

## **Papworth Trust response to the 'Moving Around' criterion consultation**

Papworth Trust is a disability charity, whose aim is for disabled people to have equality, choice and independence. We help over 20,000 people every year through a wide range of services including employment support, leisure, homes and care.

Papworth Trust welcomes the Government's decision to consult further on the mobility criteria, and in particular the 20 metre ruling. Disabled people rely heavily on Disability Living Allowance (DLA) to help them meet the extra costs that living with a disability brings. The replacement of DLA with Personal Independence Payments (PIP) is therefore of great importance to them and, as a result, to Papworth Trust.

From the outset, Papworth Trust has sought to feed into the PIP policy development process and implementation with the aim of making it fair and appropriate to the needs of disabled people. When PIP was first announced in 2011, we ran a survey to find out what claimants currently use their DLA for and to better understand what changes (if any) were causing disabled people most anxiety and concern.

### **Qualitative research**

To inform this consultation response, we sought views from people who felt they would not qualify for PIP under the moves to reduce the qualifying criteria for enhanced rate from 50 metres to 20 metres. We wanted to better understand why they felt they would not qualify, what impact not qualifying for the enhanced rate would have, and what mobility costs are associated with their disability. We have changed the names of our case studies to protect their identity, but all other information remains factual.

#### **1) Case Study A**

A has Multiple Sclerosis and currently has an indefinite DLA award for higher rate mobility. The money A receives from DLA is automatically paid towards her Motability car which she uses to get to work, hospital appointments and larger shops as she lives in a remote area. The public transport links in her area are

inadequate, buses are neither regular or stop near to where A would need to go. The taxi service is also limited.

A believes that in order to qualify for the higher rate of PIP, she would be dependent on the assessor understanding her walking difficulties. To cover 20 metres, A would have to use a stick and hold her partner's arm. She would also need to rest and sit down for at least 5-10 minutes before being able to repeat the task and it would be a slow process.

If A was to lose the higher rate mobility component and subsequently her Motability car, she would no longer have her independence.

## 2) Case Study B

B has a rare condition called Functional Neurological Disorder which affects her walking. On good days she is able to move about the house, on other days she must use crutches. She currently receives the higher rate mobility component of DLA, which was awarded to her for three years. The money A receives from DLA is automatically paid towards her Motability car.

B is concerned that she will not qualify under the '20 metre rule' because her ability to walk fluctuates so dramatically. If B didn't get the enhanced mobility rate to pay for her Motability car, she and her husband (who is also her full time carer) could not go out.

B feels that ability to move over distance alone is not a good test for benefits. She thinks that no specific criteria can be used; instead a mixture of circumstances should be taken into account for each person, such as regularity of difficulties moving, amount of pain experienced and the aids needed.

## 3) Case Study C

C has lived with chronic pain for the past 15 years and currently receives an indefinite DLA award of the higher rate mobility component. This benefit goes directly as a payment for his Motability vehicle, with any remainder contributing to (but not covering) fuel payments. C had a spinal injury and is affected by Myalgic Encephalomyelitis (ME). His ME causes a fluctuating range of mobility difficulties; some days he may be unable to get out of bed due to the pain he is in, whereas on other days he can move with the aid of walking sticks.

C is concerned that the '20 metre rule' would not take into account the fluctuating nature of his condition. C would like levels of pain and aids to be considered in the assessment, although he understands that these are highly personal and hard to quantify. In C's case the pain is tiring and debilitating and it affects his ability to move each day.

If he lost the mobility component, C would not be able to leave the house. He would be forced to rely heavily on his ageing parents and would not be able to be to see his children. The stress that this would cause him would affect his mental wellbeing in the form of depression; therefore the loss would pervade all aspects of his life.

#### 4) Case Study D

D has a variety of conditions that impact each other and combine to cause discomfort and limited mobility. These conditions include brittle asthma, bronchiectasis, severe and repeated chest infections, spinal fusion in the neck, and weakness in the wrists due to overuse of medication and arthritis. This manifests as problems with fine motor skills such as cutting vegetables or tying shoe laces, and problems with balance and mobility such as rotating her head to look at the floor. Most importantly her condition fluctuates dramatically, meaning that some days she cannot get out of bed, but on other days she may be able to move over 50 metres, with the aid of a walking stick. D cannot use a wheelchair because it causes her more pain.

D currently receives an indefinite DLA award of the higher rate mobility component. D uses her mobility payment to pay for accessible taxis, or black cabs, as these are the only vehicles she is able to use. If D lost her enhanced rate of mobility and consequently her Motability car, she is concerned she would lose her job and be forced to rely on benefits.

D feels that the fluctuating nature of her condition will make accurately assessing her for PIP difficult. She believes other factors should be considered, including pain, balance or confidence in mobility as each of these affect her ability to move.

## 5) Case Study E

E has Multiple Sclerosis and currently has an indefinite DLA award for higher rate mobility. He uses his DLA to pay for taxis to hospital and doctor's appointments, to maintain his van, exclude him from paying road tax and contribute towards petrol which ensures he has constant access to a toilet. With the van, he can maintain his independence and contribute to society through his voluntary work.

As his condition is fluctuating E does not know whether he'd be able to walk to the 20 metres on some days compared to others. On some days he can't even get out of bed. There is never any warning to when it can be a bad day so he cannot put a percentage on the amount of time he may not be able to walk 20 metres.

## 6) Case Study F

F has a variety of conditions including hip dysplasia, osteoarthritis, primary lymphedema that causes her legs, feet and ankles to swell up which causes pain. She also has Ehlers-Danlos Syndrome, fibromyalgia, depression and postural orthostatic tachycardia (POTS) that can cause unconsciousness. These conditions can affect her ability to walk over 20 metres dependent on how she is that day. It varies day to day and there is no warning on how she may feel. She cannot use a mobility scooter or an electric wheelchair due to the possibility she may pass out, she can rarely go out on her own.

F currently receives the higher rate mobility component of DLA and is reassessed every three years. She uses her DLA for taxis to get to GP and other appointments, for equipment to help her condition, and to pay for members of her local community to take her out.

F is sometimes able to walk 20 metres and sometimes she is not. She experiences attacks of unconsciousness which can last up to 5 hours and mean she is unaware of her surroundings. These can happen daily, or at least 2 to 3 times a week and contributes to her inability to go out alone or use public transport. If she were to lose her DLA she'd be completely housebound.

The reliability factors (completing activities safely, repeatedly and in a timely manner) in the PIP regulations are her main concern; it is dependent on how her

condition is in the day, how often she would have to repeat the 20 metres and how long her rest time is. G plans her weeks with the aim of having at least two rest days a week between each time she leaves the house.

## **Distance**

Papworth Trust urges the Government to reconsider the decision to reduce the qualification for enhanced rate mobility from 50 metres to 20 metres. The majority of people we spoke to believe 20 metres to be an inadequate distance to measure mobility. For many who can walk between 20 and 50 metres, their costs would not be significantly different from someone who can walk up to 20 metres. For example walking between 20 and 50 metres is not enough to reliably use public transport, yet the standard rate of PIP would not cover the costs of a Motability vehicle.

We also feel the Department's decision to reduce the mobility to criteria to 20 metres is at odds with other Government departments. For example, the Department for Transport's recent consultation on the Blue Badge scheme and PIP felt that people able to walk no more than 50 metres should be eligible for the scheme.

## **Extra costs**

In the cases of A and D, they may have to give up work if they were to lose their DLA and claim unemployment benefits. At the moment, B's husband is her main carer but this is only possible with the extra money of higher rate mobility. Papworth Trust believes these two stories will have far greater consequences and costs to the NHS and other Government-funded benefits and where we will see levels of poverty, depression and mental ill-health rise.

A 2012 report by the Commission on Rural Communities included research on the impact of social isolation on health<sup>1</sup>:

"Social isolation and high levels of psychosocial stress could also contribute directly to ill health by promoting health-damaging behaviours. A recent meta-analysis of 148 studies investigating the association between social relationships

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<sup>1</sup> Commission for Rural Communities, September 2012, *Social isolation experienced by older people in rural communities*, p. 16: <http://www.defra.gov.uk/crc/files/Social-isolation-experienced-by-older-people-in-rural-communities-final-sep-11-12.pdf>

and mortality found that various measures – including social isolation - exert an independent influence on risk for mortality comparable with well established risk factors such as smoking (Holt-Lunstad et al, 2010).”

Research from the grassroots organisation We Are Spartacus shows the value of the Motability scheme for the UK economy.<sup>2</sup> They estimate that Motability is saving £30 million per year in terms of transport to health appointments. One in 1,000 UK jobs are supported by the Motability scheme and users of the scheme contribute £1.2 billion of GDP per year through allowing them and their carers to work.

### **Recommended changes to the Moving Around criterion**

In light of the evidence we have provided which shows the impact that the loss of the higher rate mobility component would have, we believe that, in order to reach those most in need, the 20 metre rule should either be returned to the 50 metres used under DLA, or, descriptor D should be increased to 12 points.

Papworth Trust believes that by investing in this area and extending the measurement to 50 metres, it would save the Government money in the longer term.

### **Fluctuating Conditions**

Papworth Trust found that many people with fluctuating conditions are very concerned that they will not qualify for the enhanced rate mobility component. They are worried that because on ‘good’ days they are able to walk between 20 and 50 metres, it will be difficult for assessors and DWP to decide whether they meet descriptor D or E.

It is noted and welcomed that each descriptor only applies if someone is able to mobilise that distance for over 50 per cent of the days in a 12 month year. However we have remaining concerns about people whose conditions vary, since their appearance on the day of assessment may be inconsistent with how their condition affects them on another day.

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<sup>2</sup> We Are Spartacus, January 2013, *Emergency Stop*: <http://wearespartacus.org.uk/wp-content/uploads/2013/01/Emergency-Stop-final.pdf>

Evidence from professionals will be crucial in aiding assessment and decision making for claimants with fluctuating conditions. We urge the Government to make sure that evidence is always requested where the claimant states they have a fluctuating condition which affects their mobility. This will assist in fair and accurate decision making.

## **Reliability**

For a descriptor to apply to a claimant, the claimant must be able to reliably complete the activity as described in the descriptor. Reliability includes whether a claimant can complete an activity repeatedly, which is defined as “as often as is reasonably required.”

Papworth Trust is concerned that this definition is too loose for the Moving Around criterion.

While it might be reasonable to expect that a person should get dressed then undressed twice a day (in the morning and evening), many people we spoke to were worried that moving “as often as reasonably required” is meaningless.

## **Conclusion**

Papworth Trust urges the Government to reconsider the decision to reduce the qualification for enhanced rate mobility from 50 metres to 20 metres. We do not believe the costs of mobility are significantly different between those who cannot walk over 20 metres and those who can walk between 20 and 50 metres. Throughout our response, we believe we have shown the impact the loss of the high rate mobility component will have on disabled people. We believe the 20 metre rule should either be returned to the 50 metres used under DLA, or, descriptor D should be increased to 12 points. By investing in this area and extending the measurement to 50 metres, we believe it will save the Government money in the longer term.