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Mobility for All

The 'We Are Spartacus' Community Submission
to the Government Consultation on Assessment of Mobility
for Personal Independence Payments

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Chapter 1

Introduction

This is a submission to the Department for Work and Pensions consultation on the “moving around” activity of the assessment for the Personal Independence Payment[1]. It is made on behalf of the online community of disabled people, their carers and supporters, and was organised through the `wearespartacus.org.uk` website.

This consultation response is based on the input of over 2000 individuals who have direct personal experience of a range of disabilities and impairments. We have sought to incorporate all substantive issues raised by our community, many of whom did not feel equipped to make a personal response. Direct quotes from individual disabled people are indented and clearly marked, like so:

“

Sample quote to demonstrate marking.

”

Our key recommendations are shown in chapter 2 on page 5.

We, and most respondents, still have serious reservations about the fundamental premises behind PIP and the rationale behind the reform. While this consultation is in some sense more focussed than the earlier consultation on assessment[2], it is also less structured; while only the “moving around” activity is considered, the consultation document gives very broad parameters for feedback on this activity. Given the current position of reforms, we have largely refrained from recommending wholesale change to this activity. This should not be read as approval of the premise of the activity as structured, but rather that we see it as more constructive to remedy the most serious practical problems with the assessment as it stands.

1.1 About `wearespartacus.org.uk`

The `wearespartacus.org.uk` website was created following the publication of the widely-respected[3] ‘Spartacus Report’, *Responsible Reform*[4], in January 2012. It is an online information and peer support hub for an emerging movement of disabled and sick people brought together by unease over Government reforms and popular discourse around disability. The Spartacus community has sought to engage constructively with reforms, to mitigate or change elements that lead to great concern among disabled people.

1.2 How we consulted

As well as general engagement with disabled people online through a range of social media (including Facebook and Twitter), an open survey was conducted over two weeks. Respondents were asked for their views on several matters relevant to this consultation, and were able to enter whatever comments they felt were important. They were also asked some basic questions about themselves, and some more detailed questions about any mobility impairments they have.

2088 people responded to the survey. 94.5% of respondents describe themselves as having physical difficulties moving around. 88.1% of respondents state that they receive DLA; 73.5% of respondents receive the Higher Rate of the Mobility component, 10.7% the Lower Rate of the Mobility component, and 3.8% receive only the Care component (percentages may not add up as presented due to rounding).

1.3 Mobility of Respondents

Those respondents who described themselves as having impaired physical mobility were asked what distance they could “stand and move” repeatedly, safely, in a timely fashion and to a reasonable standard. They were asked to pick a range of distances based on (but not identical to) those described in the consultation document for the “moving around” activity. Those who chose to answer gave responses as described in table 1.1.

Table 1.1: Self-reported distances respondents can “stand and move”, considering repetition, safety, speed and reasonable standards

| Distance | Percentage of respondents, excluding those who did not answer |
|--|--|
| Cannot stand and move at all | 4.4% |
| No further than 5m | 11.2% |
| More than 5m but no further than 20m | 30.5% |
| More than 20m but no further than 50m | 41.7% |
| More than 50m but no further than 100m | 6.1% |
| More than 100m but no further than 200m | 2.0% |
| More than 200m but not as far as a typical unimpaired person | 3.2% |
| At least as far as a typical unimpaired person | 0.9% |

The same respondents were also asked the nature of their limitation in “standing and moving”. As I’m sure the Department will understand, we could not ask about every possible form of impairment, so we selected a few categories that we expected to cover a significant proportion of cases, and allowed respondents to specify ‘other’; respondents could select all that applied. The results are shown in table 1.2 on the following page.

Common factors mentioned as ‘other’ included:

- Joint dislocations and subluxations.
- Difficulties with balance (other than or in addition to vertigo).

Table 1.2: Factors limiting ability to “stand and move”

| Factors | Percentage of respondents, excluding those who did not answer |
|-----------------------------|--|
| Pain | 89.2% |
| Fatigue or tiredness | 77.9% |
| Shortness of breath | 35.5% |
| Vertigo | 19.5% |
| Other | 18.0% |
| Complete physical inability | 4.4% |

- Lack of sensation in one or more parts of the body.
- Lack of coordination leading to risk of injury or damage.
- Walking causing deterioration in condition or additional damage, such as to joints.

In addition, 49.9% of respondents stated that their ability to go out was limited by some factor other than difficulties with “standing and moving”, such as those that would be covered by the activity “planning and following a journey”.

Chapter 2

Key Recommendations

- We recommend that descriptor ‘e’ be amended to refer to 50m in place of 20m, with consequent changes to other descriptors.
- We recommend that descriptors ‘c’ and ‘d’ be amended to refer to 100m in place of 50m, with consequent changes to other descriptors.
- We recommend that descriptor ‘f’ be removed, and descriptor ‘e’ be amended to cover the case of being unable to stand as well as being able to move any distance not more than 50m.
- We recommend that the maximum distance considered be increased to at least 500m.
- We recommend that judgements based on aids that could reasonably be used should be made with caution, and only with explicit discussion with the claimant, not inferences from oblique questioning.
- We recommend that the necessary use of aids confer additional points in all distance bands that do not already confer enough points for enhanced rate.
- We recommend that, in the case of this one activity, the distance be considered explicitly as that which can be moved “without severe discomfort”, these factors not being clearly and unarguably covered by safety, repetition, timeliness and reasonable standards.
- Our recommendations to change the descriptors of the “moving around” activity are summarised in table 3.1 on page 12.
- We recommend that the Government uphold the spirit of their commitment to provide appropriate support to disabled people, rather than simply designing an assessment with the intention of managing cost.
- We recommend that the Government consider that costs saved in PIP by not providing appropriate support to disabled people may be matched or exceeded by additional costs to the taxpayer in other areas.
- We recommend that the Government look again at what the practical and personal impacts of reduced support are on those with mobility impairments, and disabled people in general. This should be done with a mind to ensuring non-retrogression of UNCRPD rights.

- **We recommend that assessors be briefed that their role is to determine the correct level of support in a balanced fashion, as opposed to attempting to find evidence to allow Decision Makers to deny benefits.**
- **We recommend that it be made clear whether only physical impairments are considered in this activity, or any impairment affecting the physical act of “standing and moving”. We further recommend that any impairment affecting the said physical act be clearly considered within the remit of this activity.**
- **We reiterate our earlier recommendation that the Government appoint and fund an independent assessment and monitoring project to assess the impact of recent policies, including Personal Independence Payments, on rights under the UNCRPD, particularly on the obligations to progressive realisation and non-retrogression. It is vital that any such project be carried out with the trust and involvement of disabled people, preferably led by a disabled person.**

Chapter 3

Responses to Consultation Question

The open-ended nature of the consultation question invites almost any response, but as previously stated we are focussing on constructive improvements that follow the essential model present in the “moving around” activity.

3.1 Distances

A key question from many disabled people, campaigners, charities, and other interested organisations has been around the use of 20m as the critical distance distinguishing those with only physical limitations between Standard and Enhanced rates of the Mobility element of PIP. As this distance was never mentioned in the original consultation, there has been concern and surprise at its inclusion.

We recommended, in our response to the original assessment consultation[5], that the descriptors were unclear, but considered them reasonable (if not perfect) if they were read as giving 12 points to anyone unable to get further than 50m in ambulatory fashion. 20m is a distance of such dubious utility that it seems strange to base the assessment on it in any part. It is strange that the assessment as it stands differentiates those who can walk no further than 1m from those who can walk over 1m but no further than 20m, 1m being of even less utility when out of the home; however, it does not award different points for descriptors **e** and **f**, so this is of lesser importance.

We are particularly concerned that the stated objective of this activity is to assess ability to move around outside the home, yet the current consultation states that the “benchmark of 20 metres was intended to allow us to distinguish between those who are effectively unable to get around due to reduced physical mobility for example, people who are only able to move between rooms in their house but go no further and those who have some, albeit limited, mobility”[1, paragraph 2.4]. This suggests that the enhanced rate is only intended for those who are not effectively able to move around outside their own home at all, which seems at odds with the stated aim. However, as we explain in section 3.1.1 and section 3.1.2.1 on the next page, it is questionable that 20m is even sufficient as a proxy for basic mobility outside the home.

3.1.1 Background on 20m versus 50m

Professionals involved in developing the built environment have, for many years, used the distance of 50m as a guide to the maximum distance ambulatory disabled people can be expected to walk. This is reflected in the standards and guidelines mentioned below, but it should be appreciated that these are

merely a reflection, not the full extent of 50m (and sometimes 100m) as a practical standard.

Both the BSI[6, cl. 5.1] and Department for Transport[7, sec. 2.4] have recommended that seats be placed in large public spaces, such as transport hubs, not further than 50m apart, so as to provide resting points for ambulatory disabled people. Similarly, the Department for Transport[7, sec. 5.1] specify that parking bays for disabled motorists should be within 50 metres of the facility served. As a related note, building regulations[8, para. 5.10] specify that accessible toilets be within 40m of users (although those regulations specify use by wheelchair users, accessible toilets are also required by those with a range of other mobility difficulties).

3.1.2 Survey Data

Ultimately, it remains that the greatest experts on the barriers faced by disabled people are disabled people themselves, and so our survey asked respondents to rate their agreement with various statements around the utility of being able to “stand and move” 20m or 50m. Pertinent results of these questions are explained below.

3.1.2.1 “A little over 20m is sufficient walking distance to get from one place to another, such as using public transport”

95.7% of respondents disagreed with this statement, 85.2% disagreeing strongly; only 1.5% agreed. Respondents receiving DLA were slightly more likely to disagree, and disagree more strongly, with those receiving the mobility component, particularly at Higher Rate, more likely to be strong in disagreement (at a chi-square significance $p < 0.01$ and Spearman's correlation of 0.03). Of those in the critical band, reporting a limit of over 20m but not more than 50m, only 1.9% agreed. It seems clear that those with experience of mobility impairments particularly do not consider ‘over 20m’ to be a reasonable standard for basic mobility out of the home.

3.1.2.2 “A little over 20m is sufficient walking distance to get from a parked car and use a shop, if you can rest before returning to the car”

88.5% of respondents disagreed with this statement, 70.2% disagreeing strongly; only 5.9% agreed. Among those with limitations to physical mobility, limiting them by distance, those able to “stand and move” greater distances are slightly more likely to disagree strongly, and less likely to agree strongly, than those with the greatest limitation (at a chi-square significance $p = 0.02$ and Spearman's correlation of 0.09). Particularly, those able to “stand and move” over 20m, but still with some limitation, are less likely to agree (at a chi-square significance $p < 0.01$), with 5.0% agreeing as compared to 7.4% of those unable to “stand and move” further than 20m. Of those in the critical band, reporting a limit of over 20m but not more than 50m, only 4.5% agreed with the statement. Clearly, those respondents with direct personal experience do not consider a distance only a little over 20m to be useful.

3.1.2.3 “A little over 50m is sufficient walking distance to get from a parked card and use a shop, if you can rest before returning to the car”

65.6% of respondents disagreed with this statement, 37.7% disagreeing strongly; 20.1% agreed. Among those with limitations to physical mobility, limiting them by distance, those able to “stand and move” greater distances are very slightly more likely to agree (at a chi-square significance $p = 0.04$ and Spearman's correlation of 0.05). Of those in the critical band, reporting a limit of over 20m but not more

than 50m, 23.3% agreed with the statement. It seems that mobility-impaired respondents do consider the ability to “stand and move” over 50m to be of significance in determining ability to make practical use of mobility outside the home.

3.1.2.4 Longer distances

Respondents also expressed concern of the ‘ceiling’ distance of 200m, above which no impairment is relevant:

“ It’s ludicrous to suggest that someone who can walk ... even 200m before having to stop ... has no additional needs compared to a healthy person who can walk more or less as far as they need to. ”

A realistic maximum distance (safely, repeatedly etc) for a typical person with unimpaired mobility is clearly much farther than 200m. Guidance we have seen only specifies a target maximum of 400m between homes and bus stops[7, sec. 6], suggesting only 200m for services aimed at older and disabled people. This distance may be found at both ends of the journey, as well as on the return journey. The environment of a bus is hardly conducive to resting after exertion, and bus durations will often not be long enough to reasonably considered a rest before repeating a journey on foot. The Department for Transport guidance notes that “for disabled people, bus use falls off sharply if the distance is more than 200 metres”.

We do appreciate the need for a clear line. However, we question whether 200m is the correct clear line, especially as the points awarded at the longer distances are not sufficient to be entitled to benefit unless the claimant also has difficulty planning and following journeys.

3.1.3 Comments and Recommendations regarding Distances

It is clear that ‘over 20m’ confers only the most limited degree of mobility outside the home. ‘Over 50m’ is a better standard for basic mobility outside of the home, and one which is supported in a range of standards and recommendations already in existence, as well as being better regarded by disabled people themselves. **We recommend that descriptor ‘e’ be amended to refer to 50m in place of 20m, with consequent changes to other descriptors.**

Those able to “stand and move” over 50m still face a significant burden to mobility outside the home, justifying some support even in the absence of any difficulty “planning and following a journey”. However, we accept that some clear limitation be in place on this support. As we have expressed in previous submissions, there is a potentially great improvement in PIP over DLA that those experiencing physical limitations that would not qualify them for Higher Rate Mobility in DLA may be able to receive Standard Mobility in PIP. If the benchmark for obtaining 8 points in the “moving around” activity is comparable to that used to qualify for HRM DLA, that opportunity is missed. **We recommend that descriptors ‘c’ and ‘d’ be amended to refer to 100m in place of 50m, with consequent changes to other descriptors.**

We also note that our previous concerns over multiple descriptors giving sufficient points to achieve Enhanced Mobility has not been entirely alleviated. Descriptors **e** and **f** both provide 12 points. Unless there is some intent to reduce the points given for descriptor **e** in future, there seems no reason to differentiate between the two. **We recommend that descriptor ‘f’ be removed, and descriptor ‘e’ be amended to cover the case of being unable to stand as well as being able to move any distance not more than 50m.**

Given concerns over the appropriateness of 200m as the longest distance considered, it seems appropriate to consider longer distances at the lowest scores. **We recommend that the maximum distance considered be increased to at least 500m.**

3.2 Use of Aids

The “moving around” activity only distinguishes those using aids to reach their maximum reliable distance where that distance is greater than 20m but no greater than 50m. As explained in our response to the earlier consultation on PIP assessment, we believe that more significance should be attached to the need for aids, particularly those that create greater additional barriers and costs.

If a person is only enabled to move a certain distance by use of an aid, their ability to move that distance is not equivalent to a person with the same maximum reliable distance who does not need an aid. While some of the difference may be captured by other factors, particularly speed and repetition (as some aids are very tiring to use), this does not capture everything.

Many people are enabled by aids such as crutches or walking frames without being able to obtain such aids on the NHS, or with those provided on the NHS being uncomfortable in protracted or repeated use. Many people using two crutches long-term, for instance, purchase more comfortable crutches than those provided by the NHS. The vagaries of NHS mobility support may even leave people unable to obtain aids like walking frames through the NHS at all, though they may lead to significantly increased mobility. In these cases, not only is there a cost in obtaining the aid, but in maintaining or replacing it as needed; wheeled walking frames require servicing, while other walking frames, crutches and sticks require replacement ferrules. Availability and prices of aids might be considered when considering whether it would be reasonable to use an aid, but that is not considered where the aid is already in use - even when the aid has ongoing costs associated with it.

Furthermore, there are not only the costs associated with the aid themselves. In many areas, some public transport routes are still not suitable for larger mobility aids. Large aids other than wheelchairs, such as walking frames, are handled poorly by rail operators, with varied treatment and little in the way of official policies. Users of such aids are also restricted in terms of steps and curbs in similar fashion to users of wheelchairs. Aids requiring the use of both hands most of the time provide further barriers, requiring the use of a vehicle of some sort to carry loads that might otherwise be carried in the hands.

The use of aids also creates significantly increased restrictions due to weather, as many paving surfaces are too slippery for sticks, crutches and non-wheeled walking frames when wet; ice creates even more significant problems. In such situations, additional costs are faced in the need for taxis even for short journeys that would normally be within a person's walking capability.

In response to the original consultation on DLA reform, the British Limbless Ex-Service Men's Association opined[9]:

“Assessments must not be based upon the assumption that an impairment or health condition can be overcome through the use of aids and adaptations. These items ... do not negate or remove the underlying issues and should not be regarded as doing so.”

In addition, academic studies[10–12] have found that the use of aids such as sticks and walking frames can impair balance in some circumstances, while improving them in others, can impose additional, excessive demands in terms of strength and metabolism, and may lead to increased risk of wrist, elbow or shoulder complaints.

As such, we feel it appropriate to reinforce the point that assessors must not make unwarranted assumptions as to what aids would be reasonable, and what impact they would have. **We recommend that judgements based on aids that could reasonably be used should be made with caution, and only with explicit discussion with the claimant, not inferences from oblique questioning.**

To obtain the input of those who know the barriers of disability best, those who are disabled, we asked respondents to our survey how much they agreed with the statement “apart from finding it slower or more tiring, someone who can walk over 50m using an aid such as a stick, crutches or walking frame (but excluding a wheelchair) doesn’t have any more mobility problems than someone who can walk that distance without an aid”. 93.2% of respondents disagreed with the statement, 73.0% disagreeing strongly; only 3.3% agreed. Maximum reliable distance a respondent could “stand and move” affects the likelihood of a respondent having agreed (chi-square significance of $p < 0.01$), though there is not an overall correlation between the two factors. Those who cannot stand and move at all are most likely to agree, at 12.4%, while no respondents whose ability to “stand and move” is limited by distance, but for whom that distance is over 100m, agreed. This is clearly a complex question, and the meaning that can be inferred from our data very limited, but it is clear that our respondents believe there are barriers to mobility for those using aids to travel distances greater than 50m.

Respondents to our survey also highlighted, when asked for general comments, the fact that aids do not remove disability:

“ Using crutches means that I may be able to get from a to b but I have to be careful with every step I take as a change of surface, changes in the weather, dropped litter could make me slip and fall. Using crutches I am limited in what I can carry. I may be able to get from a car into a shop, but there’s little point if I can’t carry what I buy...unless the government is going to pay for someone to be with me at all times to carry things, which I doubt. ”

This reinforces the point that someone using significant aids is not equivalently mobile to someone with the same distance limitation without aids.

We recommend that the necessary use of aids confer additional points in all distance bands that do not already confer enough points for enhanced rate.

3.3 ‘Discomfort’

Despite the Government’s efforts in explaining the new benefit, there are still concerns based on the perception that discomfort is not taken into account:

“ There is no consideration for those who are in pain or suffer being breathless. It now does seem to be the case if you can walk at all, you are OK. ”

“ An appreciation that mobility can vary from day to day, and that many people will fight pain to keep their mobility skills rather than give up and always use aids. ”

It is still unclear to what degree these factors will be taken into account in practice. They are mentioned in guidance[13, p. 110] but not in legislation. DLA explicitly considered movement “without

severe discomfort”. It is not clear at what point it is acceptable that people stop moving due to such factors as pain, breathlessness, nausea, fatigue or vertigo. Given the intent represented in the guidance, review following this consultation seems to be an opportunity to alleviate this concern without any change in eligibility. **We recommend that, in the case of this one activity, the distance be considered explicitly as that which can be moved “without severe discomfort”, these factors not being clearly and unarguably covered by safety, repetition, timeliness and reasonable standards.**

3.4 Summary of Recommended Changes To Descriptors

With several changes recommended, it seems advisable to provide a summary. **Our recommendations to change the descriptors of the “moving around” activity are summarised in table 3.1.**

Table 3.1: Suggested alternate descriptors. Note that use of aids is differentiated in the 100m–500m range band, although the difference in score cannot lead to a difference in award by any combination with Activity 11. The difference is valuable to illustrate that the Government accepts that the requirement for significant mobility aids creates additional costs and barriers. The same principle is presumably evident in the current difference between descriptors ‘c’ and ‘d’.

| | | |
|---|---|----|
| A | Can stand and then move, without severe discomfort, more than 500m unaided. | 0 |
| B | Can stand and then move, without severe discomfort, more than 500m only by using an aid or appliance. | 4 |
| C | Can stand and then move, without severe discomfort, more than 100m but no more than 500m unaided. | 4 |
| D | Can stand and then move, without severe discomfort, more than 100m but no more than 500m only by using an aid or appliance. | 6 |
| E | Can stand and then move, without severe discomfort, more than 50m but no more than 100m unaided. | 8 |
| F | Can stand and then move, without severe discomfort, more than 50m but no more than 100m only by using an aid or appliance. | 10 |
| G | Cannot, without severe discomfort, either aided or unaided, stand <i>or</i> stand and then move more than 50m | 12 |

Chapter 4

Additional Points Related to the Consultation

While we answer the Government’s question directly in chapter 3 on page 7, there are a number of points that relate to the consultation without being a direct answer to the question. While some are touched upon in our answers to the question, we feel that these issues are important enough to discuss in detail

4.1 Costs of Changes to Descriptors and Points

We understand that the Government considers it a priority to ensure that those who need support receive it:

“Clearly, anyone who needs support... will get it.” (Lord Freud, HL Deb, 17 January 2012, c487)

“My noble friend gave an example of people who are really dependent on that funding. I would expect in those circumstances that it would continue. Indeed, I would regard PIP to be a failure if it did not do that.” (Lord Freud, HL Deb, 17 January 2012, c488)

Despite the Government’s stated commitment to providing appropriate support as a priority, the consultation document makes clear[1, para. 3.5] that cost is a factor in considering the outcome of this consultation.

“In reaching our decision we will consider how any potential changes might affect individuals and the numbers of people likely to receive the benefit. We will also consider the potential impact of any changes on PIP and overall welfare expenditure and whether this is affordable and sustainable.”

This bears out the public perception that these reforms are about saving money by reducing support for disabled people, as illustrated by this response to our survey:

“ The criteria seem to be to solely save money regardless of needs of disabled people. This government has broken the link with need and provision, its an ideological choice they have made to attack the support provided to disabled people. ”

If the Government wishes to show their commitment to providing appropriate and sufficient support to disabled people, they can do so by ensuring that the assessment criteria are based on realistic parameters that genuinely reflect the degree of practical mobility of claimants. Furthermore, as explained in section 4.2, money saved in this part of the budget is likely to be offset by additional costs in other areas. **We recommend that the Government uphold the spirit of their commitment to provide appropriate support to disabled people, rather than simply designing an assessment with the intention of managing cost.**

4.2 Indirect Costs of Reform

We would like to draw the Government's attention again to Disability Rights UK's report 'Impact Assessing the Abolition of Working Age Disability Living Allowance'[14]. The removal of the support provided by DLA will lead to further costs in other areas, because DLA often provides disabled people with the 'little bit of help early on', preventing problems from escalating.

The delay in support until problems progress will lead to some conditions worsening that would not do so with early support, or would do so more slowly, leading to greater and earlier costs on such areas as local authorities and health services. More rapid progression of mobility impairments will also lead to increased and earlier joblessness among disabled people, not simply because they will be unable to travel to work, but because other aspects of their impairment (such as pain and fatigue) create additional barriers to work.

Loss of mobility support will also lead to greater burdens on services such as hospital transport, help with travel costs from the NHS, and dial-a-ride. The loss of Motability cars alone has been estimated to represent an associated cost to the taxpayer of 8 million[15, sec. 5] specifically in the area of travel to health-related appointments.

In addition, as explored in section 4.3, the impact of a loss of support for mobility is likely to lead to deleterious effects on health, which will increase costs on the NHS and providers of social care.

We are grateful to Dr Simon Duffy of The Centre for Welfare Reform, for providing an analysis of the impact to local authorities of changes in social care costs consequential to PIP. Dr Duffy finds that an average local authority will lose out financially by over 7.5 million, through direct losses of income (through charging), and increased entitlement to social care. While the activity in consideration in this consultation is not directly relevant to charging, there can be little doubt that the exacerbation of people's conditions and their reduced independence will be a component of increased entitlement to social care.

We recommend that the Government consider that costs saved in PIP by not providing appropriate support to disabled people may be matched or exceeded by additional costs to the taxpayer in other areas.

4.3 Impact of Loss of Benefits

Because of the economic consequences, much has been made of the impact on working disabled people of the loss of mobility support, limiting their ability to go to work. In response, schemes such as Access to Work are mentioned. However, Access to Work is of no benefit in any area of mobility except travelling for work; it promotes the ability to work, not independence.

When asked about what impacts the loss or reduction of mobility support would have on them, our

survey respondents highlighted issues such as: social isolation; loss of independence; increased burdens on family, friends and the NHS; worsening health, both physical and mental; and general reduction of quality of life.

“ I simply would not leave the house - living in London means that if we wish to travel into town we are dependent on taxis because there are no disabled bays in Westminster, Knightsbridge, Kensington and Camden as the secretary of state has refused to make provisions for them unless for a designated user. ”

“ My motability car is my lifeline to the outside world. ”

“ Isolation, lack of independence and lack of social interaction with family and friends. ”

Even where family and friends provide support, this can be dependent on the financial support of DLA

“ I would not be able to contribute towards my sisters petrol costs so she would no longer be able to come and help me and take me out etc. ”

A Motability car, other car or finances for a taxi are necessary because public transport is frequently unusable. Those living in towns mention inaccessible or over-crowded buses, while those in any area can experience difficulty getting to a bus, hundreds of metres away from home and/or the required destination. Bus drivers may not wait for the person to be seated. Trains require booking in advance, reducing spontaneity and flexibility. Dial-a-ride services suffer from similar lack of flexibility and independence.

“ I live in a village and my car is my lifeline, the bus stop is at least 200 meters away even if I could physically get on it. My elderly parents live 12 miles away which would involve 3 changes to get there, the another 200 meter walk to the front door. ”

“ Public transport is much more difficult, esp buses: getting up the step, finding a seat (standing causes pain and fatigue, particularly when going round bends;being jostled and noise sensitivity. All leave me drained before I've even got to destination. ”

Respondents also mentioned direct impacts on their health, including reinforcing barriers to activities that will improve their health.

“ my problem with the walking distances is that i get it under the walking 50 plus metres is with severe discomfort. however my heart rehab team have told me i MUST walk for 20 minutes at least once per day and preferably twice. i do about 300 metres with rests on my flipstick but it hurts like mad and leaves me breathless. i am terrified what PIP will do to me, it's death by a succession of cuts ”

“ I sometimes swim after being advised non weight bearing exercise would be good for, it helps, but I would not be able to do this without the help I receive. ”

There are many aspects to the impact of isolation on physical and mental health, explored for Age UK Oxfordshire by Margeret Bolton[16, sec. 3], specifically finding that:

”having weak social connections carries a health risk:

- equivalent to smoking up to 15 cigarettes a day
- equivalent to being an alcoholic
- more harmful than not exercising
- twice as harmful as obesity.”

[16, p. 10]

Similarly, academic research suggests that “social isolation is a potent but little understood risk factor for morbidity and mortality, and its negative consequences are most profound among the elderly, the poor, and minorities”[17], and the Government is well aware of the statistical correlation between disability and poverty.

There is also concern over the loss of passported benefits - blue badges, national concession passes for public transport, the Disabled Person’s Railcard, and so forth. While blue badges and concessionary passes are to be available to those reaching 8 points on the “moving around” activity, it is still unclear how many people are likely to lose their blue badges due to the changes in assessment.

It must also be remembered that the descriptors as written do not protect wheelchair-users in general, as many are able to walk some distance, but require the use of a wheelchair (often powered or pushed by another person) for practical distances, such as those required to go shopping. Reliance on another person to push the chair does not represent independence, in general, and power chairs are, in most cases, only available with NHS funding if a person both needs to use the power chair around their home, and their home is arranged in such a manner that they can use the chair around their home.

Given all of these factors, we believe that the Government has not properly considered the impact of the reduction or removal of support on disabled people. We have mentioned, in previous consultations, concerns about impacts on UNCRPD rights, and the possibility of retrogression in those rights. The Government is committed by international law to progressively realise UNCRPD rights, and in any case to avoid retrogression in such rights. **We recommend that the Government look again at what the practical and personal impacts of reduced support are on those with mobility impairments, and disabled people in general. This should be done with a mind to ensuring non-retrogression of UNCRPD rights.**

4.4 Conduct of Assessments

There remains considerable concern that assessments will be conducted in the same manner as the WCA, as performed by Atos on behalf of the Government. The form and assessment are seen as designed to ‘catch people out’ rather than attempt to find the correct level of benefit to award. Despite reforms following the Harrington reviews, the face-to-face assessments are seen as misleading, rushed and impersonal.

- “ It also amazes me that a Doctor who meets with you for 10 minutes can over rule a Doctor who has known you and your condition for any years. It is about time that the Government stopped paying companies millions of pounds to give medical reports for patients who already have perfectly qualified Doctors who know the patients . They know their background, their patients good days, bad days. If they are exaggerating etc, they have records and X-rays. ”
- “ Everyone has to have a fair assessment and full history of their condition looked at including gps and consultants reports before rejecting a pip claim. I think many people including myself don’t want ATOS involved in the pip assessments as I feel they do not give a fair assessment. ”

This relates to PIP as a whole, rather than specifically the single activity considered in this consultation. However, the assessment of mobility is directly affected by this factor, particularly oblique ‘tricky’ questions. **We recommend that assessors be briefed that their role is to determine the correct level of support in a balanced fashion, as opposed to attempting to find evidence to allow Decision Makers to deny benefits.**

4.5 Impairment Types

We are aware that the guidance provided for the testing exercises during development of the new benefit gave a summary table of the impairment types relevant to each activity. It stated that the “moving around” activity, at that time Activity 11, should only be considered in relation to physical impairments. This is concerning, as the assessment as written only requires that the impairment create difficulty with the physical act of standing and moving.

In the current guidance[13, para. 3.2.2], it is stated that the “impact of all impairment types can be taken into account across the activities”, with the caveat that “moving around relates to the physical aspects of walking”. It is possible for conditions that are not clearly and definitively physical to lead to impairment with the physical act of walking. **We recommend that it be made clear whether only physical impairments are considered in this activity, or any impairment affecting the physical act of “standing and moving”. We further recommend that any impairment affecting the said physical act be clearly considered within the remit of this activity.**

4.6 Impact of Equality Legislation

This section contains substantial elements that appeared in our earlier response to the broader consultation on PIP assessment[5]; we believe that the point remains relevant, and that the Government may still be over-estimating the impact of 20 years in improving accessibility.

We feel the need to reiterate the concern that the Government has over-stated the positive impact of the Disability Discrimination Act 1995 and Equality Act 2010. As in previous submissions, we recall that statements from the Government regarding this reform have cited improvements in accessibility in all areas of life as a driving force for reforming DLA, including the original consultation on DLA reform[18]:

"12. Since DLA was introduced in 1992, there have been significant improvements in medical treatments and in aids and adaptations that assist disabled people. Attitudes to disability have also changed. The introduction of legislation, for example the Disability Discrimination Act 1995 and Equality Act 2010, to protect the interests of disabled people and prevent discrimination has helped many disabled people lead more independent lives. It is now universally accepted that disabled people should have the same choices and opportunities as non-disabled people."

While there have undoubtedly been significant improvements, they are far from removing most of the barriers that disabled people face; indeed, some barriers would be difficult to remove without fundamentally altering the structure of our society; Sir Philip Craven of the IPC stated that transport equality may never happen[19]:

"If any person with an impairment expects to be able to go everywhere in this country that someone with two legs can do, then I don't think that's ever going to be possible."

The Department's briefing notes on PIP[20] affirm the need for a benefit that "reflects the needs of disabled people today and in the future, rather than those of the 1990s", which seems to suppose a far greater improvement in accessibility than is actually the case. While many buses and trains have wheelchair spaces, they are frequently full of other passengers' luggage or buggies; while train companies can all arrange help boarding and alighting from trains, this generally needs to be booked in advance, and often fails to appear even then; there are considerable numbers of bus routes around the country that do not even have level access; while provision for wheelchair users has made great progress, the same cannot be said for users of other unwieldy mobility aids, like wheeled walking frames. All of those problems relate to public transport, which is actually regulated to encourage accessibility. Enforcement of the duty to make reasonable adjustments on providers of goods and services in general is very lacking, with resistance to any change or any suggestion of indirect discrimination. In general, the only enforcement option is to bring legal action, which is a significant burden, particularly for a group of people who are more likely to have a low income.

Poor accessibility leads to both social exclusion and increased costs. If people can only travel by taxi, because public transport is not reliably accessible, that leads to greater costs. If someone is restricted in their choice of where to purchase goods or services, they cannot benefit from the full advantages of market competition. This is where this concern is directly relevant to this consultation; as the PIP assessment is intended to serve as a proxy for the increased costs of being disabled, extra expenses faced because of poor access and a lack of reasonable adjustments must be understood as part of those costs.

The JCHR has recently reported[21] on the right to Independent Living, as we consider further in section 4.7 on the following page. In this report, the JCHR acknowledges that the Government recognises the fact that any progress towards equal access to many aspects of life is still a long way off. It would be reassuring if the Government would publicly recognise that the Equality Act 2010, and the Disability Discrimination Act before it, while having positive results still leave huge inequalities in place in British society.

Any assumption of general accessibility or widespread provision of reasonable adjustments will reduce the validity of any policy or system based on that assumption. Rather than basing policy on the assumption of this provision, the Government would do better by disabled people by finding more rigorous ways to enforce at least the disability provisions of the Equality Act. Although entirely outside the scope of this consultation, we reiterate our suggestion that the Government consider options for this as a priority. For instance, a civil enforcement body, with suitable powers, with responsibility to enforce the rights and duties of the Equality Act 2010.

4.7 Impact on Independent Living, and Other UNCRPD Rights

This section contains substantial elements that appeared in our earlier response to the broader consultation on PIP assessment[5]; we believe that the point remains relevant, and that the Government is still neglecting the principle of non-retrogression inherent in UNCRPD. We further wish to point out that under international law the government has a duty to assist ALL disabled people, not merely those whom the government has decided through the use of a contentious test to be ‘those in greatest need’, removing support from those with lesser needs may be considered retrogression of UNCRPD right.

We note the 23rd report of the Joint Committee on Human Rights in the current session[21], expressing the United Kingdom’s obligations to progressive realisation and non-retrogression of rights under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). We will not seek to repeat their excellent examination of the state of international law and their arguments on the obligations treaties place on the Government; we note only that the convention does not protect only the rights of those “most in need” but of all disabled people. In this respect, in relation to the proposals for PIP, we have particular concerns that many disabled people the Government does not consider to be those most in need could find their independence seriously compromised. The most obvious example is that many current DLA claimants with physical impairments have expressed their serious concern that, given the particularly harsh scoring and thresholds proposed for Activity 12, their ability to get around independently will be severely curtailed, seriously affecting their quality of life, including the loss of their Motability vehicles. Some have suggested that they might have to give up work, as they would be unable to travel to their workplace, and many have expressed their fear that they will be effectively imprisoned in their homes because they are totally dependent on their Motability cars which they would be unable to afford to replace.

Given concerns of possible retrogression of rights, including the right to independent living, it seems appropriate that the Government put in place some independent provision to directly assess the likely impact of recent policies, including the Personal Independence Payment, on UNCRPD rights, and to monitor the implementation to report on any slowing of progressive realisation or possible retrogression. **We reiterate our earlier recommendation that the Government appoint and fund an independent assessment and monitoring project to assess the impact of recent policies, including Personal Independence Payments, on rights under the UNCRPD, particularly on the obligations to progressive realisation and non-retrogression. It is vital that any such project be carried out with the trust and involvement of disabled people, preferably led by a disabled person.**

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