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Consultation papers of change to DLA to PIP.

Dear Sir/Madam,

I suffer with bi-polar disorder (manic depression) and arthritis in my ankles. I receive the lowest rate of DLA Care and DLA Mobility Component. Whether 'high' or 'low' I need assistance through the day in order to live independently. I can only work full time by having the money to get a cab to work on bad days, and paying for a neighbour to pre cook my dinners to ensure I eat.

The lowest rate of DLA pays me about £36 per week. It isn't a huge sum but does allow me to remain in employment by meeting some of the costs associated with my illness. Without it, I would have to either reduce my hours or cease employment as I cannot cope unassisted and couldn't pay for help on my wages alone.

I am responding to this consultation from the perspective of a disabled person.

1. What are the problems or barriers that prevent disabled people participating in society and leading independent, full and active lives?

One of the biggest issues for me is never knowing how each day will be. I can wake up and feel "high" in which case I can forget my medication, forget to have breakfast, and act impulsively. When low I struggle to get out of bed and leave the home. The barriers are finding employers that understand that I can work flat out some days, and other days need constant supervision to function. I have been lucky enough to find such an employer who is very flexible about start and leave times.

2. Is there anything else about Disability Living Allowance (DLA) that should stay the same?

Lower rate care and mobility give just the right level of support to recognise that a person needs some, but not intensive support. It allows some one like me to work, and the Working Tax Credit (which I don't claim) gives a person incentive to manage 16 hours a week if their illness prevents full time work. Lowest rate care has made a huge difference to my lifestyle choices and ability to work.

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

Care - having someone to pre-cook or cook a meal to ensure I eat. Someone to tell me that I need to bathe/shave/change clothes because I can't sense that for myself. To be able to pay or offer gifts to a person stops me feeling like a burden on their time.

Mobility – Whilst I can usually reach places that I know well, through habit and memory, there are days when my brain goes mad and I can't think straight. On these days I need to take a cab or ask someone to escort me. Going to new places I always need an escort as I get too anxious trying to work out directions alone. For this it is important to offer a financial incentive to be helped.

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?

No, it may have short term benefits on administration costs, but wherever you mark a dividing line there will be those who just fall under it, or will have to suffer indignity simply to receive support – often more support than they would otherwise need if the lower rate was allowable.

- What, if any, disadvantages or problems could having two rates per component cause?

Someone like myself would loose out, and therefore have to consider ceasing employment. This would rapidly mean my health would worsen as I wouldn't have the routine I need for living. I would rapidly become eligible for middle or higher rate support, but at a loss of my financial independence. A lowest rate of care provides the right level of support to so many people like me, allowing us to hold down employment. To have us on middle or high rate care would make working problematic, because by that point we'd have lost independence and would be further from employment.

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

That is very hard to say, but where a condition, say epilepsy is incurable, it could be considered not cost effective to keep reviewing claims. Certainly my condition could one day be curable and I appreciate it is right to keep my claim under review. So in conclusion, I would suggest that only the most severe or terminal illness should receive automatic entitlement.

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

By comparing what a non disabled person could reasonably do, and considering what support a disabled person needs to achieve these aims.

7. How can we best ensure that the new assessment appropriately takes account of variable and fluctuating conditions?

By actually understanding the variable and fluctuating conditions – too often it is considered that if it is only 3 or 4 days then it's not a problem – but how do you work with 3 or 4 days a week out of action? That is where DLA makes a difference, by allowing me to get to and from work and be supported to get up and dressed.

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?

Whilst aids and adaptations help, it is important to remember that they don't take a disability away. People may feel embarrassed about using them, have problems using them. It is important to realise that these items only ease a problem or not, they don't take it away.

- 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? Disability Living Allowance reform

There would be a temptation to assume Social Services would "obtain" these things, or they could be easily bought. Let's not forget that Decision Makers and Occupational Therapists earn reasonable salaries, and easily forget that most people can barely manage to save £1 per week, so many aids and adaptations are out of reach and Social Services won't always provide help needed.

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?

The hardest part of the form is to answer how long in minutes it takes to do something. I had to time it over several days and guess at an average. It was really hard as I was worried about overestimating or underestimating. I would think other people found that hard to.

- 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?

It must be shown that you can work and claim. People often think I am on the fiddle when I tell them I get DLA. It could even be paid at lowest rate only on the condition that a person works say 16 hours a week, but with no conditionality for high and middle rates. This would send out a positive message about working with minor disablement.

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

A G.P Report is good, as is the testimony of a carer – they know what help we need on a day to day basis.

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?

I have doubts about these so called “professionals”. A friend who gets ESA told me that the person didn’t listen, didn’t record what she was saying, and was really unhelpful. I would feel really uncomfortable knowing that I had to try to talk to someone like that.

- 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?

People with mental health problems struggle to articulate and if the “professionals” opinion carries more weight than their doctor or carer, then they are sunk from the start.

12. How should the reviews be carried out? For example:

- What evidence and/or criteria should be used to set the frequency of reviews?

I think there should be a review every 5 years, except where a person could be expected to have a worsening condition or a potentially improving condition and then they may need a shorter or longer period.

- Should there be different types of review depending on the needs of the individual and their impairment/condition?

I would like the choice of a fresh claim form or a face to face interview to reflect the differing needs of people. I am better at writing than speaking and some people are the reverse.

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?

People should be reviewed more frequently, as I think they don't always appreciate their own changes of health.

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?

I was grateful for the help of an independent advice organisation, who explained how to claim and assured me that I could look for work and keep the DLA support. It got me off of Incapacity Benefit some years ago, and I trusted their advice. The DWP give conflicting advice all the time – I was even told I could claim income support if I worked less than 16 hours – thank god the C.A.B correctly told me it was based on income and hours or else I could have been committing fraud without knowing!

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 think this is hard to answer. Engagement with certain support groups helps, but if you work as I do, I can't tell my boss I am going to a support group one day per week as it wouldn't exactly sound therapeutic to them! I found an evening group with MIND helped me to talk about my feelings, but I couldn't realistically spend money on travel that I needed to get to work on bad days.

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

I have the help of my Nan and a neighbour and I fund this from my DLA payments. It's just a way of saying thank you for enabling me to work and ensuring I get up and dressed and take my medication, eat etc. I have arthritis in my ankles and I know that I will soon need a walking stick. I would probably fund that myself, but for others needing something more specialist a one off payment could really help. I would assume it would be a means tested support system.

17. What are the key differences that we should take into account when assessing children?

I would suspect you would need to consider what goes above and beyond the normal range of childhood behaviour

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

DLA has been fantastic for me. It has meant I can access some leisure facilities at a cheaper rate for my carer. It also allows me access to Working Tax Credit should I need to reduce my hours to sixteen. Without these functions it would be a case of work or claim benefits which would wreck my health. Knowing I can reduce my hours to reflect my health without having to stop work gives me security.

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?

Personally, I would be having to decide whether I could maintain work or if I would simply have to go onto ESA. Passporting to Working Tax Credit if I need to reduce my hours to sixteen or say twenty gives me a choice to work less if my condition gets worse. Without the passport I would have to cease work as without a top up, part time work isn't viable. Also if I want to go to museum, if I have to pay for a carer also, I simply couldn't fund it. As they go free on production of my award letter I can access this. I can also get reduced train travel for me and my carer which makes life more fulfilling.

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

I think it is important to realise that different benefits are paid for different purposes. DLA supports people to manage life, ESA is paid where someone cannot work. Blurring this would disincentivise working.



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

I cant actually make a comment on this.

22. Is there anything else you would like to tell us about the proposals in this public consultation

I am extremely anxious about losing lower rate care. I don't need the support middle or high rate care entails, but I do need support to make working possible. Without it, I wouldn't be able to access support and would have to cease employment. This would lead to my health getting worse and my eligibility into middle rate care – this surely isn't good for me or the taxpayer. Lower rate care was intended to help those who needed significant help whilst maintaining independence, taking it away would have high cost implications. I really ask you to think again about this. Many on middle care could be reduced to lower care and still survive, taking lower care away drops us into free fall.

Yours sincerely


(kindly typed up by )

