which can only have the disastrous effect of destroying our society. When talking about bringing reform into the 21st Century, please let us not enter into Social Darwinian neo-liberalism where only the rich and the healthy survive. As well, the Government should ensure that it meets its own targets to employing people with disabilities, leading by example the way in the 'Big Society'. People with disabilities who are the most socially excluded because of their dependence on the State deserve the same</p> |

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| | | <p>respect for their 'needs' now as they did when the Conservatives introduced the DLA in the early 1990's. I think the Government needs to ask at what is the cost to our society, its actions against the ill and the disabled, whether it be in ESA or in 'reforming' the DLA. What is the cost of your ideology if in the end it disables our society by greater fragmentation, denying its citizens their freedom, their privacy, and their integrity of person?</p> |
| EM849 | 14/02/2011 | <p>*DearSirs, .•*— . l .3 .</p> <p>*In my capacity as a registered disabled person please find attached reply to Maria Miller department's on the replacement of Disability Living Allowance with Personal Independence Payment. . .</p> <p>..*Kind Regards. - . -• [REDACTED]</p> <p>**CONSULT ON THE REPLACEMENT OF 'DISABILITY' LIVING- ALLOWANCE WITH. PERSONAL INDEPENDENCE PAYMENT*Ab .*am replying to your question in my capacity as a registered disabled person. The consultation is the question of an insurmountable barrier. . .</p> <p>*The proposed Human Rights; .•</p> <p>*The proposed denial of, mobility for disabled is a contemporary social enervation of the vulnerable</p> <p>*The societal ceilings of impairment aren't addressed in the consultation. . . .</p> <p>*Thank you for the opportunity to contribute to this. I hope to contribute to this.</p> <p>*Response to DLA Questions</p> <p>*1 Response -*The diversity of disabled people in terms of age, gender class, ethnicity, impairment, social deprivation and location, the bureaucratic, institutional, societal and systemic barriers preventing disabled people' participating fully actively in society are enormous.*A significant number of disabled people feel excluded from unable to lead meaningful purposeful independent lives due to .• purposeful or inadvertent restricted access to social housing, education, employment, goods and services, leisure facilities, events, building societal and career impairment: ceilings.</p> <p>*• In addition to people being excluded by society disabled people live in fear of bullying, victimisation, intimidation, hate crime as well as societal discrimination, and negative political and press discriminatory reporting all disabled people as "scroungers, cheats and a burden on the welfare state"</p> <p>*All this at a time when the recession recovery is showing negative growth, rising inflation, significant increases in indirect taxes, fuel, food, clothing, rents, heating and lighting costs, that together are perpetuating the widening of the extra cost gap of disability, whilst at the same time voluntary sector funding is being cut, employment opportunities are being neglected and there is a postcode lottery for medical</p> |

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| | | <p>*• 'care medication.</p> <p>*In addition to the aforementioned, as the barriers faced by disabled people are either caused by or result in their financial exclusion, this is why DLA is invaluable to so disabled people:</p> <p>-</p> <p>*2 Response - The claim Disability Living Allowance is, no longer fit for purpose be over stated particularly v regard to self-assessment and therefore urge the retention of self-assessment applications.</p> <p>*The qualifying period should remain the same for those diagnosed with incurable 'disabilities as the new timescales may have a substantial adverse impact on the individual.</p> <p>*• 1 An example of this is a spinal cord injured patient discharged within four months of the accident - qualifies for DLA/PIP - but has a further two months before they can apply which effectively stops them</p> <p>*- exercising their rights, whilst exacerbating their psychological and emotional wellbeing and institutional dependency.</p> <p>*The necessity for periodic reassessment for the severely disabled</p> <p>*- '(already assessed indefinite awards) in many cases may have a severe adverse impact as it would serve a reminder of their disability review difficulties, particularly no cure for severely mentally impaired, amputees, deaf/blind, haemodialysis, severely visually impaired, cerebral palsy, spinal cord injury multiple sclerosis etc</p> <p>*There continue to be the separation of mobility and the care components in</p> <p>*• The allowance is, not a benefit and therefore not be combined with any Universal Credit</p> <p>*3 Response The extra cost of disability is the amount of additional income a person with a disability would require - so as to achieve the same standard of living as a similar person without a disability - albeit problematic to assess, estimates range from £7 24 to £1 13 per week*the calculation is problematic insofar as the main extra costs for a child, young adult, middle aged adult, pre-retirement aged adult, married, partner, parent or single person are complex (with many hidden costs) and varied and dependent upon other factors such as geography, demographic and category</p> <p>*Albeit a conceptual definition of extra costs (goods and services required), comparative (goods and services used) equivalent, (standard of living) the diverse grouping above incur many additional extra costs including support services inside/outside the home (dressing, bathing, toileting cooking, eating, household chores),</p> <p>*dietary needs, health services, transport, education, hearing aids, repair and maintenance of hearing aids, sports and leisure activities. •</p> |

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| | | <p>*However, the extra costs calculation for disabled on the line can be even more problematic as individuals substitute goods and services for cheaper alternatives or disregard them altogether as they cut back (e.g. use of public transport) (petrol costs of travel) to remain within constraints from cheaper frozen food shops with adverse impacts.</p> <p>* The cutbacks disabled people face because of their disability range from socialising; social interaction with friends and family going shopping; the cinema, going to shows, going to events, hobbies and other activities of daily living. - As these activities produce a fee! good-factor; build self-esteem, self-worth, meaning and purpose in life - as well as physical and psychological well-being that enable significant reductions in health care budgets, whilst at the same time facilitating a more active, inclusive and integrated UK society within the Government's own 2025 target.</p> <p>*4. Response Any financial reduction in the number of components to any allowance or benefit should make it simpler to understand but not necessarily easier to administer, particularly where there is a lack of clarity; a degree of complexity and poor objectivity. Of which are characteristics evident in the two care rate proposal:</p> <p>*At present the middle band rate is approximately a multiple of the lower band rate whilst the higher band rate is a 1.5 multiple of the middle band rate and approximately 3.8 multiple of the lowest band rate.</p> <p>*A medium rate calculation between the middle and lower band rate components is approximately less than half the higher rate at £33.38 and based on the assumption the higher rate remains the same, those claimants reclassified downwards will suffer a significantly greater cost of disability.</p> <p>* The claim assessments are to be objective, transparent, effective</p> <p>* . . . and targeted to individual needs neglect to State what . . . assessment information — in accordance with natural justice — they will provide back to claimants? . . .</p> <p>* Improved two-way allowance for claimants to make empowered decision-making judgements regarding changes in their condition, reporting them timelessly and accordingly whilst at the same time alleviating the need for periodic reviews. . .</p> <p>* . . . Should the health condition or impairments mean an automatic entitlement to the benefit, or should all claims be based on the needs and circumstances of the individual applying?</p> <p>*Response It should be based on the individual's human right to live a dignified, independent role in society . . .</p> <p>* As the effects of numerous conditions or impairments are extremely well documented in leading International Medical Journals then surely this, above all other considerations fully endorses the case for a universal allowance.</p> |

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| | | <p>*ance;entitlArnerittbrtertaftt- conditions.</p> <ul style="list-style-type: none"> • The idea Of reviewing..and reasse.ssing indiViduals madically registered' conditions or impauments is prdposterous just a viewin a cvh a Qf an individual's abiliWrather than its ssential use• td.g – <p>*As this could mean needs are assessed on an indi ability na wheelchair rather than the fact they need a wheelchäif to unde atall! Indeed, the listS conditions orimpáirments resulting inautomatic. entitlement should be lengthened to simplify the' process and make the te fdi e ofiè to :R*6 Response - . • There are evaiuatibh tools avafable to measure -ActMties Of:</p> <p>*Daily Living including the Katzand Lawton scales that covél self care, fundamental functiohing and social interaction that are consideted esseñtlal aciMties for everyday life. –</p> <p>*Impairments;are but. alsontuñplé making'essentiài activitiesof ever li tThe consuming with prioritisation on an indi basis, including but not exclusive to, personal hygiene, grooming, dressing, undressing, feeding, functional transfers, bowel and bladder control, medication; ambulation, housework, cooking, gardening, shoppiñ social activities social uiterac exefcise, *- relaxing, skin cà health care . –</p> <p>*Prioritising support on the basis of activitiès is yndeniably flawed shdUld .fiiAdfibnal asthssmeiitjs.based on the</p> <ul style="list-style-type: none"> *• disabled persohto cairy out essential activities, impacting their life. *• chances choices. - - <p>*7 Response The besrwayto ehsUrethe assessments are appropriat& meanin and provide a comprehensive account of individual fluctuating health conditions is toforge good relatiOnship links between all parties</p> <ul style="list-style-type: none"> *• involved inthe, precess. <p>*Inthecase.-of a spinal cord injury patient, they may have bétter• knowledge as well as an 'uncanny ability' to interpret, diagnose and equest medicalornursin attention for theft physical ailthent</p> <ul style="list-style-type: none"> *• the same time fail to:recognise psychological and/or emotional issùès associated with their disability. <p>*The psychOlogical/emotional-aspect dfsustaining a spinal cord lniQry can present far greater challenges thartàdjusting to the physical asjects— “the wheelàhairbit is the easy part; dealing with the a is the difficult; challènging.task! .</p> <p>*in the,irnmediate aftermath of spinal injUry the n is torced into</p> <ul style="list-style-type: none"> *• considerihgtheftfeelings aboutthemselves, how and where- they:slbt back into society whilst at the same time face significant challenges to theiridAntity <p>*therefore asénsifive and considerate.àpproach to asséssrnt m1 ensure contributionsfrom numeroussources of expertise, take a comprehensiv account of fluctuating and variable physical and psychological issues going forward Because, even after effective rehabilitation, integratioh add return to</p> |

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| | | <p>meaningful living/employment, the psychological aspect of disability can be a ticking time-bomb just waiting!!</p> <p>*Additionally, periodic reassessment of spinal cord injured may only serve as a reminder about their incurable static physical condition and in doing so may only serve as a thrust towards negative thoughts concerning their flight. with the knock-on psychological/emotional functioning and perceived further loss.</p> <p>*I 8. 'Response' in the case of 'a disabled wheelchair user' the use of the wheelchair could be viewed as part of that person's ability rather than its essential function as a means of getting around This could mean that a wheelchair user would be assessed on their ability in the wheelchair rather than the need for a wheelchair to anything</p> <p>*Although, a procedure to the office; travel to and from the time to repair plus the monetary cost of the repair— with the true cost of the puncture was sacrificing employment prospects as well as the need to divert</p> <p>*- 'budgeted expenditure over these hidden true costs of disability!</p> <p>*The removal of employment barriers could effectively be impeded by</p> <ul style="list-style-type: none"> * unscrupulous employers the precedence set by this * The suitability, practicality, ownership usage; of personal aids makes it unrealistic, unfair and overly complicated to take a person's aids into account their mobility. . * Who decides. What is appropriate, the barrier * pre or one of the more expensive Is it the assessor or the officer, the person with the disability or some other bureaucrat? * As Whether the assessment should take into account aids and adaptations a disabled person could have is ambiguous and could * have on those forced to substitute goods and services downward , , . <p>*9. Response :The claimant should be able to complete the claim form in a</p> <ul style="list-style-type: none"> * reasonable amount of time, questions must not overlap and the claimant must feel comfortable (questions not overly intrusive) with what is being asked. * The claimant should receive one-to-one support where it is necessary * for claimant to negotiate the application/form. <p>* The current survey by commercial organisation good indicator of how to gather the most relevant information whilst at the same time sustain the interest of a diverse group of customers</p> <p>* The effectiveness of any changes to the forms needs input from the end user and disabled people throughout the testing and identifying Of the optimal point between user needs and information requirements;</p> |

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| | | <p>*The experience of disabled people and their potential input to the process of designing, implementing and providing information would be invaluable to coproduce a claim form and/or any public information on</p> <p>* PIR</p> <p>*10; Response . It is a:reco fact that people with severe disabilities have.a lower health related quality of life than those in the general population and this could be cdnftibUtedtothe associated psychäld fUnctioning.</p> <p>*Whilst some impairments are degei others although not degenerative,: only because the disabled'person learns how to niake institutionalised èacrifices. . . .</p> <p>*The presence of rtientalhèalth problems (anxiety, cognitive issues, bonsistent negative,thought& :out.of proportion reactions to;a problehi) manifests itself in those groups with severe disabilitiesè which can have a significant impact on the individual, their families, friends, colleagues and carers, so much so it is vital issues are addressed as early as pos • •</p> <p>*How tOcapture suchvital supporting evidence is challenging due to there hidden costs and most likely can best be provided by knowledgeable disabled associations, specialist consultants, therapists and psychologistsppcialising in disability.</p> <p>*In ádition:to:the-supportin evidence from professionals the timing of assessment evidence,by the applicant is just as important and should takeac status, a and whetherthey are newly Or brig term disabled. .</p> <p>*Itis social structures :ánd.environmentai Jactors That serve to contextualise age and the life course are factors that can influence the timing, meanuig and experience of Spinal cord injury research indicates patidbts are better equi to deal with a spinal cord injury at an to laterir life' èurse.</p> <p>*capiprin sppporting eyidence of the social, psychological and' biobgical aspects of aging, with limited activity and restrictive participation during lifes course is essential to assess disabled individual's ability and not just a periodic snapshot In es a clearer brighter imagsi</p> <p>*IThe cbahtidpgovernrnep cpmmitment:to measuringihe 'nation% happiness factor' through a well being exercise' with questions emotional health, social isolation, interpersonal relations and access to holidays, consumer goods and services well be an ideal opportunity in collaboration with the DLA/PIP assessment exercise to actually gauge the well being and happiness of being disabled in modeth da9 Bfltaih!</p> <p>*11 A dponse P '</p> <p>*Jherè ä ignificant obstacles relating to face-to-face discussions with regard to location, travel, scheduling, health-care exper as well as the hidden costs that make this policy highly inSppropriate to pursue</p> <p>*Societal barriers location meets everyone's needs due to numel-ousfactors including parking restrictions in town or poor</p> |

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| | | <p>transportation out of town A disabled car owner recently had to turn back from hospital appointment because they were unable to find a</p> <ul style="list-style-type: none"> * - disabled space*The scheduling-Of a disabled person can be a severe disabilities who struggle to cope with the fluctuating time it takes to complete some of the most basic everyday tasks, hence high non-attendance rates. : *What happens if appointments are missed due to *The hidden costs stress related impact on the wellbeing of disabled people Registered disabled man had his DLA cancelled and he became depressed, stopped eating, for a year and his death certificate stated malnutrition as the cause! *There is a concern that independent medical assessments will discriminate against those with complex, variable and/or hidden conditions which might, not be fully appreciated by the assessor. *A disabled woman with a hidden stress condition resulting from her disability became depressed, stopped looking after herself, which led to both her legs being amputated (pressure sores) followed by her death * shortly from associated complications from the amputation *It is also considered highly unlikely that medical would result in cost savings, as assessment by independent officers would increase bureaucracy along with the additional costs of employing specialist medical officers; officers and the legal and * administration costs involved in legal challenges and appeals... *12. Response . The objective of any review is a balanced assessment of a claimant's past, present and future medical and psychological condition * The process must be open, transparent two-way relationship built on trust . . *The process must be clear, concise and unambiguous with no hidden agendas. . . . *The process must be two-way. The process provide more information than a fail/qualify reply. *the process must tell the claimant how to exercise their rights. *The, rights to appeal, the right to information -Freedom of information *Act 2000, Data Protection Act 1998, Disability Equalities Act — the right *to protection from the Disability Discrimination Act 1995 and the *Human Rights Bill. 1998. *The process for claimant, to know the level at what they were assessed for . . . *Higher Rate One — terminal illness * • Higher Rate Two -: permanent 1-24 hour care needs. Higher Rate Three — permanent disabled / medium care needs Higher |

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| | | <p>Rate Four — disabled I daily activity needs, *Higher Rälb Five —. disabled/low, care daily:activityneeds ‘ *Thø.prodessö develop reviewcriteria foreach banding (above) *• So claiffiatits ate *13 Response. . p Inihe j Of Oa under épodingof-chahges Pah be *contributedtdanufflberb *An in change-over aconsiderable period oftime differs a significant change bye! a shoçt period of time with the latter being *- - sighificantly less diffiduit to hbtîê/idO’ntify and répo’?t. – *‘There-cab bG tremendous, demoralising impact on. a disabled person’s quality of life - when they hope - above everything else - that their condition is improving, only to be shattered when told otherwise by pecialist consultant, illusions of the mmdi Thinking there has been a.ch’angewhentere hasn’t.- or- there.hasn whèh there.: haSI *• IhlregardtOthOse aspinálcord injury autondmic4ysréflexia or a *urinary tract infection can have a smg’bificant impact on well- beirfg, bpth *over the shortand longer term and therefore is almost impossible to *accurately quafltify the of physical and/br psychological changes. *Awheeldh u thay th,i’qlcthØ reason why they-can i longer push themselves as farm their chair is down to weight gain, s?nokmng, aging and/br justa ladk:of physibal etdiSe when the real reasOn is a respiratory ailment, a secondary complication associated with their *disability. - -*These examples hopefully demonstrate the complex natthe of disability *- as well. as ‘understandingas .to under reported as well as highlighting the potential administrative ‘nightmare bfo ith:the.peed piarifychanges! *Imprdvments.to encourage reporting of changes needs the ,Ae reportingthe:changes: having a bdtter:understahding and knowledge (two-way mnformationagreement) of what to look forand how to identify repottäble changes a how to • *By makin the as clear and transparent as possible with adequate support mechanisms in place for those with mental health or communication support needs this will, without doubt help improve *• . c0mm . . *14. The basic hedds adisabled person are the same physiologibal: and safety naeds(Maslow)-fortheablebodied; the only difference betweep the- disabled and non-disabled is the bost of disability. *• Wh PIP’isa safety net or step up mechanism it.-sl7iould provide prqctectibnand:secutit with advice and informationon</p> |

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| | | <p>'deficiency *needs' with the aim of enabling esteem, parity, confidence and a route to purposeful, meaningful, fair and inclusive participation in society.</p> <p>* The type of helpful advice and information for claimants during the process are extensive and range from support services at home and outside the home, social services, care services, carer providers, day centres, rest homes, disability support organisations, local authority services, utility provider tax offices, benefit offices, pension credits, ombudsman, housing associations, advice shops, legal services/legal aid, counselling, trade unions, tribunal services, health services, transport, libraries, education, sports, leisure, jobcentre, motability and other similar disabled service/goods providers. –</p> <p>* However, all of the above advice at once without doubt would be: counter-productive and an information/administration overload * nightmare.</p> <p>* The flow of information necessitates a much more targeted and systematic approach to individual needs *(Maslow's Hierarchical Needs) changes over time that breach societal imperatives</p> <p>* 15. Could some form of requirement to access advice and support, where appropriate, help encourage the minority of claimants who might otherwise not take action If so, what would be the key features of such an initiative, and what would need to be provided?</p> <p>* Response - * I do not believe that people should be coerced into accessing support and advice for the following reasons: . . . -</p> <p>* L</p> <p>* Where the advice support is appropriate and so the sufficient information about how to access it, it is unlikely that they will need to be coerced into doing so.</p> <p>* Accessing advice and support can be a stressful process for some people, particularly those with mental health problems and/or communication difficulties People with conditions of this kind should be protected against. –</p> <p>* People may have good personal, moral or religious reasons for not accessing a particular form of advice support- their decisions should be respected.</p> <p>* It should be that people do not enjoy having their ability to live independently curtailed and to suggest otherwise just cements the image that political discourse and the media are creating of disabled</p> <p>* - be Out for: all They can get.</p> <p>* 16 Response . The funding of and adaptations for disabled people is source from their own savings, health boards, social services, district nursing services, charities,</p> |

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| | | <p>families, fund raising, legacies, donations, motability, churches, religious organisations, businesses and numerous</p> <p>*: others . . .</p> <p>*wheelchairs, scooters, adaptations and cars addresses mobility needs for many disabled people over their lifetimes - and they are considered exceptional because of their individuality and the appreciation of the diverse of customers.</p> <p>*The current highest Rate Mobility Component . the Disability Living Allowance - *Consideration to allow and Lower DLA holders the Motability hires or lease scheme will enable greater mobility for all disabled! It would also seem absolutely reasonable to allow the use of PIP to meet a one-off cost to fund an aid and/or adaptation as the alternative could have significant impact on their standard of living or force them into debts</p> <p>*18. How important or useful has OLA been for disabled people? access to other services or entitlements? Are there things we can do to improve these pass-porting arrangements?</p> <p>*Response The importance of DLA for access to services cannot be underestimated although it is sometimes poorly communicated. However one area where pass-porting could be significantly improved regards access to Justice for the most vulnerable members of society. - The disabled face hate crime, harassment, victimisation, bullying, attacks or damage to their property or belongings just because they are disabled perpetuated further by the negative rhetoric from political discourse and media reporting of the DLA Welfare Burden' resulting in further discrimination and prejudice. The disabled in employment or seeking employment can access employment support in the workplace if in receipt of the DLA albeit rather ineffectual when dealing with ceilings!</p> <p>*For disabled people to participate and be more active in society a key objective of the consultation must be protection, disabled people need to know their rights to exercise their rights and (know) where to go to get help and support they need!</p> <p>*1.9. Response - *There would be many repercussions for disabled people and service providers if PIP was no longer a passport to other entitlements and services. The repercussions could create significant disparities between disabled groups as well as within the same service provider industries, let alone considering the additional administrative paperwork and costs. *The help the most vulnerable members of society to make the process of accessing help, services and support as simple and user-friendly as possible which the right to passport to other entitlements and services enables.</p> <p>*In keeping with the stated objectives of universal Credit, a one-step process (passport) that potentially could enable the right support, at the right time, for the right people with less bureaucracy'. Service providers and particular utility service providers offer some of the most vulnerable disabled groups a</p> |

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| | | <p>number of concessions based on their entitlement to. DLA that is easy to administer and. process whilst getting the right help to those most in need!</p> <p>*22. Response - . The stated Government objective to make the benefit system fair (together with a commitment to disability equality, human rights and independent living) is contrary to the consultation proposals</p> <ul style="list-style-type: none"> * that will deny vulnerable disabled people participation, freedom, choice, dignity and inclusion in society. . * The negative political rhetoric and inaccurate use of terminology developed by the independent living and disabled peoples' movements * is so detrimental to inclusiveness the Government potentially risks undermining much of the movement's progress to date. The haste and speed of the consultation is detrimental to participation and involvement of the vast majority of disabled people and shows little consideration to their additional needs and as such the consultation is fundamentally flawed in its objectivity! . . . * The consultation neglects to address the methodology behind making the reductions in spending - is the objective to out-source the administration workload, pay staff and consultants bonus or other 'detrimental incentives? - * the gap implied between people living in residential care homes and people who are in hospital is fundamentally offensive to disabled residents and based upon the incorrect presumption that being disabled is the same as being ill. * There is also real concern that the reforms will constitute a breach of the Human Rights Act 1998 with the changes denying thousands of disabled people equal access to private and family life as they will be unable to afford contact with their spouses, parents, children and friends. - Those who can no longer afford to attend their place of worship will be denied their human right to religious freedom! - There is concern the process will not adhere to set precedents developed and established over past reviews? The DLA allowance should automatically passport awardees to other fuel allowances, fuel VAT reductions and higher personal tax allowances as to help towards covering some of the additional costs of disability. |