



Multiple Sclerosis Society

Consultation on the "Moving around" criteria for PIP MS Society response

Introduction

The MS Society strongly welcomes the decision to re-consult on the "Moving Around" criteria for PIP. This is a major issue for people with MS – 64,000 people with the condition currently receive DLA, and 94% of these qualify for the upper rate mobility component. We are acutely aware that the government's own projections suggest that by 2018 around 428,000 people will no longer qualify for the enhanced rate mobility component of PIP, and are deeply concerned about the impact this could have on the independence of people with MS.

This response is based on the feedback we have received from over 100 people with the condition who contacted us to express their views about the "Moving Around" criteria for PIP – in particular, the 20 metre qualifying distance. We have changed their names in this document to protect their identity.

Summary and statement of support

We would like to take this opportunity to express our support for the response of the Disability Benefits Consortium (DBC) to this consultation. This response will focus on reinforcing the points made by the DBC and provide supplementary evidence to these areas.

We will begin our response by welcoming the reliability criteria and comment on their application, before addressing our concerns about the 50% rule for people with fluctuating conditions. The main focus of this response, however, will be on the qualifying distance of 20 metres for people to qualify for the enhanced rate mobility component of PIP.

Based on the feedback we have received from people with MS, we believe that the 20 metre qualifying distance will lead to people with the condition:

- Losing their independence
- Dropping out of work, education and volunteering activities
- Becoming increasingly isolated and enduring the associated risks of worsening health

In particular, we will discuss how the 20 metre measure is flawed as a means of measuring mobility impairment, and the impact that the rule is likely to have on people with MS that no longer qualify for the enhanced rate mobility component of PIP as a result.

We also support the following points raised by the DBC:

- The tightened mobility criteria for PIP – in particular the 20 metre rule – are likely to push costs to other areas of (potentially more expensive) government

spending, such as unemployment benefits, the Access to Work Scheme, Social care and the NHS.

- The 20 metre rule is inconsistent with government guidance and contrary to well-established methods of determining levels of significant mobility impairment.

Please refer to the DBC response for more information on each of these areas.

The reliability criteria – “Safely, to an acceptable standard, repeatedly, and within a reasonable time period”

We strongly welcome the addition of the reliability criteria to the regulations. It is vital that assessors are compelled by law to consider whether claimants can complete activities, “safely, to an acceptable standard, repeatedly and within a reasonable time period”.

We would like to take this opportunity to stress that it is vital that the criteria are used in a consistent way and that assessors adequately follow the DWP guidance when applying them. We seek assurances that the use of the criteria is properly monitored both by the DWP and assessment providers themselves. In particular, that side effects such as pain and fatigue are adequately taken into account.

It is also necessary to point out that the reliability criteria, while taking a fairer approach to assessing whether claimants can mobilise, do not negate the impact of reducing the qualifying distance from 50 to 20 metres for the enhanced rate of the benefit. As the government’s own projections show, 428000 people will no longer qualify for this rate of the benefit.

In addition, while we recognise that claimants will be able to score points on the mobility descriptors for the ‘Planning and Following a journey’ activity, there is a significant proportion of claimants that will be applying for PIP on the basis of a physical disability alone. These are the people that will be negatively affected by this policy.

The 50% rule

The responses we have had regarding the “Moving around” criteria for PIP have reinforced our concerns about the use of a 50% rule for assessing people with fluctuating conditions. As we have stressed in previous consultation responses on the PIP criteria, the approach fails to take into account the impact and severity of MS relapses. The 50% rule fails to recognise that a severe spike in an individual’s condition can result in a sharp increase in mobility needs and significant additional costs. An individual who has severe mobility needs for 45% of the time may, for example, require a mobility scooter to get out of the house. The current assessment fails to recognise these costs. In addition, people with MS find it extremely difficult to quantify how many days they are or are not able to complete activities.

A person with MS told us:

“It is incredibly demeaning to be asked such questions about details which vary so much that I really wouldn’t have a clue how to answer them honestly. In such instances people can easily be guided into giving the answers that the assessor needs for their targets rather than the true picture”.

We are aware that the Evidence Based Review (EBR) of the Work Capability Assessment (WCA) for Employment and Support Allowance (ESA) is currently underway, and is testing an alternative approach to measuring fluctuating conditions. We seek assurances that the learning from the EBR will be taken into account when reviewing how PIP assessments are working for people with fluctuating conditions. We also seek assurances that the 50% rule will be a key focus of the monitoring undertaken for PIP.

The 20 metre rule is flawed

We will now move on to discuss the 20 metre qualifying distance that has been introduced to assess people for the enhanced rate of PIP. Based on the responses we have had from people with MS on this issue, we strongly believe that those who can walk more than 20 metres (but no more than 50 metres) face many of the same barriers to mobility, and therefore the same additional costs, as those that can mobilise for less than this distance.

People with MS have told us:

"I can do 20 metres over 50% of the time. I am sure even on my good days I would face the same additional costs as I am not able to use public transport most days due to my MS. The bus stop is around 60metres from my house, I am unable to stand for any length of time waiting for a bus as my legs go wobbly and I am in danger of falling. I would find it impossible to walk from the bus stop to my home after walking round a shop or the market".

"I am mystified by the alteration to the walking distance limit to 20m. The days when I can walk 50m are no cheaper than the days when I can walk 20m or less. I am still unable to access most shops and local services in our area without my wheelchair. I am still unable to get to the top of our road to access public transport and must rely on my own car to get anywhere. I am still unable to do the family shop or shop for clothes. The difference between 20m and 50m means that I might be able to walk further into John Lewis, for example, but I still don't have any more chance of getting around it"

"I face the same costs as someone who can do 20 metres. I have to keep a vehicle on the road as without it I'd be unable to access local facilities, even though on my income I wouldn't normally be able to afford to".

"reducing the limit from 50 to 20 metres is a meaningless, overly restrictive, condemnatory measure. It penalises somebody like myself who can manage to work, look after the house and children (with help). The fact that because I can manage another 30 metres I will be penalised financially is quite laughable. If I could skip, run, walk a half marathon then this would be significant but an extra 30 metres capability is ridiculous. I would be facing significant extra financial costs because I struggle but manage to walk 50 metres (and therefore eligible for higher mobility component) but because I am over the magical 20 metres this is taken away".

"In my opinion there is not a huge difference between 20 metres and 50 metres as a measure of mobility. Both are small distances and incur the same costs. For instance take two people - one who can walk just under 20m and the other 50m - both would probably need the use of a scooter, car or wheelchair pretty quickly on their journey - same costs surely".

Below we have provided two detailed case studies to demonstrate the similarity in costs and barriers faced by people that can walk 20 and 50 metres.

■■■■ is 44 and was diagnosed with Relapsing Remitting MS in 2012. She has been claiming DLA since September 2012. She can walk 20 metres on a very good day, but on a bad day she cannot manage this distance. She told us:

"Can I walk 20 metres on a bad day? I would say a very emphatic 'no'. Even relapse free, on a bad day, I would struggle".

■■■■ has 'bad days' for 60% of the time.

■■■■ weekly mobility costs (In her words):

Monday

No travel

Tuesday

Taxi to Brownies to drop off and then collect my daughter £9. By evening I am feeling pretty exhausted and really not able to drive.

Wednesday

Very wobbly legs after a day in work. Sister drove me to shops, I paid petrol money plus I paid for a few items for her as thank you. £10

Thursday

Out for a meal in the evening (yes I have a life – sometimes). Taxi there and back as legs always more unsteady in evenings, stayed local. £8

Friday

No travel

Saturday

Car in to garage for MOT. Couple of minor repairs and service £220. Flowers for a friend as a thank you for lifts during the day. Taxis would have cost in region of £20. Day after injection (Rebif), always suffer headaches so driving or public transport not an option.

Sunday

Went to Church. Legs quite wobbly so got taxi £9.

Total expenditure: £36 (excluding vehicle maintenance)

Long-term costs

As illustrated above, ■■■■ pays for the upkeep of a car.

According to the PIP criteria as it stands, ■■■■ should continue to receive the enhanced rate of the mobility component of the benefit to help towards the costs she faces.

■■■■ is 58 and was diagnosed with Relapsing Remitting MS in 2008. She has been claiming DLA since 2001. She told us:

"I walk around 50 metres on a good day. I would think I am able to walk about 20 metres on a bad day, but maybe not repeatedly. I have about 60% good days

and 40% bad days".

weekly mobility costs (In her words):

Monday

Taxi to and from town £10 - my legs would be too unstable after I walked to the bus stop (which is more than 50 metres away) just to catch the bus into town. Second trip to visit family return taxi £12 later in the day.

Tuesday

Taxi to and from the hospital £22 - I would not feel well enough and my legs would be too unstable to walk to and from the bus stop when I am due my hospital treatment.

Wednesday

Taxi to and from town £10 to attend a social group. My legs would be too unstable to walk to and from the bus stop.

Thursday

Taxi to and from my local hospital £8 with my dog to carry out my volunteer role. If I could travel by bus I would need to change buses, the length of the travel time would mean I would very likely be too fatigued to fulfil my volunteer role.

Friday

Taxi to and from my exercise group £12 if I had to use public transport - 2 buses, I would be too fatigued to take part in the class.

Saturday

No travel

Sunday

Taxi to and from church £42. This would be an impossible journey to make by bus for me as I would need to take at least three buses which would take around 2 hours to get me to my church, I would not attempt this journey by public transport.

Total expenditure: **£116**

Under the current PIP criteria [REDACTED] is very unlikely to qualify for the enhanced rate of the mobility component of PIP so will no longer receive any help towards the costs she faces.

The Impact of losing the enhanced rate of the mobility component of PIP

We are particularly concerned about how people's lives will be impacted as a result of no longer qualifying for the enhanced rate of the mobility component of PIP.

People with MS are extremely fearful of the 20 metre rule and the effect that the loss of PIP will have on their ability to lead independent lives. In particular, serious concerns have been raised by those who are at risk of losing their Motability car, those that are in employment, in education or volunteer, those who live in rural areas, and those who are terrified at the prospect of becoming socially isolated.

Overleaf we provide a range of comments received from people with MS on each of these points.

Case studies: Motability

██████████

"This would have a devastating effect on my life, I would lose my Motability car so I would have to give up working, work gives me reason to get up in the morning and stops me thinking about my MS. I am a very independent person and I don't want to have to rely on other people to take me anywhere for example doctors appointments".

██████████

"Without my car I would not be able to work as I cannot afford a car big enough to take my wheelchair. I WANT TO WORK FOR AS LONG AS POSSIBLE! I don't want to sit at home on benefits. I want to contribute to society".

██████████

"Without my adapted Motability car I would be stranded at home. Motability is such a great scheme as last time around I was able to buy the hoist I need with the car. Whilst I still had to pay for this, because of Motability's bulk buying power the hoist cost me £495 whereas buying it privately costs over £1000. As this is every 3 years on top of the up front cost of having a large adapted car on the scheme, any way of reducing the cost is important. There is no accessible public transport where I live which does not help matters. DLA has been a godsend to me and enables me to carry on working for at least 10 years longer than I would have managed without it and now enables me to be a useful member of society in my part time volunteer work".

Case studies: Work, education and volunteering

██████████

"Take away my car and I cannot work. It's a mile walk from my house to the bus stop since they cut our local service. Then I end up losing my house, and on benefits. I work as a teacher - ask my wonderful students if they want me to leave because I can't get to work. I couldn't afford to buy a car with the adaptations I need. I have a family to support, my husband works part time in a warehouse as he needs to do everything at home so I have enough energy to work.

"Why punish people with MS who are able to work with this small amount of support. The taxes taken from me are more than the DLA payment, so I am paying my way..... My contributions would cease if I couldn't get to work".

██████████

"My Motability vehicle is absolutely essential to my being able to still work as without it I cannot go to meet with my customers in person or even get to a Post Office to send my goods to them. It's also my only means of getting to the shops for basics like food, soap etc. There is NO public transport available within more than about half a mile of where I live! Without the Motability vehicle I will be virtually housebound. I

cannot afford to buy, maintain, insure etc any vehicle on my own".

■■■■■

"I work for the DWP and rely on my mobility payment through Motability to get to & from work. I still work 34 hrs per week over 4 days. Without this component I will lose my car and rely on Access to work to cover my taxi fares (I should qualify for this). This would mean the DWP paying £400 per month in taxi fares as opposed to approx. £250pm for DLA. Before MS I cycled to work so the additional costs of MS include transport costs. The present changes will cost the DWP more money".

■■■■■

"Without my car I will be housebound while my husband is at work and would have to give up my voluntary job".

■■■■■

"Would not be able work, which condemns me to the benefit. My sense of purpose would be taken away. I am 52 years of age and have worked all my life and had to retrain to enable me to hold the post that I have. I would be tied to the house and would be unable to keep my social network and also would be unable to attend various places where I receive Treatment for this illness. My independence would be stripped away from me putting more onus on my wife and family. I never asked for MS it chose me, if I was to end up on benefits this would damage me beyond repair".

Case studies: Rural areas

■■■■■

"Without a car I will not be able to work. If I can't work, travel independently or park close to the places I need to go to I will lose all my independence. I live in an area with no public transport and will not be able to afford taxis".

■■■■■

"I will not be able to live independently as I do not have another member of my family living locally who can drive. I cannot drive a mobility car as the nature of my disability now causes pain when I drive a car. I handed the mobility car back October 2012. The train and bus stop is too far away from my house. I have to get a taxi to the train station. I cannot use the bus as the ride is too bumpy. If I did manage to walk to the shops I would not be able to buy anything as I cannot carry things myself".

Case studies: Social isolation and loss of independence

■■■■■

"I cannot use public transport and won't be able to keep my car, so I won't go out

anywhere".

██████████

"If I do not qualify for the enhanced rate then I will not be able to afford to run my car, simple as that. I would become trapped at home as I could not afford taxis anywhere and local buses are unreliable for disabled access".

██████████

"I would be unable to afford a car and would be confined to the house and totally dependent on friends or family to get me out. My social life would be non-existent and I would need to order an ambulance to take me to see my neurologist. I see him every 4 months. I am depressed enough at times but this would make it much worse. The current uncertainty about PIP is also making me worse".

██████████

"Without a car I could not visit my grand-daughter and daughter, they live 50m away. I would not be able to see my mother, unless I got a taxi (there is no public transport to her village) costing £25 each way, I would not be able to help my mother who is disabled too. The weather would also play a part because without my car I simply would not go out. So briefly I would be stuck in my home".

Our view

We support the DBC's view that it will always be extremely challenging to use a set distance to assess the impact of different individuals' ability to mobilise. Factors such as where people live have a substantial bearing on the extra costs they face to maintain a reasonable level of independence.

However, we recognise that the department must find a workable solution in the context of the current assessment. For this reason, we urge the government to reinstate the use of 50 metres to identify those in the greatest need.

While this is not a perfect solution it is based on a degree of evidence to suggest that 50 metres is a realistic measure to gauge whether a person is 'virtually unable to walk'. The distance of 20 metres is an arbitrary figure that lacks an evidence base and automatically discounts thousands of disabled people who really do need the benefit the most.

We share the DBC's concern that the distance of 20 metres may have been set to restrict the size of the group deemed to be 'in greatest need' and keep costs down as a result. We strongly reject this approach and call on the government to introduce criteria that realistically identify those that fit into this group based on a realistic assessment of the extra costs and barriers they face, not simply the amount of money deemed to be available.

Our call

We strongly urge the government to reinstate the 50 metre qualifying distance for the enhanced rate mobility component of PIP. We hold that the use of a 20 metre

qualifying distance is flawed and will leave those with greatest needs without vital support.

More information

For more information on any aspect of this response please contact Claire Nurdén, Senior Policy and Campaigns Officer at the MS Society, on 0208 438 0753 or at cnurden@mssociety.org.uk.

