



# Personal Independence Payment

## *Moving around activity*

August 2013

### 1. About Carers UK

- 1.1 Carers UK is a charity set up to help the 6.5 million people who care for family or friends. At some point in our lives every one of us will be involved in looking after an older relative, a sick friend or a disabled family member. Whilst caring is part and parcel of life, it can affect your job, your health and your finances. Without the right support the personal costs can be high.
- 1.2 Carers UK is a membership organisation of carers, run by carers, for carers. We have 17,000 members and a reach of many more. We provide information and advice about caring alongside practical and emotional support for carers. Carers UK also campaigns to make life better for carers and influences policy makers, employers and service providers, to help them improve carers' lives.
- 1.3 Carers UK's advice and information services answer around 16,000 queries from carers and professionals every year. Our website is viewed by over 100,000 people every month, 27,000 subscribe to our monthly email newsletters, and the combined reach of our online communities and social networks exceeds 38,000. We're in regular contact with around 1,500 local organisations, including many run by carers, who are in touch with around 950,000 carers.
- 1.4 Carers UK has offices in Wales, Scotland and Northern Ireland. This response reflects the views of the organisation, UK-wide.

### 2. Summary

- 2.1 Carers UK is deeply concerned that the new *Moving around* criteria for Personal Independence Payment will leave hundreds of thousands of disabled people with some of



the highest level needs without essential support, and that this will have serious knock on effects for their families and carers.

- 2.2 In particular, rather than move to 20 metres, we urge the government to retain the existing 50 metre measure (which establishes entitlement to the higher rate mobility component in Disability Living Allowance) for the enhanced rate mobility component for Personal Independence Payment.
- 2.3 More broadly, Carers UK continues to strongly disagree with the Government's decision to sharply reduce the number of disabled people eligible for support from Personal Independence Payment.
- 2.4 We have been deeply frustrated at the consistent failure of the Government to provide adequate and timely assessment of the impact of disability benefit changes on carers or to assess the cumulative impact of the Welfare Reform Act on either families or public spending.

### 3. **The *Moving around* criteria**

- 3.1 Carers UK shares the concerns raised by the Disability Benefits Consortium about the impact of setting the qualification measure for the enhanced rate of Personal Independence Payment (PIP), which will result in significant numbers of disabled people with high level mobility needs losing support.
- 3.2 Currently, 50 metres is typically used to establish entitlement for the higher rate mobility component of Disability Living Allowance (DLA) – ie. people are considered to be 'virtually unable to walk' if they are unable to 'mobilise' for 50 metres or more. However the new test for Personal Independence Payment enhanced mobility component states that only those who 'can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided' will qualify.
- 3.3 We are also concerned at the lack of evidence presented by Government to explain the rationale behind this tightening of eligibility, leaving the selection of 20 metres as the measure appearing arbitrary. As the Disability Benefits Consortium, of over 50 disabled people's organisations, states:

*"To our knowledge, and after significant questioning of the DWP, no evidence was gathered by the department to suggest that 20 metres is a suitable point at which it can be deduced that the extra costs disabled people face start to reduce, or even differ from those who can walk a shorter distance.... In evidence we have gathered from the disabled people we represent, many of those that can mobilise for more than 20 metres (but less than 50 metres) face the same 'extra cost' as those that can only mobilise for this distance.<sup>1</sup>"*

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<sup>1</sup> The PIP 20m Rule (2013) Disability Benefits Consortium



- 3.4 In fact, 50 metres was acknowledged by the Department for Work and Pensions (DWP) itself as 'considered to be the distance that an individual is required to be able to walk in order to achieve a basic level of independence'<sup>2</sup>.
- 3.5 Government impact assessments indicate that over 428,000 fewer disabled people will qualify for the enhanced rate of PIP than would qualify for DLA<sup>3</sup>. Those no longer qualifying for the enhanced rate and instead receiving the standard rate would be £33.25 a week worse off.
- 3.6 Carers UK is deeply concerned that the change is being led by the objective of tightening criteria and reducing cost; rather than on assessing and responding to need. This would be unacceptable, and would represent a failure of the Government to meet the needs of disabled people and their families, and a failure to meet their own objective, set out in the consultation document, of targeting support on individuals who 'face the greatest barriers to independent living'.
- 3.7 As a result of the lack of clear rationale, an absence of evidence to support the change and significant fears set out below about the impact of tightening eligibility, we strongly urge the Government to retain the existing 50 metre approach within DLA.

#### **4. The financial impact of reduced support**

- 4.1 Falling from the higher rate mobility component for DLA to the standard rate for PIP would result in a reduction in support of £33.25 a week, over £1,700 a year. This loss of income could be financially devastating for disabled people and their families or could result in the loss of their Motability vehicle (which is linked to receipt of the DLA higher rate mobility component and the enhanced PIP mobility component).
- 4.2 Disabled people and organisations representing them, have set out powerful evidence on the devastating impact the loss of this support could have on their independence, family life and their ability to work and to afford to make ends meet. We share very serious concerns about the impact this change will have on financial hardship and poverty amongst disabled people and their families, their quality of life and ability to live independently.
- 4.3 The direct financial consequences for both disabled people and their carers of losing financial support could be disastrous. Alongside long-established evidence on disability poverty, Carers UK's research shows that many families affected by poor health and disability are often already struggling to make ends meet. Many are also seeing their financial situation worsen as a result of the rising costs of living. A Carers UK survey of over 3,000 carers in 2013 showed that:
- Over 4 in 10 (44%) of carers surveyed had been in debt as a result of caring.
  - 36% were struggling to afford utility bills.

<sup>2</sup> PIP criteria (November 2011) Department for Work and Pensions.

<sup>3</sup> Response to the consultation on the Personal Independence Payment assessment criteria and regulations (December 2012) Department for Work and Pensions.

- 52% say financial concerns are affecting their health.

- 4.4 As it applies to working-age disability benefits this change will affect several groups of carers and disabled people who face some of the greatest financial challenges. Ill or disabled people who are unable to work as a result of their disability or condition, and who are supported full-time by their partners may have no-one able to engage in paid work in their household. Carers of adult disabled children may face life-long caring responsibilities which mean they are unable to work at any point. Both groups may live for decades on very low level incomes, are less likely to be able to accumulate savings, save for their pensions or invest in buying their own homes.
- 4.5 This was highlighted by research by the Centre for the Modern Family and Scottish Widows which showed that carers caring for adults are the least financially resilient group of carers. Based on 1,000 interviews with carers their report *Families that care* found, of carers caring for adults:
- 43% had a household income of less than £20,000.
  - 63% said that financial support from the benefits system was insufficient for them to continue to carry out their caring role.
- 4.6 As a result, Carers UK fears consequences of sharply cutting support to carers and their families who are already facing significant financial pressure as a result of the extra costs of disability and caring, often combined with reduced earnings; and, in particular, carers caring for working-age adults facing some of the greatest financial challenges.
- 5. The risk of losing Motability vehicles, electric wheelchairs or mobility scooters.**
- 5.1 In addition to those who face a loss of income from mobility payments, many would stand to lose Motability vehicles, electric wheelchairs or mobility scooters which are linked to their entitlement to DLA/PIP. As a result of the financial pressures highlighted above, many families would not be able to afford the cost of buying their vehicle/scooter/wheelchair or alternative vehicles themselves and would also lose access to other passported support including lower insurance premiums and road tax exemptions.
- 5.2 The loss of this practical support presents significant knock-on risks for disabled people's families and carers. If disabled people are less able to afford transport costs or lose an adapted vehicle or scooter, they may require more support from family members supporting them, as they are unable to access support services like day centres, or struggle to travel to medical appointments and checkups.
- 5.3 Carers already face significant penalties to their mental and physical health and social inclusion as a result of the pressures of caring without sufficient support. The recent Census showed that full-time carers are already twice as likely to be in poor health and non-carers<sup>4</sup>.

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<sup>4</sup> Census 2011



- 5.4 If disabled people are unable to travel to alternative care settings or need additional support from carers to travel with them then this may prevent carers from having short breaks from caring, reduce carers own independence and increase the costs of accompanying travel for them. Placing this further pressure on carers as a result of cutting support to disabled people risks exacerbating existing carer poor health and wellbeing and pushing some to breaking point.
- 5.5 Disabled people and disabled people's organisations note the impact this loss of practical support could have on disabled people's ability to work. However there are also significant risks to carers' ability to work. Half of carers manage to juggle work with caring, however research from the London School of Economics has estimated that the public expenditure costs of carers being forced to given up work to care is as high as £1.3 billion<sup>5</sup>. As the case study below demonstrates, the loss of financial support with mobility can result in a series of very significant and potentially unsustainable costs to families' incomes and indeed to the Exchequer.
- 5.6 **Case study:** [redacted] live in [redacted] [redacted] cares for [redacted] who has multiple sclerosis. [redacted] receives the higher rate mobility component and middle rate care component of DLA. [redacted] had given up work to care for [redacted] when he suffered a relapse, but [redacted] has now returned to work as a librarian following an improvement in [redacted]'s condition. [redacted] is entitled to the DLA higher rate mobility component which has given them access to an adapted Motability car. [redacted] uses the car to get to work, dropping off and collecting [redacted] from a day centre on her commute.

If an assessment for the Personal Independence Payment resulted in [redacted] receiving only the standard rate PIP mobility component, they would lose their family car. This would prevent [redacted] from attending the day centre, where he accesses specialist practical and emotional support, physiotherapy and the chance to pursue hobbies and interests in a supported environment. The loss of the car would also prevent the couple from being able to spend time out of the house together and, crucially prevent [redacted] from travelling to work.

Inadequate public transport in their rural area would make commuting to work impossible for [redacted] even if they were able to find and afford replacement homecare for [redacted] and the buses often cannot accommodate [redacted] mobility needs so are inaccessible for him to use. The couple have no savings to afford to buy another car themselves and buying their Motability vehicle would cost them in excess of £8,000.

On top of the reduction in benefits, [redacted] would lose her £20,000. If [redacted] was unable to work, and [redacted] could not attend the day centre, she would have to start claiming Carer's Allowance again and they would have to claim means-tested support including Income Support and Housing Benefit. In addition to the loss of [redacted] independence, his chances to get out of the house and [redacted] career, it would cost the state thousands of pounds more a year in additional benefit payments and lost tax revenues.

<sup>5</sup> <http://blogs.lse.ac.uk/healthandsocialcare/2012/04/25/dr-linda-pickard-public-expenditure-costs-of-carers-leaving-employment/>



5.7 This example also demonstrates the risk of potentially devastating consequences for carers and disabled people's lives and remain socially included - even just to leave the house.

5.8 The case study also highlights the significance of the fact that these changes do not just apply to future claimants. The change will result in thousands of families losing support with no transitional protections. Following a PIP assessment which results in a reduction in support, families whose lives and household budgets have been built around this support, face the sudden loss of over £1,700 a year in income or their family vehicle, and other passported support.

## 6. impact assessment

6.1 Carers UK has expressed shock and frustration at the inadequate assessment conducted regarding the cumulative impact of the different elements of the Welfare Reform Act – not least the lack of acknowledgement, recognition and assessment of the impact on carers and the families of disabled people. This is further evidenced by this consultation's omission of any mention of carers and a focus exclusively on disabled people.

6.2 For many families, a failure to qualify under new criteria for the enhanced mobility component will also be combined with one or more of the following changes (this list is not exhaustive and also does not take account of changes outside of the benefits system, including increased charging for and cuts to social care services and the closure of the Independent Living Fund):

- A reduction in financial support for daily living as a result of receiving a lower rate or seeing the removal of support through assessment for the PIP daily living component.
- The loss of Carer's Allowance as a result of the disabled person not qualifying for the PIP daily living component.
- Lower uprating of income-replacement benefits including Income Support and Employment and Support Allowance.
- Time-limiting contributory Employment and Support Allowance.
- Cuts to support from Housing Benefit as a result of the changes to the size criteria for social housing tenants (also known as both the 'spare room subsidy' and the 'bedroom tax')
- The inclusion of Carer's Allowance in the household benefit cap.
- Additional Council Tax payments as a result of the cuts to, and localisation of, support with Council Tax Bills following the abolition of Council Tax Benefit.
- Reduced access to discretionary support previously provided by the Social Fund.

Work by Demos and Scope in 2013 showed that 120,000 families would see some form of 'triple cut' as they are affected by three of these changes – losing over £3000 a year<sup>6</sup>.

<sup>6</sup> Destination Unknown (2013) Scope and Demos



- 6.3 Carers UK continues to call for an urgent impact assessment of the cumulative impact of these changes, to understand both the impact on disabled people and carers and the knock on costs to other areas of public spending.
- 6.4 It is both short-sighted and illogical to look exclusively at the public spending implications of reduced expenditure on single items of benefit expenditure without assessing the risks that the costs of reducing support in one area may be seen in rising costs elsewhere.
- 6.5 Carers UK has deep concerns that, in addition to huge personal costs and distress to families, reducing access to support with mobility costs will increase the cost of unemployment benefits, the Access to Work Scheme and particularly in the NHS and social care. For example, if families are unable to maintain care packages following a loss of transport, local authorities should reassess their care and support needs and may need to provide alternative and additional support, and, in the most serious cases if families find providing unpaid care themselves financially impossible following the loss of support then the social care system may have to fund the cost of full-time residential or home care.
- 6.6 In responding to the evidence submitted to this consultation the Government must take account of how affordable and sustainable these knock-on costs and the additional pressure placed on carers will be.

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# **DBC** Disability Benefits Consortium

## **Consultation on the "Moving around" criteria for PIP Response from the Disability Benefits Consortium**

### **What is the Disability Benefits Consortium?**

The Disability Benefits Consortium (DBC) is a national coalition of over 50 different charities<sup>1</sup> committed to working towards a fair benefits system. Using our combined knowledge, experience and direct contact with millions of disabled individuals and carers, we seek to ensure Government policy reflects and meets the needs of all disabled people.

### **Introduction**

The Disability Benefits Consortium strongly welcomes the decision to consult again on the mobility criteria for Personal Independence Payment (PIP). While we recognise that throughout the development of the benefit some steps have been taken to make PIP fairer for disabled people, we strongly believe that large and unacceptable numbers of those with the greatest needs are still set to lose the support they rely on to live their daily lives. We welcome the decision to compel assessors by regulations to consider whether claimants can perform activities, 'safely, to an acceptable standard, repeatedly and in a reasonable time period' (subsequently referred to as the 'reliability criteria'). However, while this is a positive step, we are deeply concerned about the decision to use a qualifying distance of just 20 metres for people to qualify for the enhanced rate of the mobility component of PIP.

We would also like to express our disappointment that the consultation period has been limited to just 6 weeks. This time period has proved a major barrier in enabling interested parties to provide the most comprehensive responses they possibly can. Furthermore, given the lack of evidence to support the government's rationale and reasoning for the 20 metre qualifying distance, we feel that it has been very difficult to engage with the government's reasoning behind this decision. Six weeks is a very limited time period for the government to expect interested parties to produce this evidence in the absence of its own research.

### **Summary**

This response will outline areas we agree and disagree with regarding the 'moving around' activity for PIP. In terms of agreement, we will focus on the application of the reliability criteria.

In terms of disagreement, we will focus on the distance used in Descriptor E for people to qualify for the enhanced rate of the benefit – namely 20 metres. This descriptor will be particularly problematic for those people who do not acquire any points on Activity 11 – planning and following a journey. As the government's own projections show, nearly half a million people will no longer qualify for the enhanced rate of PIP. We believe that a significant number of the people that no longer qualify will fall foul of the 20 metre rule.

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<sup>1</sup> <http://disabilitybenefitsconsortium.wordpress.com/dbc-members/>

The DBC believe that the impact of the 20 metre qualifying distance will include:

- Disabled people dropping out of work, education or volunteering activities
- Increased poverty and isolation of disabled people, with the associated risk of worsening health
- Rising costs elsewhere, such as unemployment benefits, the Access to Work Scheme, social care and NHS

In this consultation response we argue that the use of the 20 metre qualifying distance is flawed as a measure for establishing the barriers and costs that disabled people face. We will outline the impact of the loss of the enhanced rate of the mobility component of PIP for a wide range of disabled people. We will demonstrate how the mobility needs of the people affected by this rule will not disappear, but are likely to be pushed to other areas of (potentially more expensive) government spending. Lastly, we will illustrate how the use of 20 metres is inconsistent with government guidelines and contrary to well-established methods of determining levels of significant mobility impairment.

### **Our evidence**

Our response is based on the direct feedback we have received from over 1000 disabled people about the "moving around" criteria for PIP. In particular, the 20 metre rule. The majority of the examples we have used in this submission have been anonymised at the request of those contacting us. All the details remain the same, but where requested we have changed individual's names.

### **Our view**

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 are concerned 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.

### **The reliability criteria**

The DBC strongly welcomes 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".

However, it is important 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, side effects such as pain and fatigue should adequately be 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 20 metre measure is flawed**

We believe that the use of the new qualifying distance of 20 metres to qualify for the enhanced rate of the mobility component of PIP is flawed. Evidence we have gathered from the disabled people we represent suggests that many of those that can mobilise for more than 20 metres (but less than 50 metres) are no more able to access the services they need to get out and about. They incur the same extra costs as those that can mobilise for less than this distance – in reality they have the greatest level of need. No longer qualifying for the enhanced rate of the mobility component of PIP will have a devastating and limiting impact on their lives, thereby contradicting one of the stated aims of PIP – to aid independence.

As the DWP has stated in correspondence with the DBC, the Department, "...chose to look at individuals' ability to participate in society as a proxy for their overall levels of need", and the department's intention is to, "... focus the enhanced rate on those with the *greatest barriers* to mobility". Our understanding of this is that the current use of the 20 metre qualifying distance is based on a belief that the distance an individual can mobilise denotes the size of the barrier to mobility they face. Yet in reality, it is an individual's ability to access the services they need to get out and about that dictates the size of this barrier. The people we represent have told us that the extra 30 metres between the 20 and 50 metre qualifying distances is not meaningful – being able to mobilise this much further does not enable them to use public transport or reduce their costs in any way.

Below we provide two case studies outlining the additional costs each of the individuals involved incur as a result of their disability – as you will see, they are very similar. Yet one should qualify under the 20 metre rule and one is very likely to lose out.

#### **Case study one: [REDACTED]**

[REDACTED] is 35 and has Relapsing Remitting MS. She has been claiming DLA for five and half years.

[REDACTED] describes how her disability affects her in the following way:

I cannot ever walk at all without using a walking frame. On an average day in terms of walking ability, which is about 60% of the time, I can use a walking frame to walk 10 metres. On my very best day - about 5% of the time - I can walk 30 metres in one go, but I can only do this once and I am completely exhausted afterwards. On a bad day in terms of walking ability - about 35% of the time - I cannot stand up and need help from a carer to transfer into a wheelchair to use around the flat (Carer paid for by Local Authority Personal Budget).

**■■■■■ tells us:**

"I cannot drive as MS has affected my vision. I cannot use buses in my area as I am not allowed to take my mobility scooter on the bus. I cannot use a manual wheelchair myself as I do not have the strength to push it. I use taxis to get around and my average single journey costs between £8 and £15. I spend a high proportion of my DLA money on taxis. I use taxis to get to doctors appointments, hospital appointments and all the essential journey's I have to make. I also use taxis to see my friends. Seeing friends and going out is so important to me, I am 34 and I want to live my life as much as I can when I am well enough to socialise".

**■■■■■ weekly costs**

We asked ■■■■■ to talk about her mobility costs over the course of the last week. This is what she told us:

**Monday**

I needed to go to the Osteopath. It costs me £8.50 in a taxi each way.

**Tuesday**

I attended a specialised exercise class at the local MS Treatment Centre. I used my mobility scooter to get there and got a taxi back as I was too fatigued to use my scooter for the return journey. The taxi was £7.

**Wednesday**

I took a rest day

**Thursday**

I went shopping with my carer (my carer is paid for out of Local Authority Personal Budget). My carer drives me to the supermarket but I pay for the petrol. Estimate cost of this is £5.

**Friday**

I went to the Theatre with friends. It cost me £10 there and £13 back in a taxi.

**Saturday**

I met with friends for lunch. Getting there and back cost me £8.50 each way.

**Sunday**

That's a busy week for me so I took a rest day!

Total cost over the course of the week approximately £69

**■■■■■ longer term costs**

■■■■■ weekly costs are just one proportion of what ■■■■■ uses her DLA payments for. She also told us:

"I cannot get a mobility scooter on the NHS so I buy my own. I buy a small travel mobility scooter which folds up and goes in the boot of a car / taxi. I do have both manual and electric NHS wheelchairs - however I cannot fold up the electric wheelchair to go in a car. Plus the NHS electric indoor-outdoor wheelchair I have is not for long distance use and must not get wet, so it cannot be used outside if it is raining / there is a chance it may rain. The mobility scooter which I buy myself is my lifeline to independence and I use it almost every day. I replace the scooter every two years - cost approx £550. I replace the battery every year - cost approx £100.

Insurance costs approx £70 a year. Maintenance service – cost approx. £40 a year."

Total cost per year: £485

██████ qualifies under the 20 metre rule so should continue to receive the enhanced rate mobility component of PIP

#### **Case study two: ██████**

██████ is 45 also has relapsing remitting MS. She was diagnosed in Sept 2001, but had her first distinct relapse in 1991. She has been claiming DLA for four years

██████ describes how her disability affects her in the following way:

On the majority of days, yes, I can do over 20 metres, but less than 50. Largely I'm on a scale of 20-50m before I'm in real trouble.

██████ tells us:

"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."

██████ relies on her Motability car.

#### **██████ weekly costs**

We asked ██████ to talk about her mobility costs over the course of the last week. This is what she told us:

##### **Monday**

Drive to university. Park in disabled bay and use access ramp to get into building. I would formerly have got the train but would now need a taxi from the station to the university as I cannot walk the 5mins between the station and university. Lunch meeting – hand £10 to a colleague to buy me a sandwich lunch from the snack bar about 150m round the corner that I am not able to get to. End up with sandwich lunch that is £1 more than I would have normally spent as I have to give generic guidelines on what I fancy. Work for afternoon. Drive over to city offices. Park in disabled parking and walk (with rests) to Council office. Leave and drive back, refuelling before joining motorway (about £32 put into tank). Collect kids from childminder and drive home. Petrol costs £32.

##### **Tuesday**

Drive kids to childminder. They live 10 minutes walk away, but I have to drive it or take the mobility scooter if the weather's ok. Work at home for the full day. Meet friend for lunch but have to drive there as well as I can't get up to the High Street (about 75-100m). Work through the afternoon, drive down to school again but get there early so can park near enough to walk the short distance to the school gate (about 15-20m). Drive home.

##### **Wednesday**

Rest day.

#### **Thursday**

It's not raining so I take the kids to school on the mobility scooter. We bought the scooter last year and I have to keep it charged, whether I'm using it or not. It uses a fair amount of electricity over the year. Come home. Do the online food order. I pay for the shopping to be delivered as I am not able to get to the big supermarkets. This averages at about £3 a week. Go to gym for exercise referral session in the car as I cannot walk the 100m to the bus stop to get there and back. Do a whole 12 mins. Come home and after lunch sleep as I'm worn out by the exercise and then get ready to get kids. Weather not so good so I can't use the scooter and so have to drive again.

#### **Friday**

Work from home and husband helps with the children.

#### **Saturday**

My husband is looking after the children and I am going to meet friends in London. I drive to [REDACTED] as I cannot walk to the local railway station (about ¼ mile) and nor can I get to the bus stop on the High Street. I have booked special assistance from [REDACTED] on the train, which works well, and I take a taxi (£12.50) from Euston to the restaurant. I would prefer to take the bus but the stop is on the other side of Euston Road but even with the station assistance it's about 200m walk. I can't take the tube either as the tunnels are too long for me to walk and I struggle with escalators owing to problems I now have with my balance and co-ordination. Have a good evening and then get taxi back from outside restaurant to station (about £14) as the bus stop is about 70-100m walk. Get special assistance from station (I can walk enough to get into the lift and from the lift to the office with my stick). Am taken to train and then drive home from station.

#### **Sunday**

Go with husband and kids to local nature. We have to take my wheelchair for this as I am not able to walk the 75-100m from the parking to the visitor centre. Once there we swap the wheelchair for a buggy they have for loan. Donations are invited and I give £5 for the loan of the off-road scooter (this seems to be the stingy side of the going rate for mobility buggy loans with National Trust properties). We can now all get over to the area of barns and picnic tables and where I can totter to one of the bird hides (about 25m). After a lovely picnic we drive back via a playground. I stay in the car as it's set about 100m into the park.

Total cost over the course of the week (in addition to those covered by her Motability car): approximately **£62.50**

#### **[REDACTED] longer term costs**

[REDACTED] also has a mobility scooter and wheelchair to enable her to get out and about. Again, these costs are in addition to those covered by her Motability car.

#### **[REDACTED] is very unlikely to qualify for the enhanced rate mobility component of PIP as a result of the 20 metre rule. She says:**

"The upper rate of the mobility component of the DLA makes an enormous difference to the functioning of our family life. It's hard to overstate its significance. My husband's work means that he travels extensively through the week and I do not have access to his car. Without the upper rate of the mobility component of the DLA we would otherwise really struggle to afford a car for me. I had no idea before my mobility was so affected of how much we take for granted in terms of getting about and how expensive it is not to be able to. I would have no independence without my car – with it I can still get to work, get

the kids to school or childcare, get to appointments and see friends and family. I can even drive to the station with my wheelchair and use the great systems for special assistance that are now in place to see family or attend meetings. I am not able to walk to the top of our road to the bus stop and we would not be able to sustain the sort of taxi fares involved to allow me to carry on working and doing all this without having access to my own car. Even so, the costs of fuel are significant, as I use the car on a daily basis for basic tasks such as school runs or meeting people."

To our knowledge, and after significant questioning of the DWP, no specific modeling or research has been carried out on the distance of 20 metres to identify whether it is, in fact, the point at which individuals face the most significant barriers to mobility, or – crucially – the point at which the extra costs disabled people face start to increase, or even differ from those who can walk a greater distance. In addition, no impact assessment was carried out to establish how people currently receiving the higher rate mobility component of DLA, but who may lose out under the new rule, would be affected by this policy.

In response to a DBC request for further information about how the 20 metre distance was reached, the department provided a number of research documents on which the 20 metre decision was allegedly based. We dispute the use of these documents as a basis for making such a decision. Indeed, as the department itself has recognised in engagement meetings with the DBC and the PIP Implementation Stakeholder Forum (ISF), the research does not provide a conclusive answer on how disability costs can be measured. We therefore dispute the decision to set criteria that depart so significantly from previously well-embedded measures of significant mobility impairment (as discussed further in the final section of this paper) without carrying out additional research. This is especially pertinent given that these reforms are so significant as to result in nearly half a million people losing out on this rate and component of PIP alone.

We would also like to question the age of the research provided. For example, the, 'Review of existing research on the extra costs of disability, 2005, DWP Working Paper 21' is already 8 years old, as are the reports that it cites. Nothing is 'newer' than 2003. We do not believe that this is a solid basis for evidence based policy-making, particularly given the radical changes in the economic context since this time. The paper also stresses that the methodology to conduct an analysis of the extra costs of disability is lengthy and complex – yet the DWP have set a consultation period of just six weeks for stakeholders and interested parties to feed into this debate and provide exactly that kind of information.

Given the lack of substantial evidence to demonstrate that 20 metres is a more accurate way of identifying those in greatest need, the DBC strongly believes that the well-established measure of 50 metres should be reinstated.

### **The Impact of losing out on the enhanced rate mobility component of PIP**

Following consultation with over 1000 disabled people, we have gathered extensive evidence around the expected impact of the proposed changes to the mobility criteria for PIP. As detailed above, many of those that we have spoken to have described circumstances in which they are able to mobilise for more than 20 metres (but less than 50 metres) while still incurring the same 'extra costs' as those able to walk for less than 20 metres.

Many of these disabled people have told us of the potentially devastating consequences of losing the higher rate mobility award, and some groups appear to be at higher risk of strong negative consequences than others. For example, those who need support to attend work, training or hospital visits, those who currently access the Motability Scheme, and those who live in rural areas, appear to be at particular risk of suffering significant deterioration of their health and their quality of life.

In the following section, we outline in more detail how the proposed changes to the mobility criteria could affect the lives of disabled people, and demonstrate how ineffective the proposed move from a 50 metre qualifying distance, to a 20 metre qualifying distance, will be.

### ***Accessing employment***

There is strong evidence that supporting people to remain in work helps maintain physical and mental health over the long term, and helps to reduce costs to both the DWP and the NHS – while also allowing disabled people to stay in employment and contribute taxes<sup>2</sup>.

As such, we are very concerned – both for the disabled people involved, and for the additional costs to the Exchequer – that many of the disabled people we have spoken to have told us that if they do not qualify for the enhanced rate of the mobility component of PIP, they will struggle to stay in employment. This was particularly notable among those who made use of the Motability Scheme, and many felt that Access to Work funding would not be sufficient to cover all their necessary transport costs.

#### **Case studies and comments from disabled people: Employment**

■■■■■ explained:

"My Motability vehicle means that I can travel to work as fresh as possible for my shifts and wherever I go I can park close by and limit to a minimum the amount of walking I do. If I lose my DLA I won't be able to afford a car as due to my health I can't work enough hours to command a decent salary. My health will deteriorate as a result and will no doubt result in my becoming unemployed then I will cost the government a whole lot more! More importantly though, I will lose independence and my social network and will stop contributing to society AND paying taxes!!!!"

■■■■■ was awarded the higher rate mobility component of DLA indefinitely in 2007. She told us:

"I have a Motability car and this has been my life line and allowed me to get out and about and enabled me to continue working part time at the ■■■■■ contact centre which is 10 miles away from where I live. If I was not awarded the enhanced element of the mobility side of PIP I would lose my Motability car and would be unable to continue working because I would have no transport to get to work as I would not be able to run a car on my part time wage.

"I don't want to sit at home staring at 4 walls feeling sorry for myself watching myself

<sup>2</sup> Waddell G and Burton, K, (2006), 'Is work good for your health and wellbeing?', London TSO



gradually get worse. I can walk 20 metres with crutches and I use a wheelchair or my mobility scooter if I need to go for example into town or anywhere where walking is involved. The [REDACTED] contact centre have been very supportive and are doing everything possible they can to keep in work, so I don't want to have to tell them I can no longer work due to a decision made by the DWP (my employer) which has meant I am no longer eligible for a Motability car because I can walk 20 metres".

[REDACTED] explains that without her vehicle, which she funds through the higher rate DLA, she would have to consider whether she could stay in her current job as she relies on her car to get her to work. Living in a rural location with poor bus services that are often not accessible means her car is her lifeline. Although [REDACTED] predicts that she is probably able to walk the length of two buses (about 20 metres) she feels that she would be too sore to then stand and wait for the bus.

[REDACTED] has severe mobility problems due to Rheumatoid Arthritis, he told us how loss of his higher rate DLA would impact his life:

"I would lose my employment as I work supporting disabled people to access services, and travel is a major part of my life. Not being able to access the Motability scheme would affect me drastically financially and socially as I love my job - I spent many years unemployed and was thrilled to get this opportunity. It would also mean having to dismiss my PA which would add to the already high unemployment rate in this country and I would not be paying taxes etc.

It would mean I would not be able to visit my friends or take part in my hobbies therefore I would lose my independence and choice on how I want to live my life which is a basic Human Right. I would become isolated and depressed which is a side effect of any disability. I would not be able to buy a car or continually pay for taxis and public transport, I dread to think of the consequences this could bring.

[REDACTED] has MS, she currently works with children with Autism teaching literacy. She said:

"I am fighting every day to stay mobile so that I can continue to work, but the pain, spasms, fatigue, bladder problems and memory issues fight back at me. Some days I can walk very short distances other days I can't get out of bed. I use my wheelchair a lot and don't want to sit around at home on benefits and vegetate but without my car and DLA I cannot carry on working. I want to contribute to this society and keep a sense of dignity and self worth that this disease is robbing from me. I am 40 years old and could, potentially, work and contribute for another 20+ years. Please, please help to keep the higher level mobility as well as the care component we desperately need and deserve.

[REDACTED] is physically disabled and has Cerebral Palsy. He told us:

"I can walk over 20m but not walk 50m repeatedly. I am very concerned that I will lose the higher rate mobility component under PIP. Under the descriptors, only people who cannot walk over 20m repeatedly will get the higher rate. This is obviously a concern to me. I currently receive a car under Motability. This is a huge help to me as it enables me to drive to work, go places, see friends, go to doctor and hospital appointments. If I were to lose Motability, then my independence would be greatly reduced. I would be forced to attempt to catch the bus, which is over 50m away. This would make it extremely difficult for me to get to work. Bus times are not good and trying to walk in bad weather makes it almost impossible. I get tired

walking too far, so catching the bus would make me exhausted. Catching the train wouldn't be any better as the station is 2 miles away, meaning I would have to get a taxi, which would be expensive. I also find it difficult getting on trains because of the gap."

■■■■■ has been disabled for 28 years. She told us:

"If I lost my access to the Motability scheme and subsequently my car I would have to give up my job meaning I would lose my house in a heartbeat and the consequences of this on my condition would be absolutely disastrous. I know I don't have a long time left at work and I need all the help I can get. Public transport is an absolute no-go for me these days. I would have to get two buses and walk a long distance from bus stop to work. I would have no energy by the time I got to work; I wouldn't be able to do my job. If I had to find another job at my age, with my health issues, it would be near impossible to get one - especially considering the economy so I would just need jobseekers allowance instead of my DLA and wouldn't contribute anything back in tax and national insurance. The security of transport makes me a more attractive prospect to an employer.

What people rarely understand (the Government included) is that I would give up my Motability car in a second and my care component if I could be disease free. But I just will never have that luxury".

■■■■■ has had rheumatoid arthritis for 15 years. She said:

"Without my DLA payments I wouldn't be able to work. I couldn't get public transport, carry books or walk the distance from the school to bus stop. I would simply have to stop working. If I lost my DLA I would certainly become depressed very quickly owing to giving up my job, it was extremely depressing going down to part-time after being diagnosed".

For those that are not able to work, volunteering can be a valuable opportunity to participate in and contribute to society. Some disabled people who are unable to work as a result of their condition or disability find that it is crucial to maintaining social networks and an active life. We have been contacted by disabled people who fear they will now be forced to stop contributing in this way if they lose out on the 20 metre rule.

#### **Case studies: Volunteering**

■■■■■ has a complex range of conditions that affect her ability to move around including Fibromyalgia, Ischaemic Heart Disease and Diabetes. She told us about the work she does in her local community and the effect the policy could have on her and those she helps.

"Presently I can stand, with pain and a walking stick. I can walk very slowly for about 40 to 50 metres. At the moment I volunteer for the sick and disabled. I help them through the various hoops and hurdles of claim forms for ESA and DLA. I also accompany many to tribunals for, industrial injury, ESA, and DLA, and also Atos medicals.

"Without my mobility scheme car this would stop outright as I can not use public

transport and taxis would be, financially, out of the question".

### ***Accessing education and training***

We know that only 46% of disabled people are in employment, compared to over 76% of the non-disabled population, and that when they are in work, disabled people tend to be concentrated in low skill, low wage work<sup>3</sup>.

As the Government has recognised in its recent publication 'Fulfilling Potential - Making it Happen (DWP, 2013)', the reasons for this are many and varied – including negative employer attitudes, isolation from the labour market, and disabled people lacking access to strong training and education programmes.

As such, it is vital that disabled people's links with training and employment are strengthened, not undermined, to ensure that we can continue working towards a higher employment rate for disabled people, and greater representation of disabled people at the highest levels of British industry and society.

However, many people currently in receipt of the higher rate of DLA mobility, but not in work, are likely to be at significant risk of losing access to training and education programmes, and hence being cut off from potential career and development opportunities. As with disabled people who will be cut off from their ability to work, preventing disabled people from accessing training is likely to have significant negative consequences in the future – both for the individuals themselves, and for the Exchequer.

#### **Case studies: Training**

■■■■ recently completed a PhD and finished a three month post-doctoral post with the hope of further funding being in place soon. She said:

"Without my Motability car there would be no prospect of my being able to do this work or manage the most basic of everyday tasks including getting to work, taking and collecting my young children from school or getting to appointments or visiting friends. The extra costs of dealing with being disabled are well-documented, not least by way of petrol needed to drive. I also have to get taxis for the shortest of distances, drive 100m to our local shop as I can no longer walk it and pay to have my shopping delivered as I can't get round the shops myself. We have had to buy a wheelchair that I take everywhere with me and also a mobility scooter for the fine days for taking the children to school.

■■■■ is a disabled teenager with cerebral palsy. He is studying at further education college about 20 miles away from home, his mum told us:

"The local FE college couldn't meet his needs. He can walk 20 to 30 metres fairly confidently around the house but at college the environment and busyness means this becomes more difficult. ■■■■ uses his DLA to pay for a taxi as we live in a coastal town ■■■■ and the public transport is a bit hit and miss. The taxi gives him independence and flexibility especially if he needs to stay late at college or go out with friends.

■■■■ has Osteoarthritis and Fibromyalgia and is currently in receipt of the higher

<sup>3</sup> DWP (2013) Fulfilling Potential - Making it happen. P.39

rate of the Mobility component for DLA. He is unable to use buses in his area as he would not be able to get on them with his scooter. Instead he relies on his payment to fund taxis to attend the hospital and adult education classes. He would be completely housebound without this payment.

■■■■■ has Cystic Fibrosis (CF) and explained:

"For the last four years I have worked part-time but due to the changes to DLA I have been very worried about money should I lose my mobility component. I therefore decided last year to try and work full-time in order to make myself as resilient as possible against any changes that may occur. I've managed almost a year but have this week had to request to go part-time again because working full-time is having an impact on my lung function and general CF related health. I feel really frustrated as I want to be self sufficient and not have to rely on any benefits but juggling everything that comes with CF makes this very hard. I'm also trying to study for a professional qualification so that I can get a better paid job and therefore feel less need to rely DLA because the changes that are coming in are terrifying and I feel very vulnerable as a result."

### ***Accessing hospital appointments***

A worrying number of respondents told us that they felt they would not be able to make it to vital hospital and doctor's appointments if they were to lose their DLA. If this came to pass, more would have to rely on accident and emergency cover to treat their declining health conditions, or rely on hospital transport to access the services they need – both of which would incur additional costs to the Exchequer.

### **Case studies: Hospital Visits**

■■■■■ explained to us:

"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."

■■■■■ told us:

I would be very concerned as to whether I could get taxis whenever I needed, as soon as I need them. If the hospital calls to tell you they have time to accommodate you because there has been a cancelled appointment and can you get there in an hour, without easy access to a car it would be near impossible. In truth it just does not compare with having a Motability vehicle.

### ***Motability***

One of the most significant impacts of the change to the criteria for higher rate mobility will be that those who no longer qualify for the higher rate – because they are able to walk 21-50m – will also lose access to the Motability scheme.

The loss of access to the Motability scheme as a result of the 20 metre rule is a particularly disturbing prospect for many disabled people. We have spoken to many who refer to their Motability vehicle as a 'lifeline', and the primary means by which they take part in everyday life. Motability vehicles are often the only way that disabled people can get to work, socialise with friends and family, or maintain the mobility they need to remain healthy. Removing access to the scheme is very likely to incur costs to the Exchequer in other ways, primarily in losses to tax revenues and increased spending on the NHS.

Although those who lose access to the scheme may still be able to apply for Access to Work funding which could help with some of the transport costs, it is unlikely to cover all the costs of the services Motability provides. For example, Motability provides the recipient with a new car, scooter or powered wheelchair every three years; insurance and breakdown assistance; servicing and maintenance and repairs; and adaptations, many at no extra cost. Some people currently on the scheme will be given the option to purchase their car, which will typically cost in excess of £8000 - a sum out of reach for the many disabled people living in or on the edge of poverty. Taking on these costs, even with a cheaper vehicle, will be unmanageable for many disabled people who are reliant on benefits to cope with the additional costs they face.

Where previously disabled people in work could use their Motability vehicle to maintain an active and accessible life, they will only be able to get taxis to and from work, and to and from the hospital, under Access to Work funding. This is likely to cost the taxpayer more money on a weekly basis, and negatively impact on the lives of disabled people.

Those making new claims to PIP who can only walk a very short distance – but even slightly further than 20 metres – will no longer be able to access motorised scooters or electric wheelchairs from Motability either. Many of these people will be confined to their homes. This is directly contrary to the government's stated intention that PIP exists to help people live independent lives.

#### **Case studies – Motability**

██████████ 47, uses the higher rate mobility component of DLA to access the Motability scheme. Although she can walk unaided sometimes, she cannot walk more than 30 metres and sometimes she cannot walk at all and has to use her wheelchair.

She would not be able to fit her mobility scooter in a normal car and so feels that without both her vehicle and scooter she would find it very difficult to get around. Public transport is completely inaccessible as the nearest bus stop and train station is 1.5 miles away and the vibrations of buses and trains can cause her to experience relapses.

Since going on the Motability scheme, ██████████ says her life has been transformed for the better, improving her mental health and feeling less isolated and depressed. Without it, she would no longer be able to go into town or take part in social activities, and she would struggle to make medical appointments.

██████████ has calculated what losing the higher rate mobility component would mean and has found that she would not be able to pay for another adapted car as it would take one year and 7 months to save up for the hoist alone. The lower rate of mobility would not be able to meet the costs of keeping mobile with her condition.

■■■■ had the following to say: "I need as much help as someone who can walk 20m does. At 30m walking capacity I still have to use my wheelchair in my flat at least for part of the day just a little less often than when I can walk 20m. So the claim that the reduction to 20m is about how someone can move around in their home does not make sense to me. It certainly doesn't mean I can move freely around my home at say 25m walking distance. (My home is only a 1 bed flat, not some huge house). My needs haven't changed, just the rules."

■■■■ also uses the Motability Scheme. She said:

"I work part time as a dental technician, although this is sometimes difficult for me I would like to continue doing so as long as I possibly can. I pay income tax and national insurance, just the same as any abled bodied person. I use my benefit to receive a car from Motability, without this service I could not afford a vehicle and would not be able to get to work, it simply would be too expensive and would make me too tired and unfit for work. I would lose my independence and would have to rely on others for tasks I can now do myself such as hospital and doctors appointments sometimes out of town. Now [the benefit] has changed I am not sure if I will receive it next time. I find it very stressful not knowing the outcome and am worrying about it all the time which is affecting my health. Without this benefit, I feel I will become one of the many on full benefits unable to work because of ill health, and therefore not making any sort of contribution into income tax or national insurance".

■■■■ described his situation:

"I am one of the people who would probably be affected by the 20m compared to 50m rule and have a Motability car. I would come easily under the " can walk more than 20m but less than 50m but require walking aids " category which would give me 10 points rather than 12 points.

"I cannot use a manual wheelchair and am a powered wheelchair user outside the house. No public transport is accessible in my town which really doesn't help matters. I use a motability car with a hoist to lift my powered wheelchair into the car. It counts as heavily adapted and as a result I can keep it 4 years rather than 3 due to the large upfront costs so I was devastated to hear I might not be counted as disabled enough and lose my mobility as a result. The Motability scheme has been a godsend to me and is the most important part of DLA".

■■■■ gave us this account of what her Motability car means to her:

"I'm 35, have MS (between us, that's Mighty Special) and currently receive the higher rate mobility component of DLA under a lifetime award which I use for a car. And yes, most mornings I can walk that 20m. But not every day, sometimes I can in the morning but not in the afternoon. Sometimes fatigue knocks me off my feet; literally. Sometimes the heat or even the cold leaves me more like a slug than an upright human being. And sometimes, you know what? I do pretty well and experience a glimpse of what it's like to be MS free, like I once was.

"The car I have is the first one under the Motability scheme, I got it because I developed a tremor in my 'clutch' foot with left sided weakness leaving me unable to drive a manual car so I got a fabulous automatic. My inability to drive a manual car hasn't changed, and as time passes the unavoidable truth is that I'm getting weaker. But at the moment I can still walk like I said. I limp after a short time, have drop foot, pain and the sheer effort of bumbling along in my own special way, wears me out and I know it won't be long before I'll be designing my own fantabulous walking stick but

that car, provided under the scheme is my life line. It means I can still go to work at the moment. Still pay those precious taxes that Mr. Osbourne is so fond of and claim no other benefit. That would inevitably change if the Government gets its way as it stands".

■■■■ told us what his Motability car has meant to him:

As a result of the failed surgery I qualified for the higher rate of DLA and claimed Motability. The Motability scheme immediately improved my life and the lives of my family. In many respects I would go as far to say that the scheme helped save my life at a most difficult stage. Having access to a vehicle also helped my family lead a normal life as possible under very strained conditions. It was not their fault that I ended-up losing my career and being disabled.

For anybody disabled mobility remains a crucial component to the functioning of normal life. The Motability scheme helps alleviate many stresses associated with vehicle ownership but more importantly helps retain a degree of normality and a sense of security, knowing that you have the means to hold down employment or escape the suffocating effects of becoming isolated and housebound.

■■■■ has had rheumatoid arthritis for 15-16 years. She told us:

Without a Motability car I would just stay at home all the time and be cut off from society. As an athlete who took part in the Paralympic Games last summer it would be devastating as I wouldn't be able to do my sport, I would just have to give up. It would mean having to pay for a taxi to compete and I just can't afford to do that. I would have nothing without my sport – it would cut off all my social links, it would destroy me. I also use my vehicle to go to physiotherapist, hospital, GP, food shopping, post office and see family and friends, as well as archery training, so I would be stopped from doing these things too.

I think the Paralympics have actually had a negative effect on perspectives of disability because all people see is disabled people competing, not all the behind the scenes help to get them there. There was a whole team of people who used to carry my equipment around for me, as well as load and unload my bags. I used to stand to compete but I can't do that anymore because multiple day competitions take their toll on me.

■■■■ has had rheumatoid arthritis for 15 years. She explained:

I need my Motability vehicle because it gets me from home to work, door-to-door. I use my car for work, shopping, travel to other parts of the country and visit people. Without it my social life would be hugely hampered if not choked off completely. I wouldn't be able to meet any of my friends which alongside losing my car would be an enormous addition to the depression. I would be left without any independence and in the periods of my life when I have lost my independence I have become suicidal.

The vehicle means I can do so many things that I just would not otherwise be able to do. I have access to the outside world and importantly for me can get to the swimming pool which is great for my condition – so not having it would mean my physical condition would deteriorate as well.

It is also important to recognise the impact on people who do not necessarily use the Motability Scheme, but who use their DLA to run a car.

#### **Case study: Personal vehicles**

■■■■ told us about her experience:

"I was medically retired 12 years ago, I am 49. I was placed straight into the Support Group for the ESA but looking at the proposed changes with the new PIP I stand to lose the higher rate mobility component of the DLA.

"If this happens I will not be able to use my car every day to enable me to get out because although my car is my own and not a Motability car my DLA pays for petrol, insurance etc. Walking to the nearest bus stop is impossible for me and there aren't many buses with disabled access if I were to use my mobility scooter. I certainly could not afford to pay for taxis either. Therefore I would be isolated at home while my husband is at work.

"The 20 metre rule is totally unfair as I can just about manage to walk it but after that I am reliant on either 2 sticks or mobility scooter depending on how good my legs are that particular day".

#### **Rural areas**

We are particularly concerned about those that live in rural locations with poor access to public transport or community schemes. Many respondents told us that even if they could access public transport, the local bus stop or train station was too far away for them to walk to. For example, some people told us that the bus stop was often half a mile or more away from their home.

#### **Case Study: Rural Areas**

■■■■ explained to us:

"I live with severely restricted mobility in a rural location, miles from shops/hospitals, and rely on my Motability car to live, as well as to 'have a life'. There are no bus routes through our hamlet - nearest bus stop is over a mile away.

"20 metres isn't far even in a town. 20 metres in the countryside is meaningless - have 'the powers that be' considered this?"

In many cases, whether people can walk 20 metres or 50 metres will be irrelevant to the costs they incur as a result of their disability – they will no more be able to access the shops, public transport or the high street if they can walk 45 metres than if they can walk 20 metres.

Indeed, depriving people currently in receipt of higher rate mobility is likely to leave them stranded at home. Many people who are disabled are unable to afford taxis to access their local community; many will be forced to give up work that they currently access with the support of the Motability Scheme; and many will be isolated,



deprived of vital human interaction, and left in a condition where their health is likely to decline. Those in rural areas are particularly vulnerable to this isolation – and the costs of providing care to them as their conditions worsen, is likely to be particularly high.

#### **Case studies: Rural areas**

##### **described:**

"The train and bus stop is too far away from my house for me to use. I have to get a taxi to the train station. I cannot use the bus as I cannot wait at the bus stop due to stiffness and 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.

"In short I would be reduced to living a life of solitude with my muscles wasting and becoming an ever increasing burden on the State."

##### **explained::**

"One thing they don't seem to have factored in is that, in my opinion, their limit of 20m actually limits us to within 10m of our home as of course we would have to walk back.....? If I was to try and walk to the bus stop it is about 2 blocks away, slightly more than 20m. And then do whatever I am doing, working, shopping etc, and then walk back home from the bus stop. Just a tad unrealistic and grossly unfair!"

##### **has Cystic Fibrosis. She told us:**

"I live in a rural area, with my partner who is in full time employment. My CF Unit is over 15 miles away with no direct public transport links. Without my car I would be dependent on my partner or parents taking me to hospital appointments, both scheduled and urgent and doing everyday activities that most people take for granted, for example seeing a friend or going to the local shop for milk".

#### **Costs will be pushed elsewhere**

Many of the 428,000 physically disabled people affected by the 20 metre qualifying distance are likely to have been in continual receipt of the higher rate of the DLA mobility component for many years. Impairments that cause problems for locomotion are known by DWP to be amongst those that cause the highest costs.<sup>4</sup>

We are deeply concerned that the sudden and immediate withdrawal of reliable travel cost support for disabled people has had no full *cross government* assessment of the impact of this on disabled people's lives or other areas of public expenditure. As we have outlined clearly above, many of the people that will lose out as a result of the 20 metre rule have the same needs as those who cannot mobilise for this distance – their needs will not disappear but are likely to be pushed to other areas of (potentially more expensive) government spending.

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<sup>4</sup> Page 21, Review of existing research on the extra costs of disability, 2005, DWP Working Paper 21.

In 2012 the Hardest Hit (supported by the DBC) issued a major report on how the many cuts to disabled people's support would impact on their lives. The report included the prospect of the change from DLA to PIP.<sup>5</sup> While this did not focus just on mobility payments it did find that:

- 8 in 10 (84 per cent) of disabled people believe that losing their Disability Living Allowance would drive them into isolation and struggling to manage their condition.
- 9 in 10 (94 per cent) of disabled people fear that losing their Disability Living Allowance would be detrimental to their health.
- 65 per cent of respondents in work stated that without DLA they would not be able to work.
- Three in ten disabled people stated that without DLA their carer would not be able to work.
- Three quarters of disabled people said that losing DLA would mean they would need more social care support from their local council.

Our research shows that likely areas of increased government expenditure will include:

### ***Transport***

The Transport Select Committee's current inquiry on access to transport for people with disabilities, has been investigating the range of challenges that disabled people face. It is clear that many physically disabled people are unable to physically or financially access public transport as an alternative.

In oral evidence on 3 June 2013 the Minister for Transport, Norman Baker MP, acknowledged that more consultation between his department and the DWP would have been helpful, specifically in respect of the Motability scheme. However he indicated that overall, *no assessment* had been made of disabled people's ability to access public transport in light of the PIP mobility policy. The knock on impact and costs to transport services are therefore unknown.

It is inevitable that loss of mobility will push costs onto formal services as disabled people will be unable to independently afford to pay for their mobility needs. Individuals will be forced to rely on already overstretched social care support to complete basic tasks, such as food shopping and access to doctor and hospital appointments.

In DWP research<sup>6</sup> it was noted of participants that they were using their DLA to pay for mobility items they could not wait for on the NHS, or for taxi fares to hospital appointments. It is clear that essential trips and items will have to be funded now through the NHS, yet there is no reference of the impact of this in the Department's assessment.<sup>7</sup>

It was also very clear in the Low Review's inquiry<sup>8</sup> into the use of DLA mobility in residential care that DLA mobility is key to meeting the personal mobility needs of

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<sup>5</sup> The Tipping Point (Hardest Hit) (2012)

<sup>6</sup> Page 60 'The impact of DLA and AA: findings from exploratory qualitative research (DWP research report No. 649)'.

<sup>7</sup> DWP PIP reform impact assessment (May 2012)

<sup>8</sup> Independence, choice and control, DLA and personal mobility in state funded residential care (2011) The Low Review.

care home residents, offering flexibility and freedom. It concluded that there was no overlap between the support offered by local authorities and that if DLA mobility were removed from those in residential care, local authorities would lack the resources to meet any shortfall.

In addition, recent research<sup>9</sup> shows that over two-thirds of local authorities in England have already decided to make cutbacks to buses. Many more bus services are likely to be lost as 77% of local transport authorities in England are either planning to, or cannot rule out, further cuts in the future. It is clear that there is a reducing public transport alternative: even if it was fully accessible to those with physical disabilities affected.

### ***Disabled people's access to work***

We strongly feel that the removal of enhanced rate mobility support from 428,000 people will in fact leave a vast number unable to access employment. It could also leave people more reliant on the Access to Work scheme, and increase cost pressures on the finite funding available from the scheme as illustrated by the case study below.

#### **Case study: Employment**

██████ told us:

"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. The present changes will cost the DWP more money".

It is clear that many disabled people who feel able to work do use their DLA to cover their costs of getting to work. If they are unable to work, there is a subsequent loss of tax revenue to the exchequer or increased costs as they see other mechanisms to maintain in work.

In an earlier Disability Rights UK analysis<sup>10</sup> on use of DLA, more than 1700 responses were received. Of those responding, 56% of people in work said they would have to stop or reduce work if they lost DLA. This chimes with the Hardest Hit analysis of 65% of those surveyed for that report saying they would give up work.

The DWP estimate that 9%<sup>11</sup> of people receiving DLA are in work, although other bodies state that actual figure may be higher (see below). Therefore it may be deduced that of the 428,000 people who will no longer qualify for the enhanced rate of the mobility component of PIP that 9% are employed. According to the Disability Rights UK analysis, 56% of working disabled people will have to either stop or reduce their hours as a result of losing this benefit. This suggests that a further 21,500

<sup>9</sup> See the Campaign for Better Transport Save our Buses research  
<http://www.bettertransport.org.uk/campaigns/save-our-buses/map>

<sup>10</sup> Impact assessing the abolition of working age DLA (Disability Rights UK 2012)

<sup>11</sup> Disability Living Allowance and work: Exploratory Research and evidence review (2010).  
DWP

disabled people will either become unemployed or face working reduced hours as a result of the implementation of this measure.

Another published assessment by Disability Rights UK<sup>12</sup>, based on loss of DLA across the mobility and care caseload (and so a higher estimate of 25,200 losing work) placed:

- £146.7 million loss in NI/income tax to the Treasury and
- an additional cost between £90.8 million to £127.7 million in out of work benefits.

A significant number of those who have contacted us about the 20 metre rule have highlighted their concerns about no longer being able to access employment. We have provided a number of case studies in the section above about the impact of no longer qualifying for the enhanced rate of PIP.

### ***Isolation, ill health and impact on carers***

We feel that that the DWP's own impact assessment<sup>13</sup> dramatically underestimates the impact on disabled people's health from increased poverty and isolation that is likely to occur as a result of the tightening of the mobility criteria for PIP. Below we will explore in greater detail how the result of deteriorating health could prove costly to both the NHS and social care services. The Department's own research shows that DLA and Attendance Allowance<sup>14</sup>:

*"has a key role in reducing potential demand for formal services..."*, and,

*"the benefits have preventative roles in helping people avoid moves into residential care, and maintaining or avoiding deterioration in health"*

Crucially in 2010 prior to PIP reform, DWP asked both DLA and AA recipients in its own research what would happen if their income was reduced by £50 a week, it provoked strongly negative reactions. Comments from DLA recipients of working age were that they "would not be able to live", and couldn't manage or think how they could cope. Some said they would have to cut the social activities that helped maintain their physical and mental health.<sup>15</sup> We have already provided some examples of the negative impact the tightening of the mobility rules could have on disabled people's health, but would like to reinforce this point with some additional case studies below.

#### **Case studies: preventing deterioration in health**

■■■■■ has Parkinson's. She explained:

"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."

<sup>12</sup> Impact assessing the abolition of working age DLA (DRUK, 2012)

<sup>13</sup> DWP PIP reform impact assessment (May 2012)

<sup>14</sup> The impact of DLA and AA: findings from exploratory qualitative research (DWP research report No. 649). Page 4.

<sup>15</sup> The impact of DLA and AA: findings from exploratory qualitative research (DWP research report No. 649). Page 86-87

■■■■ was an active member of her local community until she suffered a stroke at the wheel of her car, age 50, and acquired a serious brain injury.

She currently attends a day centre two days a week for people with brain injuries, which she says is really helping her to strive forward and be able to be more independent in many ways, including improving her walking.

She is very concerned that her improving condition, alongside the tightening regulations around PIP, will lead to her higher rate of mobility DLA being withdrawn, which would prevent her attending the centre, and also her many hospital, physiotherapy, occupational therapy, and speech therapy appointments.

She fears that as a result her condition would deteriorate significantly, and all the work she has put into recovering will be wasted, and that she will become a significant burden on her family, and the State.

Again there has been no assessment of the impact and likely increase in demand from the NHS and social care services arising from the mental and physical impacts of loss of DLA mobility. In a Disability Rights UK survey<sup>16</sup>, of those responding, 16% suggested cuts to DLA would result in higher NHS use and 14% suggested a likely need for more use of council services. When the charity calculated the potential costs (albeit across all recipients due to lose DLA) they estimated this could be in order of over £700 million to social care alone.

In addition, we are deeply concerned about the impact of the loss of DLA upper rate mobility on family carers. Many will be forced to bear the financial cost, as well as the impact on their own health and wellbeing from the additional stress that the loss of a vehicle or covering additional costs like petrol, taxis, aids and adaptations will bring.

If families become more isolated the knock on costs to the NHS and care services are very likely to increase. In Contact a Family's study<sup>17</sup> the charity found that 65% of parent carers of disabled young people feel isolated all or most of the time. The study found isolation causes almost three quarters (72%) to experience poor mental health such as anxiety, depression or breakdown, with one in five (21%) saying isolation due to a lack of services had led to the break up of their family or marriage. The cost of mental ill health and family breakdown alone is in the order of billions (£126 billion<sup>18</sup> and upwards of £20 billion<sup>19</sup>) yet the proposals are set to make these issues worse.

#### **Case study: Impact on carers**

■■■■ told us:

<sup>16</sup> Impact assessing the abolition of working age DLA (DRUK) 2012

<sup>17</sup> Forgotten Families 2011. Contact a Family.

<sup>18</sup> No health without mental health: a cross-government mental health outcomes strategy for people of all ages (2011) Department of Health and Centre for Mental Health, £105 billion for England, Scotland £10.7 billion, Wales £7.2 billion, Northern Ireland £3 billion.

<sup>19</sup> Centre for Social Justice (2007) and The Relationships Foundation's annual index of the cost of family failure (2011).

"At the moment having DLA mobility means we get out of the house, together. Parking the car and knowing it is there saves us both the terror of being stranded when Parkinson's at its worst strikes. Try finding a taxi or trying to get on public transport when your other half is frozen to the spot or shaking uncontrollably. A life outside of the home is what we both want and that is the freedom DLA mobility gives".

### **The 20 metre rule is inconsistent with government guidelines and established methods of measuring mobility impairment**

In the May 2011 DWP consultation, 'Personal Independence Payment: initial draft of the assessment criteria'<sup>20</sup> all four of the benchmark categories relating to difficulty walking a short distance were set at 50 metres.

For example Category C:

"Can move up to 50 metres unaided"

*Notes: identifies individuals whose mobility is severely restricted and do not or cannot use aids and appliances - for example, someone with severe Chronic Obstructive Pulmonary Disease. Includes individuals who can move up to 50 metres but then require a wheelchair for anything further."*

In fact, all subsequent PIP consultation documents proposed 50 metres as the similar benchmark figure.

This is unsurprising - 50 metres has long been established as a benchmark distance to identify those whose mobility is severely restricted.

For example, 50 metres is used in relation to disability and incapacity for work benefits, parking concessions, and in creating an accessible built environment, including the location of disabled parking spaces in relation to public and commercial buildings.

In contrast, in consideration of the severity of the mobility restrictions affecting a disabled person's ability to walk outside we can find *no record* of the figure of 20 metres ever being used as such an indicator.

Regulation 12(1)(a)(ii) of the Disability Living Allowance outlines four factors to be taken into account in deciding whether a physically disabled person is 'virtually unable to walk'; the test is whether their 'ability to walk out of doors is so limited, as regards':

- the distance over which, or
- the speed at which, or
- the length of time for which, or
- the manner in which [they] can make progress on foot without severe discomfort, that [they are] virtually unable to walk'.

<sup>20</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/153719/PIP-draft-assessment-criteria-note.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/153719/PIP-draft-assessment-criteria-note.pdf)

There is a striking similarity to the requirement under PIP that any walking that a disabled person can undertake must be considered in terms of its 'reliability':

"Consideration must be given to whether a claimant can carry out the activity, as described in the descriptor:

- safely;
- to an acceptable standard
- repeatedly; and
- in a reasonable time period

Factors which will be particularly relevant here are, but are not limited to, the individual's gait; their speed; the risk of falls; and symptoms such as pain, breathlessness and fatigue."<sup>21</sup>

The DLA statutory virtually unable to walk criteria have remained unchanged since 1992. Indeed, the virtually unable to walk regulatory criteria were actually imported into DLA in 1992 from its predecessor benefit Mobility Allowance. Mobility Allowance was introduced in 1975. As a consequence, the statutory test for welfare benefit to help with mobility costs has therefore been the same for over 35 years.

Both in terms of legal precedent and day-to-day DWP decision making the higher rate of the mobility component of DLA is awarded to those who are unable due to physical disability to reliably walk up to 50 metres - and as such are accepted as being "virtually unable to walk". There will therefore be some disabled people who have been assessed, acknowledged and paid benefit towards help for extra transport costs for over 35 years.

The PIP 20 metre rule means that there will be a stark inconsistency in the way that disabled people will be treated by the Department of Transport (DoT). It is significant that unlike the DWP the DoT will continue to recognise the significant limitations on the mobility of a disabled person who can walk only up to 50 metres. The DoT has fixed the automatic qualifying criteria for Blue Badge car parking permits to include both those who are awarded the enhanced PIP moving around rate and the standard moving around rate explaining:

"1.3 The Government remains committed to ensuring that the Blue Badge scheme continues to be focused on those people who will benefit most from the parking concessions that it offers, and that it is sustainable in the future.

1.4 Therefore, having carefully considered the responses to the consultation, Ministers have decided that, when DLA is replaced by PIP, there should still be a legislative link that means those people who score 8 points or more in the 'Moving Around' activity of PIP will be automatically eligible for a Blue Badge. This activity assesses a person's physical ability to get around and a score of 8 points or more will be awarded to people who are either unable to walk or who cannot walk further than approximately 50 metres. This means that eligibility for a Blue Badge will continue to be as similar to the current eligibility criteria for the scheme as possible."<sup>22</sup>

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<sup>21</sup> Paragraphs 4.15. and 4.16 of the consultation document

<sup>22</sup> P2 DoT Consultation Report: Personal Independence Payment and eligibility for a Blue Badge

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/68967/consultation-response.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/68967/consultation-response.pdf) ).

The above decision is perhaps also unsurprising in the context of official guidance on creating an accessible built environment, including the location of disabled parking spaces in relation to public and commercial buildings setting a benchmark of 50 metres.

The DWP has itself acknowledged this by holding that:

"50 metres is considered to be the distance that a claimant is required to be able to walk in order to achieve a *basic level of independence* such as the ability to get from a car park to the supermarket." <sup>23</sup>

It is difficult to see why a disabled person can be held to be among those to "benefit most from the parking concessions" by the DoT while at the same time not being held by the DWP to be eligible for a Motability car.

In addition, the benchmark distance of 50 metres will still be used by the DWP itself to determine a disabled person's limited capability for work. Disabled people will continue to be placed in the 'support group' for Employment and Support Allowance if they cannot either:

"(a) mobilise more than 50 metres on level ground without stopping in order to avoid significant discomfort or exhaustion; or  
(b) repeatedly mobilise 50 metres within a reasonable timescale because of significant discomfort or exhaustion."

The support group of ESA is intended to include those people with the most severe illnesses or disabilities. It is for claimants who the DWP consider to have such severe health problems that there is no current prospect of their being able to undertake work or work-related activities. The main differences between the ESA support group and the ESA work-related activity group are that:

- ESA support group members do not have to attend work-focused interviews or undertake work-related activities, such as training or condition management programmes;
- ESA support group member get more money because the support component is paid at a higher rate than the work-related activity component;
- The one year limit on claiming contributory ESA does not apply to members of the support group.

Yet under the moving around PIP criteria the same disabled person is not deemed to be facing the greatest barrier to mobility and will receive £33.25 a week less in benefit or have their Motability car taken away.

### **Weight given to the use of aids and appliances**

Much of the focus of this consultation response outlines why the distance of 50 metres rather than 20 metres should be used in the assessment of eligibility for the enhanced rate of the mobility component of PIP.

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<sup>23</sup> P74 *The Government's response to the consultation on the Personal Independence Payment's assessment criteria and regulations*, 13 December 2012  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/181181/PIP-assessment-thresholds-and-consultation-response.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/181181/PIP-assessment-thresholds-and-consultation-response.pdf) ).



However, as this consultation refers to the entirety of the 'Moving around' descriptor, we would also like to take the opportunity to stress that the present differentiation in weighting given to those using aids in Descriptors C and D is unnecessary.

A clear example of why this is not necessary is actually provided in the consultation document itself in the case of Sabeen. As is clear in this case study, Sabeen suffers from breathlessness and Descriptor C is applied – she can stand and then move unaided more than 20 metres but no more than 50 metres. Yet, there is no aid or appliance that Sabeen can use to aid her mobility. We would like to question why Sabeen's case is dealt with differently than someone who, for example, suffers from hip pain and can move this distance with the aid of a walking stick.

We submit that in either case the crucial factor is the distance that claimants can cover. This is because a person who suffers from breathlessness, for example, has the same extra costs as a person who uses an aid or appliance to move the same distance.

### **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. We believe that Descriptor E should be amended to read:

*"Can stand and then move more than 1 metre but no more than 50 metres, either aided or unaided."*

### **More information**

For more information on any aspect of this response please contact DBC Co-chair Claire Nurden on 0208 438 0753 or at [cnurden@mssociety.org.uk](mailto:cnurden@mssociety.org.uk)

