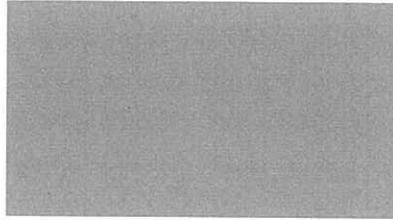


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DLA Reform team, 1st Floor, Caxton House, Tothill Street, London, SW1H 9NA

Dear Sirs,

PUBLIC CONSULTATION: DISABILITY LIVING ALLOWANCE REFORM

Thank you for the opportunity to comment on these proposed changes to Disability Living Allowance (DLA). I am responding to your Consultation paper on an individual basis, as a joint carer (with my wife) for our son. Our son is 27 years old, is autistic and has learning difficulties. He currently lives at home with us and relies on us for his care.

He is classified by adult social services under the heading of "learning difficulties", a description that I find to be extremely misleading as his difficulties stretch beyond "learning" into all aspects of his adult life – something that I will touch on in more detail later in this letter.

I would also like to put your consultation in a personal context. Currently I have just responded to a consultation paper from our County Council proposing that support previously provided to disabled adults should in future be chargeable (the justification for which is put clearly at the feet of central government in reducing the county grant). I am also facing another consultation from the County Council proposing the closure and re-provision of day and respite care (which will also move from non-charging to charging at the same time). Finally, I am also in discussion with my local authority () who are intending to abolish their housing list and replace it with a needs only based system (my son has been on the housing list for some time in the, perhaps vain hope that he might, in the future have his own accommodation).

You will understand therefore why I find these proposals somewhat unwelcome. I am drowning under consultations – all of which appear, to the hard pressed carer profoundly negative in impact. Proposals which implicitly state that their intention is to reduce the numbers of disabled individuals able to claim DLA (Executive Summary, paragraph 2) are, in my view, iniquitous. Welfare expenditure is unsustainable only if there is no longer a willingness to undertake it. There should be an open acceptance of the significantly adverse impact that cuts of 20% (your headline figure) will have on the lives of vulnerable individuals.

You also seem to an unrealistic view of the effectiveness of the Disability Discrimination Act 1995 and Equality Act 2010 (Chapter 1, paragraph 12) in changing overall attitudes to disability. Neither of these Acts have, to any measurable extent improved the ability of individuals with the type of disability from which my son suffers to "lead more independent lives". Your statement that: "It is now

universally accepted that disabled people should have the same choices and opportunities as non-disabled people" has not improved my son's personal circumstances in any way. And the subsequent paragraph (paragraph 13) is, in my view, simply nonsense.

Finally I would like to return to my earlier point regarding my son's disability. My son has a "mental" disability which has a profound effect on his physical environment. Your proposed method of assessment, whilst it fits well within the context of a physical disability does not fit easily with the problems arising from a "learning" disability which can manifest themselves in different ways (but requiring an equal or greater level of support). I do not believe it possible to produce a single set of criteria (or an objective test) that will adequately model all of the different consequences of disability and the questions in your consultation document reinforce rather than dispel my belief.

This point has a bearing of why the current process for assessing awards for DLA has become so complex and why claims are greater than originally anticipated. The answer is "simples". Disability is significantly more complex than legislators imagine.

If I may turn to your individual questions:

Question 1: What are the problems or barriers that prevent disabled people participating in society and leading independent, full and active lives? I have to say from the outset that I am surprised that you need to ask this question. Surely you should have considered this point in detail before proposing such significant changes to a key disability benefit.

There are many barriers that prevent disabled people participating fully in society. These range from physical difficulties and lack of support, to ignorance and prejudice (which are still disturbingly strong – even it appears on the House of Commons). But one of the biggest barriers is poverty. The true costs of being disabled are still not fully recognised or understood and last a lifetime. Your idea that work can alleviate these disadvantages is true but only in the case of a relatively limited range of disabilities and never completely. Often if work is available it is low paid and menial and in a recession (such as we are currently experiencing) can be almost impossible to find.

Either society values its disabled members or it discriminates against them. Currently, despite the progress that has been made (and progress has been made) the balance still falls towards the latter.

Question 2: Is there anything else about DLA that should stay the same?

The benefit should remain as stated in paragraph 9 of Chapter 2. It should not be means tested or taxable, or linked to NI contributions. It should also include a statutory annual up-rating condition to maintain its real value

Terminally ill individuals should continue to be treated under special rules

Question 3: What are the main extra costs that disabled people face?

Physically disabled people face additional costs in respect of aids and adaptations, extra support to undertake normal day to day activities, additional costs to be mobile and support costs where they are unable to undertake normal tasks. Mentally disabled people often need, in addition to their own aids and adaptations, greater personal support both in the home and socially. It is not possible, for example for my son to socialise outside the family without personal support.

The use of the current comparators in the existing benefit are subjective, and are often defined in slightly differing ways in order to take account of the total disability. But this is not a limitation – this is a sign of the maturity of the benefit in that it accepts that it is not possible to put a strait jacket around definitions of disability.

Your paragraph 15 in chapter 2 is to be welcomed in principle but runs the risk that it will in itself become too prescriptive and thus unfairly restrict financial support to certain physical conditions which are relatively easy to assess and measure.

Question 4: The new benefit will have two rates for each component:

- **Will having two rates per component make the benefit easier to understand and administer, while ensuring appropriate levels of support?**
- **What, if any disadvantages of problems could having two rates per component cause?**

Currently DLA has three bands and you present no evidence as to why it is necessary to move away from the existing system. I do not agree with your contentions in paragraph 16. I do not agree that reducing awards to two bands will reflect, "the range of individual needs". In a time of financial stringency the pressure to place individuals consistently in the lower band will be overwhelming. This is a case of feast or famine.

Question 5: Should some health conditions mean an automatic entitlement to the benefit, or should all claims be based on the needs and circumstances of the individual applying?

I would support the retention of automatic entitlements for those who are terminally ill.

Looking at the range of disabilities contained in Annex 1 I am surprised that you see a need to remove these as automatic entitlements as any objective assessment would surely lead to the level of award stated. Is there something in your proposal that I have missed?

Question 6: How do we prioritise support to those people least able to live full and active lives? What activities are most essential for everyday life?

The activities most essential to daily life for disabled people are the same as those for "normal" people: they are those, as you state as being necessary to live full and active lives. It is unrealistic to try and separate one activity from another in the manner that

you suggest. It is like asking what is more important: washing your face or cleaning your teeth.

Again your proposals seem to show an emphasis towards physical disablement. Evidence based assessment (paragraph 23) is easier to provide in respect of physical disablement than learning difficulties. Having sat in on many case conferences regarding my son where two experts have produced differing assessments of the same condition I also have doubts whether it will lead to more consistent outcomes. There is also the cost and difficulty that the individual will face in providing this evidence. How are you intending to specify what evidence will be required, how will it be collected and how will it be assessed? Will this evidence requirement differ between different conditions? These questions need to be answered in order to assess the effectiveness of your proposals

This move to evidence based assessment emphasises the need for a clear, robust and independent appeals system which is included in the primary legislation.

Your point at question 5 seems to be at variance with your intentions in question 6. Simplifying the awards system runs the inherent risk that you will not prioritise support to those who are least able to live full and active lives.

You should view the social model of disability as a whole rather than considering component parts individually. Ideally your test should concentrate on how the allowance can provide support across the complete range of activities rather than concentrating on individual activities. Your intention for a broader, more objective assessment (paragraph 25) is to be welcomed. What is less clear is how your intended approach will achieve this aim.

Question 7: How can we best ensure that the new assessment appropriately takes account of variable and fluctuation conditions?

Do you need to take this element specifically into account if the condition varies? Periods of remission are not periods of cure. You do not state in your consultation paper why this is a problem. Surely what is required is a means of assessing improving conditions – unlikely in most instances and this information is largely already available within the medical system.

Question 8: Should the assessment of a disabled person's ability take into account any aids and adaptations they use?

- **What aids and adaptations should be included?**
- **Should the assessment only take into account aids and adaptations where the person already has them or should we consider those that the person might be eligible for and can easily obtain?**

I believe that aids and adaptations should be ignored in any assessment as there are differing levels of provision between different authorities and that provision of an aid does not remove the disability. Differing individuals may have the same type of wheel chair for example but have different levels of ability using the equipment.

Often central provision of aids and adaptations is basic and the individual may purchase an improved item from his or her own resources and therefore demonstrate a greater ability to undertake a particular activity. Including the adaptation would penalise that individual and may not take into account other factors associated with the disability.

Question 9: How could we improve the process of applying for the benefit for individuals and make it a more positive experience? For example:

- **How could we make the claim form easier to fill in?**
- **How can we improve information about the new benefit so that people are clear about what it is for and who is likely to qualify?**

Claiming for benefit is unlikely to ever be a positive experience. The existing form is complex and concentrates on physical aspects of disability which frequently do not represent the total sum of difficulties associated with an illness such as autism. This makes filling out the form repetitive and somewhat anomalous to the condition.

A simpler form would be a bonus but your tenor of this consultation mitigates against this. A meeting with a health professional would be of value but should not be the sole determinant of benefit award. Unless the professional had a detailed knowledge of autism and an understanding of the background and history of my son's illness they might be led into making a judgement that do not correctly represent his true circumstances. Equally high levels of stress can affect my son's behaviour quite dramatically and this would affect his response to any interviewer. You should not underestimate the effects of the stress resulting from such an interview on vulnerable adults with learning difficulties. This is why a robust appeals process is a necessity.

Also in my son's case there has been little continuity between social workers (care managers). Knowledge of the individual is not necessarily current or comprehensive. Social workers, of necessity concentrate on crises cases rather than long standing cases where there is not an immediate need to be involved.

Question 10: What supporting evidence will help provide a clear assessment of ability and who is best placed to provide this?

The best supporting evidence (after that of the claimant) is that from medical or other individuals who have been involved in the treatment or management of the disability.

However, whereas a physical disability is often supported by current medical reports associated with the treatment of the disability this is often not the case with learning difficulties, which are often difficult to understand and categorise. The supporting services for individuals with learning difficulties are and have been for a long time under considerable strain and are often directed to crises management. There may not be current "medical" or other supporting evidence for a learning difficulty condition.

Question 11: An important part of the new process is likely to be a face-to-face discussion with a healthcare professional.

- **What benefits or difficulties might this bring?**
- **Are there any circumstances in which it may be inappropriate to require a face-to-face meeting with a healthcare professional – either in an individual's own home or another location?**

A face to face interview not necessarily bring out any meaningful evidence, a conversation with my son would be largely meaningless. Anxiety in certain situations can be intense and the individual's ability to answer questions degraded. An interview could also have serious negative effects in management of a disabled person's condition. In my son's case his abilities and behaviour can change significantly depending on his level of stress.

An interview is a very superficial test of disability. Also if the interviewing individual is appointed by the reviewing authority here is a danger that he/she will not be considered impartial. There is not a good history with directed interviews and the disabled community are very suspicious of the impartiality of this type of process. If an interview forms part of the assessment there must be legislative restriction that does not allow the placing of targets or other direction (other than specific criteria) on that professional.

There also needs to be an empowered advocate for the claimant involved in all of this process, particularly the interview process. Undue weight should not be placed on the outcome of the interview when considered in the light of the other evidence. This is necessary as many claimants are vulnerable individuals and will not present well at an interview.

Question 12: How should reviews be carried out? For example:

- **What evidence and/or criteria should be used to set the frequency of reviews?**
- **Should there be different types of review depending on the needs of the individual and their impairment/condition?**

The evidence and criteria should be medical and other criteria dependent on type of disability and managed through the relevant profession. Reviews should not be a review of underlying condition but assessment of actual permanent changes to the underlying condition.

Reviews can be easily managed as at present by regular reminders of need to review condition and signing that circumstances remain unchanged supported by more in depth reviews at regular interviews. What is more important is a clear understanding of the criteria under which the review is made.

What is clear however that there needs to be a strong and independent advocate acting on the claimant's behalf throughout both the assessment and review processes.

Question 13: The system for Personal Independence Payment will be easier for individuals to understand, so we expect people to be able to identify and report changes in their needs. However, we know that some people do not currently keep the Department informed. How can we encourage people to report changes in circumstances?

I find your contention (paragraph 31) that this system will be simpler and easier to understand unproven at this stage when you have yet to develop your process and assessment. Your supporting statement that "Personal Independence Payment is better equipped to reflect further change in our society" appears somewhat meaningless in current circumstances (unless meant in the negative?)

The document that you refer to in paragraph 31 indicated (on a sample of 1200 cases) an estimated overspend of £730M (9.1%) and an estimated under spend of £200M (2.5%) on a 95% confidence level (total population not stated). Of these totals £630M of overpayments and £190M of underpayments were assessed to be the consequence of a change in customer circumstances.

What is not clear is the basis on which the initial sample was selected so there is no consideration in this report of the period of time over which these errors had accumulated or the potentially wide variance (£480M - £800M in respect of overpayments) that a 95% confidence level represents. There is therefore less certainty in the conclusions of this study than your consultation paper suggests.

In the assessment process under DLA there is no clear indication as to which part of the assessment relates to the award. It is therefore difficult for the claimant or his/her representative to assess whether a change is material or not. Equally as you state changes can be minor and occur over time (and may be balanced by deteriorations elsewhere in the condition that offset improvements).

Your question also shows a lack of understanding of the effect of disability on personal circumstances, especially financial. A reduction in benefit is a terrifying prospect for many disabled people and can lead to loss of home, independence and significant degradation in quality of life. Management of benefit needs to be handled in an intelligent way, gradual reductions linked to wider circumstances (not just the pure measure of degree of disability) need to be taken into account. Working through the wider care system is vital.

A penalty system will be counter productive as, in the majority of cases you will simply further degrade the financial circumstances of the claimant. In truth the punitive nature of your statements in paragraphs 34 and 35 of Chapter 2 are perhaps the most disturbing statements in the entire consultation document.

Question 14: What types of advice and information are people applying for Personal independence Payment likely to need and would it be helpful to provide this as part of the benefit claiming process?

The application pack should explain purpose of benefit, criteria for claiming and information requirements such as process and review. It should explain the specific

evidence required and also how to appeal if the application is rejected. It should also include the type of information that you refer to in your question 15.

Question 15: Could some form of requirement to access advice and support, where appropriate, help encourage the minority of claimants who might otherwise not take action? If so, what would be the key features of such a system, and what would need to be avoided?

I do not see the need for a requirement for individuals to access advice and support. Most claimants are directed towards benefits by advisors within the care professions. Claiming benefits is neither an easy or positive experience in a large number of cases and the associated uncertainty is always of great concern.

Embedding an independent element in the process, particularly a claimant's representative would do much to reduce this uncertainty and the constant concern that the system is biased against the claimant.

Question 16: How do disabled people currently fund their aids and adaptations? Should there be an option to use Personal Independence Payment to meet a one-off cost?

Aids and adaptations are financed by council grants, charities, benefits and often families. I see no reason why Personal Independence Payments should not be used to finance aids and adaptations..

Question 17: what are the key differences that we should take into account in assessing children?

Children's needs will be different to adults and their disabilities may not be fully present or as debilitating as they will be when the individual is older. They will also vary during childhood depending on age.

Benefits should not be reduced on the basis of parental care!

Question 18: How important has DLA been at getting disabled people access to other services or entitlements? Are there things that we can do to improve these passporting arrangements?

The value of DLA in passporting disabled people to other services and entitlements has not been either clear or consistent. Services and entitlements should be clearly linked to the award of DLA as one amongst a number of criteria defining eligibility.

Clearer direction to other authorities of the role of Personal Independence Payments and the benefits that should be automatically granted as a consequence would be advantageous. This would stop different practices between different local authorities.

Question 19: What would be the implications for disabled people and service providers if it was not possible for Personal Independence Payment to be used as a passport to other benefits and services?

Quite bluntly, more poverty and isolation for disabled individuals and continued difficulty in gaining access to wider benefits that would improve the quality of life for vulnerable individuals.

Question 20: What different assessments for disability benefits could be combined and what information about the disabled person could be shared to minimise bureaucracy and duplication?

A universal test for all disabilities does not exist and it is a panacea to seek one. The current assessments for different benefits are for different purposes and the only way to combine different assessments would be to combine the benefits with the consequent risk of inequality between claimants.

Greater sharing of information on disability between the medical, welfare and benefit systems would help, especially if this allowed a single assessment to allow access to a range of benefits without further assessment.

Question 21: What impact could our proposals have on different equality groups (our initial assessment of which is on page 28) and what else should be considered in developing the policy?

Your current policy will increase disabled poverty and is probably in breach of the Human Rights Act (though I will leave the latter point to the lawyers). I think that you will, as a certainty reduce the likelihood of some minority groups claiming benefit. Your proposals for assessment also seem to be biased towards physical disability.

You need to consider the effects of your proposals on carers. Your proposals have the potential to cause a significant negative effect of carers and their quality of life. It seem strange that this has not been more central to your proposals. The effects of disability stretch more widely than solely to the individual.

Question 22: Is there anything else that you would like to tell us about the proposals in this public consultation?

I have read your consultation paper several times in preparing this response and I have come to two conclusions:

- These proposals, if implemented on the basis that you have announced and as detailed in this consultation paper will significantly increase disabled poverty. You overstate the effect of changed in society and make no allowance for the effects of the current economic recession;
- Your proposals are heavily biased towards the Department. It will be difficult for the claimant to collect the required evidence and for him/her or their representative to present this evidence to a professional assessor. There is a

clear need for an independent element and a strong appeals process within the overall assessment and review process.

I am afraid that I do not view your proposals with any enthusiasm, particularly as a carer. I have to say I expected better from a government whose leader has a personal knowledge of disability.

Yours sincerely,

