

PIP Assessment Development Team  
Department for Work and Pensions  
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Tothill Street  
London  
SW1H 9NA

5<sup>th</sup> August 2013

*By email and post*

Dear Sir or Madam,

**Consultation on the PIP assessment moving around activity**

Parkinson's UK welcomes the opportunity to respond to this important consultation. We also wholeheartedly endorse the Disability Benefits Consortium (DBC) comprehensive response to this consultation, of which we are a member.

For these reasons we concentrate our response on the needs of those with Parkinson's while the DBC response picks up the wider points about the impact of the cuts to at least 428,000 disabled people with physical difficulties walking and the likely costs this will lead to elsewhere in the system.

Parkinson's UK position on who should qualify for the enhanced rate of mobility PIP remains as it was in the response to the April 2012 consultation. The government should award 12 points and enhanced mobility PIP for people who have difficulty mobilising up to and including 50 metres (either with or without an aid or adaptation). This would maintain a semblance of the "status quo" with DLA and reassure those with Parkinson's on high rate DLA mobility that they have less to fear from the PIP reforms. It would also be consistent with other mobility assessments.

Parkinson's UK believes the introduction of a 20 metre threshold for enhanced rate mobility PIP is both arbitrary and driven by the intention to force people with physical difficulties walking, including those with Parkinson's, off a benefit in order to save money.

The consultation question asks:

*What are your views on the Moving around activity within the current PIP assessment criteria? We would like to know what people think about the current Moving around criteria, including the current thresholds of 20 and 50 metres; what they think the impact of the criteria will be; and whether they think we need to make any changes to them or assess physical mobility in a different way altogether.*

We provide our detailed response below.

## **Background**

Presently the latest DWP statistics indicate around 7000 working age people with Parkinson's receive Disability Living Allowance. Of these nearly 6000 receive the high rate mobility component, in other words 85% of the working age Parkinson's caseload.<sup>1</sup>

People with Parkinson's need the mobility component of Disability Living Allowance as Parkinson's is a condition that has an increasing impact on mobility as it progresses. Symptoms can include rigidity and muscle cramp, involuntary random movement ("dyskinesias"), sudden loss of movement ("freezing"), slowness of movement or difficulty beginning movement ("start hesitation") and loss of balance.

Proposals to reform DLA in recent times have highlighted how much people with Parkinson's need the help that DLA brings. Surveys undertaken to help us respond to the reforms consistently show the top three things that people with Parkinson's use DLA for are paying bills, transport costs and support/care around the home. Paying for food, mobility aids and health treatments also feature prominently.

For example 300 respondents with Parkinson's to a Disability Benefits Consortium survey<sup>2</sup> in 2010 described the top three things they used their DLA for and it can be seen mobility and transport feature extremely highly:

<b>DLA used for</b>	<b>% of DLA user responses</b>
Paying bills, eg electricity, water	47.6%
<b>Transport (excl Motability scheme)</b>	<b>42.8%</b>
Support/help from someone	42.8%
<b>Motability scheme</b>	<b>40.9%</b>
Buying essentials	34.5%
Food	28.4%
Health treatment	25.9%
<b>Mobility aid</b>	<b>22.0%</b>

## **The case against a 20 metres threshold**

This consultation provides some reasons why the Department has chosen a 20 metre proxy for those who are in "greatest need".

*DWP quote: The benchmark of 20 metres was intended to allow us to distinguish between those who are effectively unable to get around due to reduced physical*

<sup>1</sup> DWP figures from November 2012 using the tabulation tool <http://tabulation-tool.dwp.gov.uk/100pc/tabtool.html>

<sup>2</sup> See Benefitting Disabled People? (2010) Disability Benefits Consortium. 6000 disabled people responded. This data was derived from the unpublished detailed survey results on respondents with Parkinson's. <http://www.disabilityalliance.org/dbcreport.htm>

*mobility – for example, people who are only able to move between rooms in their house but go no further – and those who have some, albeit limited, mobility. We thought that these criteria could be applied consistently*

The Department's claim that 20 metres is an easier distance to assess against is contradictory, given that 50 metres is in many other instances of benefits and mobility seen as a practical distance to assess against for the greatest barriers to mobility. So for example:

- In official guidance on creating an accessible built environment
- In criteria for the support group of Employment and Support Allowance (those who are accepted as too ill or disabled to work)
- As a distance that can deem blue badge eligibility
- As an established benchmark for DLA mobility

More of the detail of these benchmarks is in the Disability Benefits Consortium response.

Moreover 50 metres is already noted by the Department, in prior consultations on PIP, to be:

- the distance that an individual is required to be able to walk to *achieve a **basic level of independence**, such as the ability to get from a car park to a supermarket* (April 2012); and
- in the initial draft of the criteria was described as a benchmark that *identifies individuals whose mobility is **severely restricted***. (May 2011).

It is also contradictory to state the PIP is for "independence". A 20 metre benchmark leaves those who cannot achieve a "basic level of independence" ie walk up to 50 metres with no hope of qualifying for the most helpful element of the PIP benefit, despite it being a lifeline.

*DWP quote: Our intention has always been to focus the enhanced rate on those with the greatest barriers to mobility. We thought that these criteria ..... would make it easy to differentiate between people who should be receiving the enhanced and standard rate.*

In discussions with officials it is clear the DWP use "greatest barriers" and "greatest needs" by way of a proxy of additional costs, the logic being that those with the severest mobility impairment have the most costs.

However in the case of PIP moving around criteria this logic is flawed. As an example, for those who are unfortunately in the most advanced stages of Parkinson's, who have lost mobility, their travel and transport costs could be much lower because going out has become a much rarer occurrence.

Those with Parkinson's who are in earlier stages and are determined to maintain a level of independence for their own physical and mental wellbeing could well have greater costs:

*"My mobility has deteriorated over the past 18 months. I try and walk as much as I can with my walkers because I want to keep mobile as long as I can. However this does not mean I could compete in a marathon. The effort takes it out of me but I try and carry on."*

*"Most of these people, like me, will hate any restriction on their freedom of movement but know that the nature of a chronic and progressive disease makes it inevitable. Surely the role of government should be to help people with Parkinson's maintain their independence rather than confining them to their homes".*

Furthermore there does not appear to be any rationale or government evidence to suggest that costs are greater for those who cannot walk up to 20 metres as opposed to those who cannot walk up to 50 metres. The following case illustrates this well:

*"I can see no difference whatsoever in the finances needed by someone unable to walk up to 20m as opposed to 50m. Anyone unable to walk over 50m is effectively unable to generally walk to a bus stop or a train station, and then to reach their destination at the other end. After walking 50m my husband often grinds to a halt, or the dyskinesia kicks in, rendering him unable to walk. This happened the other day, so I left him sitting on a bollard while I went to get the Motability car. At other times we've had to get a taxi."*

*"Taxi to and from work today cost £14 - my legs are very unstable after I have walked around 30 metres which make it impossible for me to get to a bus stop"*

Nor can the use of aids and adaptations be relied upon as a proxy of impairment with Parkinson's. For example for many people with Parkinson's walking sticks are not always an option given the dexterity problems caused by the condition and an inability to hold on to the stick for any period of time.

Time and again people with Parkinson's have told us that DLA mobility is a lifeline because of the unpredictable nature of Parkinson's – where sudden problems with walking when out mean a person can get home eg. call a cab, or go out with the certainty of having their car parked nearby.

### **What the impact will be on people affected by Parkinson's**

The mobility component caseloads published with the consultation demonstrate that with reform the PIP enhanced rate mobility caseload will be 602,000 in May 2018 at the end of the PIP reassessment period. If PIP had not been introduced then the DLA high rate mobility caseload would be 1,030,000. The difference of 428,000 is a staggering number and the impacts will clearly be felt far and wide.

The DWP consultation now asks what the impact of the change will be. This should be apparent to the DWP but it is clear that in posing the question it has failed to analyse the impact of the policy for itself.

The DWP must have "due regard" for advancing equality of opportunity for disabled people, yet it is shocking to people affected by Parkinson's that - having planned to leave 428,000 people without mobility support - no comprehensive assessment exists of what this loss will mean.

The prospect of loss of DLA high rate mobility, which the vast majority of those with Parkinson's on DLA receive, has prompted the following personal and heartfelt comments to Parkinson's UK.

*I know without my mobility allowance I wouldn't be able to afford taxis to take me to different activities to make my life purposeful. I go to a Nerve Centre where I have picked up painting. And when I can't get out it is very therapeutic.*

*Without it I would be very restricted in getting out and about, doing my shopping and visiting friends. I don't have the confidence to travel by public transport because of being unable to predict when I might freeze and feeling foolish if it does happen or appearing drunk because I am unsteady.*

*I can use my scooter to get to friends or up the shops. I have to use taxis a lot, just this week physiotherapy and to see my consultant has cost me £50. I have to use taxis every week and am unable to use public transport. I have also brought most of my own mobility aids, waiting for the NHS can be too long to wait.*

*If I were to lose DLA I would become a prisoner in my own home, unable to get out and about and more reliant on family and friends.*

*If I lose my DLA without the financial support for taxis to work I would not be able to stay in my current job, as I was out of work for 8 months before finding this job, when my Parkinson's was only just evidence. I don't hold much hope of getting another job if I have to leave this one.*

*It is also important for an individual's well-being and mental health to be able to get about and to maintain a normal life as far as is possible with this terrible condition. The government's costs are likely to increase in other departments (such as social services and mental health services) if people are isolated and restricted.*

Professionals involved in supporting people with Parkinson's have also commented to us:

*I feel that patients will not be compliant with their drugs so the assessor can see what they are really like and how their mobility is affected. This is very dangerous for their own health and wellbeing. What a sad state of affairs that people feel they are going to have put their health at risk to have any chance of getting the benefit.*

*There is no definitive cure for Parkinson's, a horrible degenerative disease, but there is something that can be done to help remedy the causes of depression. If these payments are reduced then the quality of life of many people will be seriously affected.*

### **What changes should be made**

Unlike daily living PIP, where you can score cumulatively, the PIP moving around criteria is, for those solely with a physical impairment, the only chance of securing support towards mobility costs. It is the one criteria that signifies independence, and the supposed purpose of the payment, more than any other.

For these reasons it must address the needs of those who can still manage journeys out of the house but face significant challenges to do so.

Parkinson's UK position on who should qualify for the enhanced rate of mobility PIP remains as it was in the response to the April 2012 consultation.

The government should award 12 points and enhanced mobility PIP for people who have difficulty mobilising up to and including 50 metres (either with or without an aid or adaptation). This would maintain a semblance of the "status quo" with DLA and reassure those with Parkinson's on high rate DLA mobility that they have less to fear from the PIP reforms. It would also be consistent with other mobility assessments.

Various statements have been made by DWP ministers in recent times on PIP reform to assure disabled people:

*"I have always been clear that I would not make any change that would stop disabled people from getting out and about."*

Maria Miller, Minister for Disabled People, December 2011.

*"I say to those watching today and who are genuinely sick, disabled or are retired. You have nothing to fear."*

Speech by Iain Duncan Smith, Conservative Party Conference, 5 October 2010.

*"The fact is that we are not cutting the money that is going into disability benefits. The question is how best to reform those disability benefits so that disabled people actually get access to the benefits that they require. The reform has been led by many of the disability groups, which want to see something that is much more related to people's disability and faster to access, too."*

David Cameron, Prime Minister, 12 September 2012

We urge the DWP to make adjustments to the PIP criteria to reflect upon these clear ministerial and prime ministerial assurances.

Yours faithfully,

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