



wearespartacus.org.uk



---

## Together We Shout

---

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

Sam Barnett-Cormack BSc MSc

Sarah Campbell BSc PhD

Bethan Morris

Fiona Nicholson MA(Cantab)

Pamela Stock

Steven Sumpter BSc(Hons)

Jane Young LLB(Hons)  
PGCert(Disability Studies)

April 2012

# Acknowledgements

*This document could not have been produced without the support and involvement of many people, including the authors and editors of the [wearespartacus.org.uk](http://wearespartacus.org.uk) guides to the proposals, all of the disabled people and their allies on our forums, and all those who worked to spread awareness of the PIP assessment consultation. Particular thanks to those who have provided technical support to enable us to draw input from so many people.*

*We would also like to thank the wider community of disability activists, and especially the MPs and Peers who strive to uphold the rights of disabled people in Parliament.*

# Contents

<b>Acknowledgements</b>	<b>i</b>
<b>Contents</b>	<b>ii</b>
<b>Foreword</b>	<b>iv</b>
<b>1 Introduction</b>	<b>1</b>
1.1 About wearespartacus.org.uk . . . . .	1
1.2 How we consulted . . . . .	2
<b>2 Key Recommendations</b>	<b>3</b>
<b>3 Answers to Questions</b>	<b>12</b>
3.1 Question 1 . . . . .	12
3.1.1 Significant Issues Not Captured By The Second Draft Criteria . . . . .	12
3.1.2 Activity 1 . . . . .	14
3.1.3 Activity 2 . . . . .	17
3.1.4 Activity 3 . . . . .	18
3.1.5 Activity 4 . . . . .	18
3.1.6 Activity 5 . . . . .	20
3.1.7 Activity 6 . . . . .	22
3.1.8 Activity 7 . . . . .	23
3.1.9 Activity 8 . . . . .	23
3.1.10 Activity 9 . . . . .	24
3.2 Question 2 . . . . .	25
3.2.1 Activity 2 . . . . .	26
3.2.2 Activity 3 . . . . .	26
3.2.3 Activity 5 . . . . .	27
3.2.4 Activity 7 . . . . .	27
3.2.5 Activity 9 . . . . .	27
3.3 Question 3 . . . . .	28
3.3.1 Activity 10 . . . . .	28
3.3.2 Activity 11 . . . . .	30
3.4 Question 4 . . . . .	32
3.4.1 Activity 10 . . . . .	33
3.4.2 Activity 11 . . . . .	33
3.5 Question 5 . . . . .	33
3.6 Question 6 . . . . .	34

3.7	Question 7 . . . . .	36
3.8	Question 8 . . . . .	38
3.9	Question 9 . . . . .	41
3.9.1	Information to be Provided . . . . .	41
3.9.2	Face-to-face assessments . . . . .	42
<b>4</b>	<b>Overarching and Additional Points</b>	<b>45</b>
4.1	Inflexibility and Narrowness of Conception . . . . .	45
4.2	Impact of Equality Legislation . . . . .	46
4.3	The Cost of Aids . . . . .	47
4.4	Unsatisfactory Conduct of Consultation . . . . .	47
4.5	Handling of Specific Conditions . . . . .	48
4.6	Impact on Independent Living, and Other UNCRPD Rights . . . . .	48
4.7	Indirect Costs of Reform . . . . .	50
	<b>References</b>	<b>52</b>
<b>A</b>	<b>A Personal Example of the Need for Expensive Equipment for Management of Condition, Pain, and Sleep</b>	<b>54</b>
<b>B</b>	<b>Illustration of Perverse Results of Draft Regulation 4(4)(c)(ii)</b>	<b>56</b>
<b>C</b>	<b>The Experience of an Incontinent Adult—A Criticism of the Second Draft’s Treatment of Incontinence</b>	<b>58</b>
<b>D</b>	<b>Compliance with Government Code of Practice Consultation Criteria</b>	<b>61</b>

# Foreword

*by Baroness Grey-Thompson DBE*

The Welfare Reform Bill will see some of the biggest changes to the how the State provides for disabled people, in perhaps several decades. While no-one can dispute that there is a need for reform, there is also a need to ensure that disabled people, including some of the most vulnerable in society, are not only protected but have the opportunity to play an inclusive role.

The research by We Are Spartacus has been informed by consulting with disabled people who have a wide range of impairments, but who are users of the system of support at every level. Many of these disabled people have been through the changes in the system that have got us to this point, but are also experts in what it takes to live day to day with an impairment.

‘Welfare’ is a complex issue and this report outlines in great detail some positive recommendations, but also calls on the DWP to look again at certain assumptions that have been made.

During my work on the Welfare Reform Bill, virtually everyone who I came in to contact with recognised the need for reform, to improve the system, and to make it more efficient, not just in monetary terms but in supporting the lives of disabled people. It is essential that support is given to the right people, but a real concern amongst many is that if a small amount of support is not given to some disabled people, they will be ghettoised and pushed in to having far greater needs further down the line.

I therefore commend this evidence-based report, which provides a positive view on how to take forward the proposals for PIP at a challenging time for many disabled people.



# Chapter 1

## Introduction

This is a submission to the Department for Work and Pensions consultation on 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](http://wearespartacus.org.uk) website.

This consultation response is based on the input of over 600 individuals who have direct personal experience of a range of disabilities and impairments. Our response is both wide-reaching and detailed. 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 3. For the most part, these are quite small changes, and in some cases very much technical changes rather than fundamental changes. We hope they will all be accepted, at least in part, and inform the next draft of PIP assessment regulations.

We, and most respondents, still have serious reservations about the fundamental premises behind PIP and the rationale behind the reform. The recommendations and observations in this document are in keeping with the stated scope of the consultation, however, at least as well as we understand it. This should not be taken as approval of the premise of PIP; we are simply trying to help the Government to design the assessment in a way that will lead to the least harm to disabled people.

### 1.1 About [wearespartacus.org.uk](http://wearespartacus.org.uk)

The [wearespartacus.org.uk](http://wearespartacus.org.uk) website was created following the publication of the widely-respected[2] ‘Spartacus Report’, *Responsible Reform*[3], 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 is extremely concerned that the proposed reforms will not work as intended unless the Government is prepared to listen to the people who are experts in managing their own condition.

Table 1.1: DLA Components and Rates of Survey Respondents (excluding 18 respondents who gave incomplete information), with figures from DWP caseload analysis[4].

Components	Percentage of Respondents	Percentage ignoring “No DLA”	Percentage in DWP Caseload 2010/2011
Higher Mobility, Highest Care	19.5%	23.1%	16.1%
Higher Mobility, Middle Care	16.0%	19.0%	13.6%
Higher Mobility, Lowest Care	14.3%	17.0%	13.7%
Higher Mobility, No Care	4.4%	5.3%	8.4%
Lower Mobility, Highest Care	6.3%	7.5%	6.2%
Lower Mobility, Middle Care	7.5%	8.9%	18.0%
Lower Mobility, Lowest Care	7.3%	8.7%	9.4%
Lower Mobility, No Care	0.9%	1.0%	2.5%
No Mobility, Highest Care	0.5%	0.6%	0.3%
No Mobility, Middle Care	1.7%	2.0%	2.2%
No Mobility, Lowest Care	5.8%	6.9%	9.4%
No DLA Received	15.7%	N/A	N/A

## 1.2 How we consulted

As well as extracting views and observations from comments on the wearespartacus site itself, the wearespartacus forums, and the Spartacus Report Facebook group, an open survey was conducted over slightly more than a week. Respondents were asked for their views on several aspects of the reform, able to enter whatever comments they felt were important. They were also asked a number of basic questions about themselves, and their views on the second draft PIP assessment criteria.

604 people responded to the survey. 82.6% of respondents said they receive DLA; 77.0% receive the care component, and 74.5% the mobility component. A full breakdown of the percentage of respondents receiving different combinations of rates is given in table 1.1. 25.2% of respondents make use of the Motability scheme to access a vehicle or mobility aid.

When analysing the correlation of the sample profile of DLA recipients in our survey with the caseload profile published by the department[4], we obtained a Spearman’s rank correlation coefficient of 0.89, a Kendall tau value of 0.73, and a Pearson correlation value of 0.81; all of these tests gave  $p < 0.01$ . We would therefore suggest that there is a strong fit between the claimant profile of those of our respondents who are in receipt of DLA and the claimant profile of the overall DLA caseload.

## Chapter 2

# Key Recommendations

- We recommend the addition of a new activity, or some form of non-functional scoring, based on the need for general supervision. A possible set of descriptors for this activity is shown in table 3.1 on page 13. Of note is that we recommend that the requirement for continual or near-continual monitoring throughout either the day or the night give entitlement to the Standard rate of the Daily Living component, and such monitoring being required throughout both day and night give entitlement to the Enhanced rate of the Daily Living component.
- We recommend that either: a further activity be added to encompass sleeping and waking; or another activity, such as Activity 6, be expanded in scope to encompass these areas.
- We recommend that all references to drinks be removed from Activity 1.
- We recommend that the elements of preparing and cooking a meal, for the purposes of Activity 1, be specified in regulations or otherwise given statutory force.
- We recommend that the elements of Activity 1 be sufficiently well specified to realistically represent preparation of a meal from start to finish, including retrieving ingredients and equipment from storage.
- We recommend that a difficulty using a typical 'waist height' work surface or hob be considered in the assessment of Activity 1. A suitably adapted kitchen and appliances may be considered an aid, but should be given greater consideration than aids in general, as they represent considerable cost.
- We recommend that the Department strongly consider awarding points in Activity 1, perhaps the same as awarded for microwave use, for being unable to use either a hob or an oven. It would not be reasonable to assume that the oven were at or above waist height.
- We recommend that the Government accept that a difficulty bending should potentially result in awarding some points for Activity 1, to represent the rarity of a kitchen in which all utensils and foods are stored at or above waist height. Where a claimant has such a kitchen, deliberately arranged in order to avoid bending, we recommend that this be considered an aid.
- We recommend that it be made particularly clear that a person must be able to complete this activity and then be in a fit state to consume the meal.



- We recommend that Activity 1 descriptor C be clarified, such that it is clear that the simple meal must still be prepared from fresh ingredients.
- We recommend that the Department give consideration to how assessors may handle the situation of claimants reporting the use of other cooking methods, and instruct assessors to work with the claimant to realistically and fairly determine their ability to use the specified cooking methods.
- We recommend that the Department investigate the different levels of barrier and costs associated with different therapeutic sources of nutrition, and differentiate between them in the descriptors of Activity 2.
- We recommend that a need for puréed food, or food that otherwise does not require chewing, be reflected in either Activity 1 or Activity 2. We recognise that additional points need not be awarded where a claimant is capable of preparing their own food in this manner without an aid or appliance.
- We recommend at Activity 2 descriptor D be clarified to refer to both prompting during the meal to continue eating, and prompting to take action to obtain a meal.
- We recommend that Activity 2 be clarified to refer to meals, and exclude snacks, particularly highly convenient and unhealthy snacks.
- We recommend that the Department consider what evidence they will expect for medication recommendations. This concern must not, however, be allowed to prevent consideration of recommended medications; rather, necessary methods and procedures should be developed to allow for the greatest inclusion of recommended medications.
- We recommend that 'monitoring a health condition' be defined so as to clearly include both formal monitoring of signs and symptoms and informal, ongoing monitoring.
- We recommend that Activity 3 descriptors D, E and F include monitoring a health condition as well as therapy; it may be appropriate in this case to exclude 'ongoing' monitoring, such as helping a person be aware of their moods to manage mental health, from descriptors D, E and F only, but not descriptor B.
- We recommend that Activity 3 be amended to encompass the need for special equipment or furniture to manage pain and reduce the likelihood or speed of deterioration in underlying conditions.
- We recommend that ability to bathe be assessed based on bath or shower, or such other reasonable method as the claimant may prefer.
- We recommend that 'torso', in the definition of 'bathe', be clarified to the inclusive definition used in anatomy.
- We recommend that the activity of bathing also incorporate the cleaning of the entire body, including limbs and extremities.
- We recommend that the activity of bathing clearly include thorough drying.

- We recommend that the activity of grooming be amended to include the cutting of fingernails and toenails, shaving, and the washing of hands and face.
- We recommend that help required for changing clothes be included in the consideration of managing incontinence, where that assistance is greater than that required in normal dressing and undressing.
- We recommend that help required to change bedding be included in the consideration of managing incontinence, at least where it occurs frequently.
- We recommend that an additional descriptor be added to Activity 5, awarding points for incontinence where a claimant can manage it themselves. This descriptor could be phrased as “Can manage incontinence unaided or with the use of an aid or appliance”. The words “or incontinence” would then be removed from descriptor A and descriptor B. We suggest that the new descriptor score 4 points.
- We recommend that Activity 5 be clarified to explicitly encompass the management of menstruation.
- We recommend that Activity 5 be clarified to include washing hands.
- We recommend that Activity 5 consider getting to the toilet, using any aids normally used or that could reasonably be expected to be used, as an element of managing toilet needs.
- We recommend that a clear list of examples be given, without limitation, of the sorts of adapted clothing that may be considered in Activity 6, and that adapted footwear be included. The assumption of slip-on shoes in this activity should be replaced with a requirement for suitable footwear, taking into account both general advice on footwear and any advice given specifically to the claimant by a healthcare professional.
- We recommend that Activity 6 descriptor C point (ii) be clarified to include people who need physical assistance to retrieve their clothes, though they may be capable of choosing clothes in intellectual, cognitive and sensory terms.
- We recommend that remembering a communication well enough to act on it also be a consideration in Activity 7.
- We recommend that Activity 7 be modified to encompass the creation of written information as well as the ability to access written information. Descriptor D should be amended to include expression as well as access of written information.
- We recommend that Activity 8 descriptor C be clearly extended to cover needing a person present to support the claimant physically or emotionally during social activity, without requiring that they be specially trained.
- We recommend that Activity 8 descriptor B be clarified to ensure that it encompasses encouragement to face activities that the claimant finds physically debilitating.
- We recommend that the scope of Activity 9 be clearly extended to encompass retrieving necessary information and resources, and acting on decisions, as well as simply making them. This can be achieved with minimal changes to the descriptors, to encompass aids and assistance as well as prompting.

- We recommend that the descriptors for Activity 9 also address the need for supervision.
- We recommend that, if writing is not to be considered part of Activity 7, that it must be considered part of Activity 9.
- We recommend that Activity 9 be re-titled 'Managing finances and handling financial decisions'.
- We recommend that the thresholds for both rates of both components, announced in the consultation document as 8 points for Standard Rate and 12 points for Enhanced rate[1], be left unchanged.
- We recommend that differentiated descriptors be considered for each activity regarding the use of aids and appliances, given that some are considerably more expensive than others. Options should be examined to identify, for each activity, clear categories of aid and appliance that provide a reasonable proxy for the initial and ongoing costs of different aids and appliances.
- We recommend that Activity 2 descriptor C, needing a therapeutic source, score 4 points, and descriptor E, needing assistance with a therapeutic source, score 8 points.
- We recommend that, given the huge costs of acquiring and maintaining some aids used to manage symptoms, slow deterioration and promote recovery, there be descriptors added to Activity 3 that potentially score up to 8 points, to enable the Standard rate of Daily Living to be awarded to those with these high costs to meet.
- We recommend that Activity 7 descriptor C score 4 points, to reflect the generally higher costs of hearing aids and voice synthesisers when compared to low vision aids.
- We recommend that the highest descriptor(s) for Activity 9 attract a score of 8, enabling a claimant who only has needs in this area to qualify for the Standard rate of the Daily Living component on the basis of this activity alone.
- We recommend altering the distinction between descriptors in Activity 10 to those who require supervision, ongoing prompting or a support dog as distinct from those who require prompting to initiate a journey.
- We recommend that, in Activity 10, the word 'overwhelming' not be used in respect of psychological distress.
- We recommend that being unable to leave the home, like requiring a person or support dog with you for all journeys, score sufficiently in Activity 10 to give entitlement to the Enhanced rate.
- We recommend that the descriptors for Activity 10 specify where a journey involves public transport, or that this be made clear in regulations with statutory force.
- We recommend that consideration of aids be included in Activity 10. It would be appropriate for aids that are required purely to move around be disregarded, as they are considered in Activity 11.

- We recommend that the words “up to” not be used in Activity 11 descriptors, but instead each descriptor refer to a specific benchmark distance, requiring that the claimant be able to move further than that distance.
- We recommend that the benchmark for considering wheelchair use, and the use of motorised devices, be increased. We suggest it be set at 200m.
- We recommend that use of aids other than wheelchairs and motorised devices not be considered equivalent to using no aid at any distance, or at least in the 50–200m distance range. This is most important for aids that require the use of both hands for most of the time they are in use, such as walking frames and pairs of crutches.
- We recommend that the requirement for an aid to move 50m clearly entitle a claimant to at least Standard rate of the Mobility element in Activity 11. The example in the explanatory notes suggesting this would only be available if a more significant aid were needed to travel further than 50m should be removed or altered. A claimant who can move unaided to some distance shorter than 50m, but requires an aid other than a wheelchair to travel as far as, or further than 50m, should score per descriptor D in the second draft assessment criteria.
- We recommend that descriptors scoring over 12 points be reduced to 12 points.
- Our recommendations concerning Activity 10 are summarised in an alternate set of descriptors shown in table 3.2 on page 29
- We recommend that using an aid for any distance lead to a greater score in Activity 11 than not using an aid.
- We recommend that descriptors scoring over 12 points be reduced to 12 points, and descriptors merged to remove distinctions that are no longer relevant to assessment, including the distinction between different kinds of wheelchair and motorised device.
- Our recommendations concerning Activity 11 are summarised in an alternate set of descriptors shown in table 3.3 on page 32. Please note, however, that these recommendations are all predicated on a proper treatment of the factors reliably, repeatedly, safely and in a timely fashion, as described in section 3.7 on page 36. Without improvements to those factors, these changes are not sufficient.
- We recommend that it be clear that aids attracting significant expense not be reasonably expected to be used, in the terms of Regulation 4(4)(d)(ii).
- We recommend that a set of normative examples of aids that may and may not reasonably be expected to be used, in the terms of Regulation 4(4)(d)(ii), be given, in binding form.
- We recommend that Regulation 4(4)(d) be supplemented by a new point: “(iii) is either provided by the NHS or is inexpensively and easily obtainable.”
- We recommend that regulations provide that no aid be assumed to be reasonably expected to be used, in the terms of Regulation 4(4)(d)(ii), without an attempt to determine that it is suitable in the claimant’s individual circumstances.

- We recommend that assessors and Decision Makers, and by extension tribunal members, be cautioned in binding regulation or statutory guidance to carefully consider what benefit may be gained from any particular aid being considered under Regulation 4(4)(d)(ii).
- We recommend that, where an aid is considered under 4(4)(d)(ii), appropriate signposting be provided for assessment and potential provision of that aid.
- We recommend that 4(4)(c)(iii) be clarified, that if descriptor A of any activity is satisfied on less than 50% of days, one of the other descriptors will be chosen.
- We recommend that 4(4)(c)(ii) be redrafted such that, if more than one descriptor is satisfied on more than 50% of days, the descriptor that scores the greatest number of points is selected.
- We recommend that the factors **Reliably, Repeatedly, Safely and In A Timely Fashion** have legal force, for example by being included prominently in regulations and training material for assessors and Decision Makers.
- We recommend that normative examples be provided to aid in the application of the factors “**Reliably, Repeatedly and In a timely fashion**”, and that the Government consult widely on these examples. We do not feel it essential that such a consultation be formal, but it must be open to all interested parties.
- Provided that the factors of “**Reliably, Repeatedly, Safely and In a timely fashion**” are given legislative force, and feature prominently in training, we recommend that they not be mentioned specifically in the activities or descriptors.
- We recommend that a fifth factor be added to supplement “**Reliably, Repeatedly, Safely and In a timely fashion**”; the assessment should also ask what they can do “**Without severe discomfort**”.
- We recommend that assessor training include guidance on the ways that disabled people may think of things, and the terms they might use, as they may not think of things in the same terms used in legislation or official guidance.
- We recommend that the definition of ‘**Safely**’ clearly encompass emotional harm and damage to property.
- We recommend that it be made clear to assessors, Decision Makers and tribunal members that people may perform an activity despite it being unsafe, and that performing the activity is not proof that they can do it **Safely**. Similar arguments hold for the other factors that are to be considered, but **Safety** is the most paramount factor in this respect.
- We recommend that the definition of ‘**Repeatedly**’ clearly refer to the impact on ability to perform other activities on subsequent days as well as the same day.
- We recommend that the definition of ‘**Repeatedly**’ clearly consider the impact on all reasonable activities of a person’s day-to-day life, not only those activities considered in the PIP assessment.

- We recommend that regulations make it explicitly clear that the activity must be able to be performed **Reliably, Repeatedly, Safely and In a timely fashion**, as well as any other factors that may be considered, all at the same time.
- We recommend that point (c) in the definition of “aid or appliance” be made clear, and then further consulted upon.
- We recommend that point (a) in the definition of “aid or appliance” be extended by the inclusion of ‘maintain’ in the list of properties in relation to function.
- We recommend that the definition of ‘cook’ be amended to specify that the food is initially raw, and is heated to the point of being safe to eat.
- We recommend that, if the phrase “overwhelming psychological distress” is to be used, it not be defined by reference to the forms of condition or impairment that it derives from; if a restrictive definition is to be used, it should be made more inclusive, for example by the addition of the phrase “or the significant psychological impact of a physical impairment or disfigurement”.
- We recommend that, if a reference to an “enduring mental health condition” is retained, it have its meaning made explicit.
- We recommend that the definition of ‘supervision’ encompass safety in a broad sense, extending beyond prevention of physical harm to include harm, without limitation, to mental health, emotional state, reputation and property; in all senses, it should extend to the safety of other persons (and their property) as well as the claimant.
- We recommend that the definition of “support dog” be made broader, and the more usual term “assistance dog” used instead. Notwithstanding other recommendations, it would be possible to define in terms of the fact the dog allows the person to travel otherwise unaccompanied. Alternatively, it could be defined by the substitution of the word ‘specific’ for the word ‘sensory’ in the current definition.
- We recommend that support or assistance dogs not be specified in individual activities, but that regulation provide for a general treatment of assistance dogs.
- We recommend, provided that aids are considered in Activity 10, that assistance dogs be considered in all activities based on the form of support they fulfil the need for; where they perform broadly equivalently to an aid, they should be considered an aid, and where they fulfil the need for human supervision or assistance, they should be considered as such.
- We recommend that the Department publish and consult informally on guidance as to what therapy would be considered ‘long-term’.
- We recommend that Regulation 5(1)(b) be removed.
- We recommend that the period of time specified in Regulation 5(2) be specified to take account of public holidays.
- We recommend that Regulation 5(2) specify “such longer period as is reasonable”, so this may be determined other than by the Secretary of State; for example, when appealing a

decision to stop benefit due to information not being provided, a tribunal may then determine whether the longer period was, in fact, reasonable. It would be fair to require that a claimant notify the requesting party of the delay, however.

- We recommend that Regulation 6 specify that a negative determination only be made after efforts to contact the claimant have failed, or the claimant does not provide the information even after this contact.
- We recommend that at least Regulation 6, and preferably also Regulation 5(2), be clarified to only apply to information requested from the claimant.
- We recommend the Government take every regulatory, contractual and advisory opportunity to ensure that problems reported with the WCA, particularly those recognised by the Harrington Reviews, do not occur in the PIP assessments. We specifically caution that the assessment is liable to act as a 'snapshot' even where this is explicitly not intended.
- We recommend that assessors be cautioned against inferring functional capability without checking their conclusions with the claimant, and giving them the opportunity to challenge their inference.
- We recommend that contracts and training for assessors and contractors clearly define their position as balanced and independent, there to ensure that claimants get the right level of benefit, as opposed to attempting to deny benefits. This must also be followed-through in practice as well as on paper.
- We recommend that any software used to support the assessment be person-focussed on the claimant, rather than any convenient structure that might allow assessors to avoid going into detail and understanding the individual needs of each claimant.
- We recommend that the Department ensure that assessors respect claimants' choices to use, or not use, any given aid.
- We recommend that the Department ensure that assessors respect claimants' right to choose or refuse treatment, and ensure through regulation that benefits will not generally be affected by claimants' choices regarding treatment (notwithstanding the effects of that treatment on the claimant's condition).
- We recommend that the Department ensure, through regulation, contracts and guidance, that assessors must note all caveats given by claimants, and justify any decision to disregard them. This must be part of the formal report filed for each assessment.
- We recommend that guidance and training materials for assessors make it clear that they cannot rule out any pain, nausea, vertigo, fatigue or other discomfort reported by a claimant. If they are given any guidance on observable signs of discomfort, it must be accompanied by a clear reminder that these are not conclusive, and in particular that their absence should not be taken to demonstrate the absence of discomfort.
- We recommend that the Government ensure that assessors are cautioned against any over-generalisation, and the limitations of observations made during the face-to-face assessment.
- We recommend that the Department re-examine the points awarded for the use of aids, with a view to increasing them in many cases.

- **We recommend the Department examine different classes of aids that might be used in each activity, to allow for more points to be awarded for aids that represent greater barriers or expense.**
- **We recommend that the Government examine conditions that lead to a reasonable presumption of a certain minimum level of PIP entitlement. Examples of levels we consider may be appropriate may be found in table 4.1 on page 49. These levels should be awarded pending full assessment, and if the total benefit awarded after assessment is less than the presumed level, no overpayment should be deemed to have occurred.**
- **We also recommend that the Government examine conditions that so clearly lead to Enhanced awards that a full assessment would be wasteful, and instead award based on confirmation of those conditions. We anticipate the number of conditions that would justify this would be small.**
- **We recommend 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

# Answers to Questions

### 3.1 Question 1

The Government consultation asks:

#### **What are your views on the latest draft Daily Living activities?**

In the explanatory note we set out revised proposals for the activities relating to entitlement to the Daily Living component (activities 1-9). These include three new activities: Communicating, Engaging socially and Making financial decisions. We would welcome your views on the activities. Are the changes and the new activities an improvement? Do you think we need to make any further changes?

There is considerable feeling that these criteria are not simple or straightforward. 88.1% of respondents disagreed with the statements “the assessment criteria for Daily Living in PIP are easy to understand and apply”, 50.0% disagreeing strongly; only 2.0% agreed with the statement.

#### **3.1.1 Significant Issues Not Captured By The Second Draft Criteria**

We have found two areas that our data leads us to believe are problems experienced by many disabled people, but that are not captured by the second draft PIP criteria, and are not closely enough related to existing activities to be addressed by a simple adjustment of any activity. They are as follows:

1. A need for general supervision, such as in people at risk of self-harm or being unaware of hazards.
2. A need for support in waking up and getting up or going to bed and going to sleep.

There is also the issue of night-time needs that are not covered by any of the existing descriptors, such as night-time supervision or needing to be turned during the night. However, we believe that some of these issues can be seen as part of those listed above, and those that are not will overwhelmingly occur only in individuals who score highly in several other activities.

We understand that the Department will be reluctant to add any new activities. However, both of these areas are of vital importance. General supervision is a matter of personal safety, while sleeping and

waking at appropriate times is vital to maintenance of health and engagement in society. Furthermore, both are expensive to provide.

Consider the case of a person with significant mental health problems leading to self-harm and suicidal ideation. The general approach is that people with such conditions are supported in the community wherever possible. It is unclear if a general need for supervision will fit the descriptors for supervision in specific activities; even if they do, the points gained by supervision and help with medications (to prevent overdose) are only 7 points: Activity 1 descriptor E (4 points), Activity 3 descriptor B (1 point) and Activity 4 descriptor E (2 points). This is not enough to give entitlement to even the Standard rate of the Daily Living component. We recognise that scoring points for general supervision under Daily Living may lead to double scoring; this could be alleviated by clarifying the use of supervision descriptors in other Daily Living activities as only applying to supervision above and beyond what a claimant requires generally. **We recommend the addition of a new activity, or some form of non-functional scoring, based on the need for general supervision. A possible set of descriptors for this activity is shown in table 3.1. Of note is that we recommend that the requirement for continual or near-continual monitoring throughout either the day or the night give entitlement to the Standard rate of the Daily Living component, and such monitoring being required throughout both day and night give entitlement to the Enhanced rate of the Daily Living component.**

Table 3.1: Suggested descriptors related to a need for general supervision

A	Requires no supervision beyond that required for specific activities in this assessment	0
B	Requires monitoring, involving the physical presence of another person, beyond supervision required for specific activities in this assessment, at least once a day to ensure safety	2
C	Requires monitoring, involving the physical presence of another person, beyond supervision required for specific activities in this assessment, repeatedly during the day	4
D	Requires regular monitoring involving the physical presence of another person, beyond supervision required for specific activities in this assessment, regularly and frequently throughout the day <b>or</b> night	8
E	Requires regular monitoring involving the physical presence of another person, beyond supervision required for specific activities in this assessment, regularly and frequently throughout both the day <b>and</b> night	12

Sleeping restfully and waking up at an appropriate time are vital both to ongoing health and participation in society, so support for this should be provided under Personal Independence Payments. Such support is considered under Disability Living Allowance as part of the consideration as to whether support is needed repeatedly during or throughout the day or repeatedly during the night. No such consideration is present in PIP.

Particular concern has been raised by some respondents with narcolepsy, a rare and commonly misunderstood sleep disorder which can cause a wide range of difficult symptoms. While the most popularly recognised symptom of narcolepsy is sudden onset sleep attacks during waking hours, technically known as “excessive daytime sleepiness”, a number of other symptoms exist and are catalogued in such sources as *The International Classification of Sleep Disorders*[5]. While some of these may engage other activities, we do not feel that this could be relied upon in the current draft, and respondents to our survey indicated that they felt that their difficulties are not well-recognised in the second draft criteria. While they, with many other groups, would also benefit from recognition of a need for general supervision, there

are some key problems that persist even in those for whom the sleep attacks are well-controlled. One particular problem that is particularly relevant to this current point is known as “confusional arousals”, or the more poetically descriptive “excessive sleep inertia”. This describes the phenomenon of significantly impaired consciousness on waking, and a tendency to return to sleep. This can be addressed in a number of ways, none of which could be assumed to be without cost. One is the use of a large number of separate alarm clocks in different places; some sufferers find that the exercise of finding all of the alarms to deactivate them is sufficient to wake them to the point where they can stay awake with the aid of their medication. In this case, the large collection of alarms requires suitable devices to be bought and maintained should be considered an aid. Another technique involves the intervention of another person, to sit with them while they gradually wake up sufficiently to get up and function; this person must often repeatedly wake them.

Other sleep disorders may allow the sufferer to wake and go to sleep naturally and comfortably, but at the cost of having a precessing out-of-phase sleep cycle when compared to the population at large. These people face increased costs and barriers to participation due to sometimes unpredictable variations in their sleep–wake patterns leaving them sometimes awake when others are asleep, and vice-versa. In some cases the choice is between medication that may not be very effective, with side effects and consequent costs and disruptions, leaving them experiencing more classical sleep disorder symptoms like excessive daytime sleepiness and insomnia, or comfortably following an alternate, sometimes varying, sleep–wake-cycle. Given the essential premise of freedom of consent in medical treatment, neither of these should be treated fundamentally more favourably than the other in the PIP assessment.

Sleep disorders provide a strong illustrative example of help needed to wake up, or the disruptive effects, but there are many instances where a person needs prompting or assistance to sleep in appropriate manner, time and place. People may need prompting to go to bed, or may need reassurance or other assistance to fall asleep. People may need physical assistance to get in and out of bed. They may need equipment or assistance to get into a suitable position to sleep, and equipment for these purposes is expensive and requires servicing (see Appendix A on page 54 for examples). We do not believe that any of these factors are currently considered in the current draft.

There are various possibilities to add consideration of these factors to the PIP assessment, though we believe that these fall into two broad categories. Either an additional activity is added, such as “sleeping and waking”, or another activity that has a clear connection to these areas is expanded in scope to cover them, as may be argued for Activity 6, “dressing and undressing”. We believe that either of these approaches can be workable, and urge the Department to do one or the other. **We recommend that either: a further activity be added to encompass sleeping and waking; or another activity, such as Activity 6, be expanded in scope to encompass these areas.**

### **3.1.2 Activity 1**

We have noted several concerns about this activity. As is generally accepted, a healthy balanced diet, with fresh fruit and vegetables, is key to maintaining and improving health. We are pleased to report that our concerns are principally technical. However, there are several concerns that are more general, from which we make no specific recommendation.

Keeping a kitchen hygienic is essential to the preparation of healthy meals. There is considerable feeling that this should be reflected in this activity. We have no specific recommendation as to how this should be achieved.

We note that drink is mentioned only in the title of this activity, and in descriptor G. We are concerned that a person who is unable to prepare and cook a simple meal, even with assistance, may be denied the full 8 points if they are able to get themselves a glass of water. It currently seems that having a problem only with pouring a drink does not lead to the award of any points, but being able to do so may result in a reduced points score. **We recommend that all references to drinks be removed from Activity 1.**

There is considerable concern that assessors will base their assessment of this activity on some highly abstracted typical basic meal. This is an understandable strategy, one that may be necessary to enable objective assessment; the components of food preparation listed in the explanatory notes are a good beginning to a description of such a typical basic meal. However, this risks being unfair to those with specific dietary requirements that require different or additional preparatory steps that are not included in the abstract typical basic meal. We feel it is essential that such differences are accounted for. **We recommend that any preparatory steps needed in preparing meals for a claimant, for example due to special dietary requirements, be considered as part of this activity.**

We consider it vital that the actions that are envisaged as necessary to produce a basic meal are considered part of this activity and given legal force. This includes the elements listed in the explanatory notes: opening packaging (including using a tin opener), peeling and chopping vegetables, serving food, and cooking or heating on a hob or using a microwave. Notwithstanding any additions that may be made to this list, we feel that fair and consistent assessments and appeal tribunals require the elements of this activity to be specified in regulations, or elsewhere with statutory force. **We recommend that the elements of preparing and cooking a meal, for the purposes of Activity 1, be specified in regulations or otherwise given statutory force.**

There is concern that the assessment of this activity, as currently specified, will not be sufficiently end-to-end. Before food can be prepared, it must be taken out from storage in a cupboard or fridge; similarly, cooking utensils must be got out and placed on the work surface and cooker hob. One commenter states:

“ Sitting on my perching stool, after my carer has gotten a vegetable for me I can chop it and cook it on the hob, but I would need help to get a pan from a low cupboard. If I wanted to roast it in the oven instead I would need help to get a roasting tin from a low cupboard and then help to put it into our oven which is below waist height. ”

This is a particular concern with consideration of the use of aids, as many report that Decision Makers already assume that a perching stool solves more problems than they generally do:

“ All the perch allows me is access to the taps to wash dishes, the boards if I'm well enough to help prepare food which others have to put onto the boards for me as I can't access them. ”

Assessing a person based on what they can do with the ingredients and tools neatly got out for them is not a realistic assessment, and does not accurately reflect the barriers and costs involved. **We recommend that the elements of Activity 1 be sufficiently well specified to realistically represent preparation of a meal from start to finish, including retrieving ingredients and equipment from storage.**

Several separate problems have been suggested with the fact that the entire activity is assumed to take place at or above waist height. The first is that this is arbitrary, specified only to avoid awarding points on

the basis of difficulty bending; this is a particularly appropriate criticism given that a difficulty bending is a limiting issue for many people, but does not appear to be recognised anywhere in the assessment. Another is that the meaning is simply unclear, best summarised in the question "waist high on who?" Does the assessment assume that everyone, regardless of height, wheelchair use or any other factor, has a cooker and work surfaces at waist height? **We recommend that a difficulty using a typical 'waist height' work surface or hob be considered in the assessment of Activity 1. A suitably adapted kitchen and appliances may be considered an aid, but should be given greater consideration than aids in general, as they represent considerable cost.**

Similarly, the restriction of cooking method to a hob seems arbitrary, and when taken with the assumption of waist-level preparation reinforces the intention of avoiding any consideration of difficulty bending. Oven cooking is often more suitable for people with certain impairments, as it generally requires less stirring and checking of cooking progress. **We recommend that the Department strongly consider awarding points in Activity 1, perhaps the same as awarded for microwave use, for being unable to use either a hob or an oven. It would not be reasonable to assume that the oven were at or above waist height.**

Considering the question of waist height together with the question of end-to-end preparation of a meal, it becomes particularly impossible to assume all parts of this activity take place at or above waist height. **We recommend that the Government accept that a difficulty bending should potentially result in awarding some points for Activity 1, to represent the rarity of a kitchen in which all utensils and foods are stored at or above waist height. Where a claimant has such a kitchen, deliberately arranged in order to avoid bending, we recommend that this be considered an aid.**

We are concerned that the separation of the preparation and consumption of a meal into two activities may lead to the assessment ignoring the fact that these two events generally occur in quick succession. People suffering from various impairments may be able to cook food once a day, without considerable impact on the day as a whole, but be too fatigued, nauseous or similar to then eat the food they prepared. **We recommend that it be made particularly clear that a person must be able to complete this activity and then be in a fit state to consume the meal.**

There is widespread concern that descriptor C will be applied where a person can heat up pre-prepared food, such as a ready-meal, in a microwave oven:

“ Yes cooking has become re heating, but you cant live on microwave foods, it would cost to much money and make you sicker, cooking needs to include using an oven and grill as well as hob and microwave ”

We do not believe that this is the intent of this activity, but we do not feel it is clear enough to be sure that it will not be applied in this way. While we understand that the intent in the phrasing of this descriptor may have been to be clear that it is related only to ability to cook, and not to prepare, we understand the concern that it may lead to problematic decisions. As there are no lower-scoring descriptors related to a difficulty preparing the food to be cooked, there seems little danger is specifying that the descriptor only applies if the meal can be prepared. **We recommend that Activity 1 descriptor C be clarified, such that it is clear that the simple meal must still be prepared from fresh ingredients.**

We are concerned that assessment may become awkward where a claimant reports that they use a cooking method other than hob or microwave oven, or conventional oven if our recommendations are accepted. A claimant may use an electric steamer, a rice cooker, or a slow cooker, for instance, as

an adaptation against difficulties they have preparing and cooking food in a more conventional way. An assessor may have difficulty determining how a claimant may be able to cook a meal by any method specified in the assessment, and claimants may disagree with this determination if it is made without clear consultation with them. **We recommend that the Department give consideration to how assessors may handle the situation of claimants reporting the use of other cooking methods, and instruct assessors to work with the claimant to realistically and fairly determine their ability to use the specified cooking methods.**

### 3.1.3 Activity 2

There is concern that the simple description of “therapeutic sources” of nutrition is overly simplistic, and does not capture the variation in different sorts of therapeutic sources leading to different barriers, and different levels of increased cost. **We recommend that the Department investigate the different levels of barrier and costs associated with different therapeutic sources of nutrition, and differentiate between them in the descriptors of Activity 2.**

We note that the explanatory notes for this activity show that eating is considered to include chewing and swallowing. Where someone is unable to swallow, it may be assumed that they need a therapeutic source. However, where someone is unable to chew sufficiently, this does not seem to be considered in this activity, and as Activity 1 does not currently ensure that the meal prepared is suitable for the claimant’s dietary requirements, this need is not clearly reflected anywhere in the assessment. **We recommend that a need for puréed food, or food that otherwise does not require chewing, be reflected in either Activity 1 or Activity 2. We recognise that additional points need not be awarded where a claimant is capable of preparing their own food in this manner without an aid or appliance.**

There is concern that descriptor D, “needs prompting to take nutrition”, is unclear. This could be taken to refer to a situation where a claimant will stop eating a meal before they have finished, if they are not reminded or encouraged to continue, or it could be taken to refer to a situation where a claimant will take no action to obtain suitable nutrition unless reminded or encouraged; we believe it should be engaged in both instances. This would not lead to double-scoring with Activity 1, as a person needing encouragement to “eat something” is distinct from that person needing encouragement to “cook a proper meal”. One of the ways that an inability to prepare and cook a meal is resolved, at additional expense, is to use pre-prepared or take-away meals. Where a claimant eats such food due to an inability to prepare and cook a meal, they should be awarded points if they will forget to obtain such food, or otherwise neglect to do so, without prompting by another person. Where a person needs such prompting, and does not receive it, they are likely to either take insufficient nutrition, or to satisfy hunger with ‘junk foods’, such as crisps. Either of these will be likely to lead to worsening health conditions. **We recommend at Activity 2 descriptor D be clarified to refer to both prompting during the meal to continue eating, and prompting to take action to obtain a meal.**

Even if the preceding recommendation is accepted, we are concerned that a claimant eating ‘junk food’, such as crisps, without prompting will be taken as evidence that they do not require prompting to take nutrition. This risks withdrawing support that would help such claimants to move to a healthier diet involving proper meals. **We recommend that Activity 2 be clarified to refer to meals, and exclude snacks, particularly highly convenient and unhealthy snacks.**

### 3.1.4 Activity 3

We recognise and appreciate the inclusion of medications that are recommended as well as prescribed. We are concerned, however, that claimants may be expected to prove what medications have been recommended; pharmacists do not routinely keep records of such recommendations, and even doctors do not reliably record all recommendations. **We recommend that the Department consider what evidence they will expect for medication recommendations. This concern must not, however, be allowed to prevent consideration of recommended medications; rather, necessary methods and procedures should be developed to allow for the greatest inclusion of recommended medications.**

It is unclear if monitoring a health condition includes informal, ongoing monitoring, such as helping a person be aware of their moods to manage mental health. Such monitoring can be of vital importance to people with mental health conditions including depression and bi-polar disorders. **We recommend that 'monitoring a health condition' be defined so as to clearly include both formal monitoring of signs and symptoms and informal, ongoing monitoring.**

It seems appropriate that more points are awarded the more time is needed for assistance with therapy. However, some health conditions require in-depth monitoring that may consume significant amounts of time, taking readings like peak flow, blood pressure, blood glucose, and so forth. **We recommend that Activity 3 descriptors D, E and F include monitoring a health condition as well as therapy; it may be appropriate in this case to exclude 'ongoing' monitoring, such as helping a person be aware of their moods to manage mental health, from descriptors D, E and F only, but not descriptor B.**

We feel this activity is a good opportunity to capture costs and barriers associated with the management of pain and discomfort by means other than medication and therapies. A wide range of health conditions can lead to pain and discomfort best managed, in full or in part, by the use of specialised equipment or furniture: chairs, mattresses and other equipment specially designed or adapted to help manage chronic health conditions, for example by relieving pressure on joints or providing postural support to relieve pain or breathlessness. These items are considerably more expensive than their everyday counterparts, and need servicing or replacement to maintain their effectiveness. They can be sufficiently effective, however, to reduce or eliminate the need for pain-relieving medication, and can play a role in reducing deterioration of underlying conditions, thus avoiding or delaying medical interventions that may include surgery and hospitalisation. This equipment is frequently neither prescribed nor formally assessed, but is nevertheless a significant enabling factor in the lives of disabled people. An example of such equipment and some of the costs associated with it can be found in Appendix A on page 54. **We recommend that Activity 3 be amended to encompass the need for special equipment or furniture to manage pain and reduce the likelihood or speed of deterioration in underlying conditions.**

### 3.1.5 Activity 4

The definition of 'bathe' is a source of great alarm. As it stands, the definition would appear to include a flannel wash, which would be a most unsatisfactory form of cleaning to a great many people, and not something that many people would even know whether they could do. The naive understanding of 'bathe' indicated from our sources would include a bath, or a shower, but not a flannel wash:

“

Bathe seems to lend itself to a all over wash not just the top, I automatically think bath, what they are describing is more like an upper body wash. . .

”

“

It is insulting that “bathing is defined as being able to wash one’s torso”

”

Indeed, while the explanatory notes indicate that this activity has been simplified from the initial draft, removing the distinction between washing and bathing, it seems that this has been done by taking the term ‘bathing’ but the definition that had been applied to washing:

“

The Second Draft Assessment Criteria definitions are stricter than the first draft regulations: for instance, the definition in the latter of ‘Bathing’ is “Take a bath or shower” whereas in the second draft it is “Clean face, hands, underarms and torso” which is totally inadequate and contrary to common sense and all dictionary definitions. ”

In addition, cleanliness to the standard that is socially expected is vital for social engagement and full participation in society:

“

Anyone who could only clean their upper half are also potentially unable to access the community or employment due to the smell and negative feelings arising from being dirty, increasing isolation and creating unfair barriers. ”

It may be appropriate to consider a flannel wash where that is the preferred method of personal cleaning for a claimant, but not in cases where a person habitually baths or showers. We were pleased to hear the Government’s assurances that PIP assessments will not include the ‘imaginary wheelchair test’ that has become notorious in the Work Capability Assessment; this definition of bathe runs the risk of creating an ‘imaginary flannel test’. Allowing any reasonable choice of bathing method will also be maximally culturally sensitive, without having to specify a criterion of cultural appropriateness. **We recommend that ability to bathe be assessed based on bath or shower, or such other reasonable method as the claimant may prefer.**

The specification of cleaning the ‘torso’ is a source of considerable concern and confusion. The Department’s own easy-read material puts this as the “top half”, which we believe most would understand as meaning above the waist. However, definitions from anatomical textbooks and the Oxford English Dictionary consider the torso as the body aside from the limbs and head; the OED gives *torso* as “the trunk of the human body”, with *trunk* in turn given as a person’s ...body apart from the limbs and head”[6]. This definition would certainly include the groin area. Given the tension in meaning between the documents produced the Department, however, we feel the intent is unclear and should be clarified. We feel that it is important the more inclusive definition be used, as proper cleanliness of the genital area is vital in preventing a range of health conditions that would prove disruptive the life of the individual and put greater burden on health services. **We recommend that ‘torso’, in the definition of ‘bathe’, be clarified to the inclusive definition used in anatomy.**

There is significant unhappiness with the definition of ‘bathe’ excluding the limbs, and particular concern regarding the lower extremities. There are many health conditions, particularly those putting someone at risk of circulatory problems or peripheral neuropathy, in which regular care of the feet is very important. Not only is bathing is a key opportunity to examine the feet, but cleanliness of the feet is vital to prevent problems. Both the NHS[7] and the Society of Chiropodists and Podiatrists[8]



recommend the regular cleaning of feet. In cases of immune compromise, cleanliness of the entire body is felt to be crucial:

“ bathing all over is really important for those people with co-morbidities: if say someone has immune issues, and also mobility issues, then infections can become really serious. ”

We are also concerned that this definition will set a precedent, and that social services may follow its example in terms of care offered. **We recommend that the activity of bathing also incorporate the cleaning of the entire body, including limbs and extremities.**

Concern has been raised over the exclusion of drying from the bathing activity. Prevention of a range of health conditions, such as fungal skin infections, requires thorough drying of the body after cleaning, particularly in closed areas of the body (such as between the toes, the genital area). These conditions are both more likely to occur and more likely to lead to complications in people with a range of chronic illnesses, such as diabetes. As previously stated, the NHS[7] and Society of Chiropractors and Podiatrists[8] recommend the regular cleaning of the feet and reinforce the need for thorough drying between the toes. Advice from NHS Direct[9] also makes clear the importance of cleaning *and drying* the groin area to manage and prevent infections in that area. **We recommend that the activity of bathing clearly include thorough drying.**

A number of additional elements have been suggested for the activity of grooming. Many felt that it should include such other, normal grooming activities as most people take for granted, such as the application of make-up and wearing of jewellery. While there is a strong moral point that disabled people should not be expected to accept a lower standard of life, and exclusion from such normal, every day things, we understand that for a benefit targeted at those with the greatest needs, and an assessment acting as a proxy for the increased costs of disability, the full range of activities required for participation in society may not be represented. However, there are some elements that are necessary to a basic standard of living and maintenance of health that should be included in grooming. **We recommend that the activity of grooming be amended to include the cutting of fingernails and toenails, shaving, and the washing of hands and face.**

### 3.1.6 Activity 5

There is widespread concern among those with experience of incontinence that this activity does not accurately represent the additional costs of incontinence, including a greater amount of cleaning of clothes and bedding, the costs of pads and greater risks of health complications. The second draft of the PIP assessment seems entirely ignorant of the problems related to incontinence. We have included a submission from an individual with double incontinence, including a stoma, as Appendix C on page 58.

We understand that the changing of clothes following incontinence is excluded from this activity because it may lead to double scoring with Activity 6. This misunderstands the difference between normal dressing and undressing, and the undressing and cleaning required following incontinence. Where a person requires greater help to change clothing following incontinence than they do for normal dressing and undressing, this should be recognised in this activity. **We recommend that help required for changing clothes be included in the consideration of managing incontinence, where that assistance is greater than that required in normal dressing and undressing.**

In addition, changing of bedclothes is excluded, even though this may be needed far more frequently than people normally change bedding:

“ It also does not allow for somebody being there to actually change the bedding when messed up - which I need. I have spent many a night on my own in a bed with no bedding on it - even ended up on my sofa. ”

Clearly, this is not what anyone would consider a reasonable standard of care or independent living. **We recommend that help required to change bedding be included in the consideration of managing incontinence, at least where it occurs frequently.**

Incontinence in itself leads to considerable extra costs. Given that this assessment is intended to serve as a proxy for additional costs, this should be considered. The awarding of no points for incontinence where a claimant can manage it themselves is thus contrary to the purposes of the PIP assessment. Some of this cost would be recognised if such basic incontinence aids as pads were recognised as aids; the ongoing costs of these are greater than many of the example aids listed in the explanatory notes, however. Furthermore, it is likely that the vast majority of incontinent individuals use such aids, making explicit recognition of them redundant. **We recommend that an additional descriptor be added to Activity 5, awarding points for incontinence where a claimant can manage it themselves. This descriptor could be phrased as “Can manage incontinence unaided or with the use of an aid or appliance”. The words “or incontinence” would then be removed from descriptor A and descriptor B. We suggest that the new descriptor score 4 points.**

The Government has indicated that they consider this activity to encompass the management of menstruation. However, we are aware that some women experience difficulties managing menstruation without having equivalent difficulties with toilet needs; for example, they may suffer a psychological difficulty with managing menstruation. **We recommend that Activity 5 be clarified to explicitly encompass the management of menstruation.**

It seems obvious that sensible, hygienic management of toilet needs or incontinence will include the washing of hands. **We recommend that Activity 5 be clarified to include washing hands.**

Concern has been expressed that this activity does not consider difficulties getting to the toilet:

“ There are no descriptors to allow for actually getting to the toilet, in my case I need help especially at night to get out of bed quickly enough to actually get to the toilet to help me from messing myself in my bed. ”

While problems getting to the toilet may also score points in Activity 11, that activity scores points of the Mobility component, which is intended to support mobility outside the home. Furthermore, if ability to get to the toilet were assessed with aids, it would not necessarily follow that every claimant scoring points in Activity 11 would score points in Activity 5 on the same grounds; a person who is sufficiently mobile to get to the toilet with an aid would likely score points for needing that aid in Activity 11, but could be considered able to reach the toilet for Activity 5. A further safeguard against unintended automatic scoring lies in the fact that the distance from any point in the home to the toilet is generally shorter than the distances considered in Activity 11; only the most profoundly immobile claimants would be able to claim a need for assistance with toilet needs on the grounds of mobility. **We recommend that Activity 5 consider getting to the toilet, using any aids normally used or that could reasonably be expected to be used, as an element of managing toilet needs.**

### 3.1.7 Activity 6

Impairments may require shoes of specialised design to allow them to be placed on the foot or securely fastened to account for joint abnormalities, variations in shape or size, or altered gait. For example, below-knee supports/calipers are normally only used with adapted laced shoes, as slip-ons provide insufficient support to the foot, ankle and caliper. Even where specialised shoes or appliances are not needed, disability may lead to more expensive footwear being needed, although that footwear may be of a sort that is also worn by unimpaired people out of choice:

“ I can’t buy cheap shoes because they don’t fit well, and wear out even more quickly I have to wear sturdy, supportive shoes or shoes with a flexible thin sole designed to allow good proprioceptive feedback. ”

Furthermore, the Society of Chiropractors and Podiatrists recommends against slip-on shoes in general, saying “should have lace-up fastenings to keep the feet firmly in place” for those who walk much, and more generally that fastenings should be “laces or straps with buckles or touch fastenings help to hold the foot securely within the shoe”[10]. **We recommend that a clear list of examples be given, without limitation, of the sorts of adapted clothing that may be considered in Activity 6, and that adapted footwear be included. The assumption of slip-on shoes in this activity should be replaced with a requirement for suitable footwear, taking into account both general advice on footwear and any advice given specifically to the claimant by a healthcare professional.**

The meaning of “assistance to select appropriate clothing” is unclear. Assistance is defined as physical intervention. There is concern that this will not be considered in an appropriately inclusive manner. Illustrated examples in the official easy-read consultation materials indicate that a person with a severe visual impairment may be considered to need assistance to select clothing; we agree that this is appropriate. We also feel that it would be appropriate for such consideration to be extended to people who are physically or psychologically incapable of retrieving their clothes from whatever storage they use, particularly in cases where they are nonetheless able to put that clothing on for themselves, as described by one commenter:

“ I can get dressed sometimes on my own if carer brings clothes to the bed ”

Thus a person suffering from severe fatigue, which may occur in conditions as diverse as ME, fibromyalgia or Multiple Sclerosis, may be capable of dressing once they have their clothes, but would be incapable of retrieving their clothes, especially of then dressing themselves afterwards. We strongly believe that it would be appropriate for such people to be considered to satisfy descriptor C of this activity. If they do not, it is likely that this difficulty will instead be established on appeal to satisfy a higher-scoring descriptor. **We recommend that Activity 6 descriptor C point (ii) be clarified to include people who need physical assistance to retrieve their clothes, though they may be capable of choosing clothes in intellectual, cognitive and sensory terms.**

### 3.1.8 Activity 7

In order to act on any communication, be it written or verbal, it is not only vital to read or hear it, and understand it, but also to remember it. This is particularly essential with regards to safety information. Many conditions lead to a sufficient degree of cognitive dysfunction to make this problematic; while the claimant may hear and understand a message, they will not necessarily remember it clearly enough for the communication to be said to have been effective. **We recommend that remembering a communication well enough to act on it also be a consideration in Activity 7.**

Many disabled people are physically unable to write. However this is not covered under communicating nor under making financial decisions. This was a source of great concern:

“ There is no descriptor for being unable to express simple or complex written communication, a vital task for filling in DWP forms, social communication, bill paying, and many other purposes. This is a serious oversight. ”

Writing remains an essential task in today's society. While communicating electronically, or with word processed and printed text, is sometimes an option, people still regularly exercise their choice between methods of writing. Indeed, while anyone may choose to spend money to give themselves the ability to write electronically, and print their compositions, for many disabled people this is not choice, but necessity:

“ The RA in my hands means I can't hold a pen long than a few seconds so filling out a form or writing a letter has to typed. I use a laptop because I find the flat keyboard is reduces the stress on my wrists and fingers but they are not cheap. ”

As this contributor indicates, even starting from an assumed position of access to a computer, there can be additional costs in suitably ergonomic equipment; if one is unable to type, these costs grow further with the use of speech-to-text software—beyond the license costs of the software itself, speech-to-text requires a higher specification computer. Even once a computer is in use, many forms, for example, are provided in hard copy and can only be filled in by hand. This can take a long time and cause great discomfort or may need to be done by another person. **We recommend that Activity 7 be modified to encompass the creation of written information as well as the ability to access written information. Descriptor D should be amended to include expression as well as access of written information.**

While the need to express written information is most fundamentally important in relation to financial matters, we consider it a broader point. To avoid double-scoring, however, our recommendations regarding Activity 9 are not intended to give points for difficulty writing within that activity. However, if expressing written communication is not considered within Activity 7, we would see it as included within the scope of our recommendations regarding Activity 9.

### 3.1.9 Activity 8

Disabled people may be limited in social interaction not only by emotional distress or confusion, but by the effects of pain, fatigue and other discomforts. A key factor in socialising for many people with chronic illnesses is knowing that they will be able to rest, change their level of participation, or leave

when they feel the need, and that someone will be available to help them do this. Those who are incontinent may struggle to socialize due to a rational fear of embarrassing leakage or odour. An example from one commenter recalls:

“ There was a case a couple of yrs back which went to 1st tier tribunal, this lady had Crohn's and was refused HRM. She won on appeal, as the tribunal held that even though she was physically capable to walk or run, the fear and anxiety that she would soil herself amounted to her being unable to move. That to me is a perfect example of overwhelming psychological distress. ”

While this refers to consideration of DLA Mobility, it is an indication of the reasonable consideration of distress originating in physical problems. Support in such situations may not meet the definition of social support as given in the draft regulations. **We recommend that Activity 8 descriptor C be clearly extended to cover needing a person present to support the claimant physically or emotionally during social activity, without requiring that they be specially trained. We recommend that Activity 8 descriptor B be clarified to ensure that it encompasses encouragement to face activities that the claimant finds physically debilitating.**

### 3.1.10 Activity 9

While welcoming the Government's decision to broaden the scope of the benefit to include making financial decisions which is a vital part of maintaining independence in our modern society, we note a few serious oversights as well as several concerns brought to our attention by respondents to the wearepartacus website and forums[11, 12]. It is unclear, but a conservative interpretation of this activity seems to exclude obtaining the necessary information to make decisions, and to act on them. The government has the laudable aim of a benefit which will help support disabled people regardless of their diagnosis or disability. It is therefore surprising to us that this activity is designed in such a way that it precludes those people with physical disabilities in favour of those with cognitive ones. Regardless of the underlying reason, being unable to manage one's finances and paperwork has serious repercussions on one's life as expressed by one respondent:

“ As a personal example I am unable to write. I am unable to open my own mail or handle my paperwork. As part of my care package half an hour a week is devoted purely to paperwork. Before this was arranged I was behind on my bills, was late with my benefit forms (unopened) and was receiving unannounced visits from gasmen etc as I had been unable to open letters telling me they were coming. This is currently in part paid for by my DLA through my care contribution. ”

Making financial decisions involves more than simply making the decision itself. One needs to have the information to hand before being able to make the decision. Further tasks are required in order to follow the decision through, ensuring for instance that bills get paid, letters answered, forms returned, tasks which are essential to independent living. A number of physical tasks have to be performed before this can be done. This may include opening mail, handling letters, retrieving relevant paperwork from files, using a simple calculator, filing paperwork, putting letters into envelopes, addressing and stamping envelopes, posting letters or forms, getting money from cashpoints. This list is by no means exhaustive.

A physically disabled person unable to do some or all of the above may need specialist equipment and aids to help them. Some disabled people may require specialist storage systems for their paperwork. Others may require aids to help open post. Others will require aids such as copy holders to hold paperwork in place to read. Some will require extremely expensive aids. For instance someone unable to use a pocket calculator may be obliged to use a laptop or computer even for simple calculations. Many will rely on carers to assist them as observed in the previous example and here:

“ Finanical [*sic*] wise I can make my own decisions but I rely on carer to go to cash point for me, to post bills, to return things to shops, all the kind of mundane stuff thats needs to be done, but since I can make these decisions for myself there is no recognition [*sic*] [in the draft descriptors] that you need someones help to follow these through. ”

This all comes at great extra cost. In addition, those with cognitive dysfunction may use spreadsheets to aid in budgeting, and they and others with a range of cognitive impairments may need to use a calculator. While any person may choose to use such aids, disabled people may *need* to use them, so meeting the cost of them is not an option. While we understand the desire to avoid double-scoring, many of the elements we have described are not encompassed by any other activity. **We recommend that the scope of Activity 9 be clearly extended to encompass retrieving necessary information and resources, and acting on decisions, as well as simply making them. This can be achieved with minimal changes to the descriptors, to encompass aids and assistance as well as prompting.**

Furthermore, given a suitably broad interpretation of safety (as discussed in section 3.7 and section 3.8), it is clear that the need to make financial decisions is rife with opportunities for significant adverse events. **We recommend that the descriptors for Activity 9 also address the need for supervision.**

If our recommendations are followed regarding Activity 7, this activity need not encompass writing. However, if writing is not considered part of communication, it is vital that it be considered as part of financial decision making. Management of finances invariably requires considerable written communication, including, on occasion, writing cheques. **We recommend that, if writing is not to be considered part of Activity 7, that it must be considered part of Activity 9.**

The name of this activity encourages a narrow view of its scope. If any of our recommendations are accepted, it would be appropriate to rename it to reflect the appropriate broad scope. **We recommend that Activity 9 be re-titled ‘Managing finances and handling financial decisions’.**

## 3.2 Question 2

The Government consultation asks:

### **What are your views on the weightings and entitlement thresholds for the Daily Living activities?**

In the explanatory note we set out proposals for the weightings of descriptors in the activities relating to entitlement to the Daily Living component (activities 1–9). In this document we have set out the entitlement thresholds for the benefit. How well do you think they work to distinguish between differing levels of ability in each activity? How well do you think they

work to prioritise individuals on the basis of their overall need? Do you think we need to make any changes to weightings or thresholds?

There was significant concern with the weightings and thresholds for Daily Living. 82.6% of respondents disagreed with the statement "the scores and thresholds for Daily Living are mostly appropriate", 51.5% disagreeing strongly; only 3.8% agreed with the statement.

We consider that it is best to consider the scores for descriptors based on a relatively fixed background of given thresholds. Thus we have considered this question, and Question 4, on the premise that 8 points is the threshold for Standard Rate in both components. We found no disagreement with the idea that, given 8 points is sufficient to award Standard Rate, 12 points would be appropriate for Enhanced Rate. This means, for example, that someone with enough points from one descriptor to be awarded Standard Rate would be awarded Enhanced Rate with only minor additional difficulties. This appropriately reflects the synergistic effect of multiple impairments, or impacts of a single profound impairment in multiple areas of life. **We recommend that the thresholds for both rates of both components, announced in the consultation document as 8 points for Standard Rate and 12 points for Enhanced rate[1], be left unchanged.**

We note that for most of the daily living activities, relatively low scores are allocated for the use of aids or appliances. However, some aids and appliances, such as adapted kitchens (Activity 1) and equipment such as specialist beds, mattresses and armchairs (which we suggest including in Activity 3) incur significant cost and it is appropriate that suitable descriptors and scoring be included to reflect this extra cost. Some claimants will choose to purchase aids and appliances as an alternative to seeking assistance from others, and such claimants should not be penalised for this choice. **We recommend that differentiated descriptors be considered for each activity regarding the use of aids and appliances, given that some are considerably more expensive than others. Options should be examined to identify, for each activity, clear categories of aid and appliance that provide a reasonable proxy for the initial and ongoing costs of different aids and appliances.**

### 3.2.1 Activity 2

There is considerable concern that the use of therapeutic sources of nutrition should attract more points, particularly parenteral nutrition. Total parenteral nutrition currently leads to an automatic award of the Higher rate of the Care component of DLA; this is not without reason. The current draft of PIP assessment, on the other hand, does not lead to any level of Daily Living on the basis of any form of therapeutic nutrition, even if assistance is needed to manage the source, this scoring only 6 points with descriptor E. Most forms of therapeutic nutrition lead to greater risks of infections, complications and failures with the source, leading to more hospital visits and other interventions. This increases costs due to disability due to the need to travel to appointments, car parking fees, and the myriad other costs associated with medical care. **We recommend that Activity 2 descriptor C, needing a therapeutic source, score 4 points, and descriptor E, needing assistance with a therapeutic source, score 8 points.**

### 3.2.2 Activity 3

To appropriately reflect the overriding importance of managing medication and therapy and monitoring a health condition, as well as the need to add descriptors to provide a proxy for the cost of equipment to manage pain and prevent deterioration, we recommend that both descriptors and scoring be significantly

adjusted for this activity, as explained in section 3.1.4 on page 18. The need for regular, frequent monitoring, for example of blood sugar, blood pressure etc should be reflected in the higher scoring descriptors, in addition to assistance with therapy, and should be scored accordingly.

This activity is a particularly obvious case of a common flaw in the second draft assessment criteria; while considerable acknowledgement is given to achieving a proxy for the costs of needing help from another person, there are many cases where the costs of aids are not sufficiently recognised, a point elaborated on in section 4.3 on page 47. An illustrative and true example of these costs related to this activity is given in Appendix A on page 54. **We recommend that, given the huge costs of acquiring and maintaining some aids used to manage symptoms, slow deterioration and promote recovery, there be descriptors added to Activity 3 that potentially score up to 8 points, to enable the Standard rate of Daily Living to be awarded to those with these high costs to meet.**

### 3.2.3 Activity 5

As explained in section 3.1.6 on page 20, there are considerable costs associated with managing incontinence, even where a person can manage this themselves; again, the costs of aids, especially consumables, are given substantially less recognition than help required from another person, as explored in section 4.3 on page 47. As described above, **we recommend that an additional descriptor be added to Activity 5, awarding points for incontinence where a claimant can manage it themselves. This descriptor could be phrased as "Can manage incontinence unaided or with the use of an aid or appliance". The words "or incontinence" would then be removed from descriptor A and descriptor B. We suggest that the new descriptor score 4 points.**

### 3.2.4 Activity 7

The principal problems with Activity 7 relate to the wording of the descriptors, which need to be expanded to include producing as well as accessing written information. However, we consider it incorrect that descriptor C, 'Needs to use an aid or appliance to express or understand verbal communication' scores only 2 points. Since hearing aids and communication aids such as voice synthesisers incur greater cost than low vision aids which are considered in descriptor B, descriptor C should score more points. **We recommend that Activity 7 descriptor C score 4 points, to reflect the generally higher costs of hearing aids and voice synthesisers when compared to low vision aids.** A superior, though more complex, approach may be to delineate between these two scores based on characteristics of aids other than the impairment they are designed to support. This approach is expanded upon in section 4.3 on page 47.

### 3.2.5 Activity 9

In addition to the need for significant changes to descriptors, as explained above in section 3.1.10 on page 24, we believe that the scoring for this activity should reflect the fact that the inability to manage money and make financial decisions can result in exploitation leading to significant harm. **We recommend that the highest descriptor(s) for Activity 9 attract a score of 8, enabling a claimant who only has needs in this area to qualify for the Standard rate of the Daily Living component on the basis of this activity alone.**



### 3.3 Question 3

The Government consultation asks:

#### **What are your views on the latest draft Mobility activities?**

In the explanatory note we set out revised proposals for the activities relating to entitlement to the Mobility component (activities 10–11). Are the changes an improvement? Do you think we need to make any further changes?

We have significant concern about both of the Mobility activities. They are not clear and easy to apply; 85.9% of survey respondents disagreed with the statement “the assessment criteria for Mobility in PIP are easy to understand and apply”, 52.3% strongly. This contrasts with 2.32% agreeing with the statement. There are gaps in the recognition of significantly increased costs and significant barriers to participation. We address these issues for each activity separately.

#### 3.3.1 Activity 10

There are great concerns over the conception behind the “overwhelming psychological distress” descriptors. Treating limitations differently depending on their origin is, as the Government has consistently pointed out, counter to the principles of PIP. There is also uncertainty over how high a bar it is setting. The fact it is required to be a limiting factor for “all journeys” does not capture well the complexities of conditions such as agoraphobia, where a number of factors alter the difficulty of leaving one’s home. However, we can see a valid distinction between the functional limitations implied by descriptor B when compared with descriptor C, in that descriptor C seems intended to imply a need to be accompanied, while descriptor B may only require encouragement or persuasion to set out in the first place. **We recommend altering the distinction between descriptors in Activity 10 to those who require supervision, ongoing prompting or a support dog as distinct from those who require prompting to initiate a journey.** If this recommendation is not accepted, we strongly urge that the word ‘overwhelming’ not be included. An inability to leave the home is the important point, and if distress is so great that it creates that inability, it would seem to be overwhelming. It being present opens the door to long disagreements over what level of distress is ‘overwhelming’. **We recommend that, in Activity 10, the word ‘overwhelming’ not be used in respect of psychological distress.**

A person who is unable to leave their home at all faces arguably greater barriers from participation than those who need to be accompanied for all journeys. It is thus strange that it is a lower scoring descriptor. The additional financial costs of being unable to leave one’s own home are considerable. One has vastly narrower choices when purchasing, and will thus be unable to get the best offers available in many cases. There are also additional delivery costs. Provision of services that are normally provided outside of the home, such as getting a haircut, are similarly limited. **We recommend that being unable to leave the home, like requiring a person or support dog with you for all journeys, score sufficiently in Activity 10 to give entitlement to the Enhanced rate.**

The explanatory notes make clear that a journey to an unfamiliar destination is assumed to include the use of public transport. There was substantial feeling that this should be stated on the face of the activity. **We recommend that the descriptors for Activity 10 specify where a journey involves public transport, or that this be made clear in regulations with statutory force.**

An inability to undertake journeys due to distress is not limited to distress that is psychological in origin. A person may be distressed about travelling due to the risk incontinence and the lack of facilities to deal with it. **We recommend that 'distress' in Activity 10 not be restricted to that which is psychological in origin. Correspondingly, the definition that corresponds to this should not require an enduring mental health disorder. A definition allowing discretion in determining whether distress is genuinely experienced may be appropriate.**

We note that this activity amounts to a reversal of the recent regulatory change affording DLA Higher Rate Mobility to people who are severely visually impaired. We urge the Government to strongly consider whether this is appropriate; has the justification in extending HRM to severely visually impaired individuals somehow lost validity in the last year?

The need for aids to safely follow a journey (as opposed to aids that are required to move around in itself) seems to be completely ignored. We consider this a significant omission. For example, visually impaired people who use a cane often purchase more suitable canes than are provided, and additional canes in case of breakage; visually impaired respondents tell us that free provision of canes is limited to one at a time, meaning that if they do not buy a spare themselves they are left extremely vulnerable if their cane is damaged while they are out. This is not an unusual occurrence, as canes are fragile, and useless once damaged; We are particularly unclear why, in the case of visual impairment, the use of guide dog attracts points while the use of white cane does not, particularly given the fact that Guide Dogs will cover the costs of the dog's feeding and veterinary care[13], and is not used specifically by people of particular character or severity of impairment. Similarly, people with visual impairments or cognitive difficulties may be enabled to journey more widely by electronic navigational aids, which are very expensive and may require maintenance. None of these aids would be considered in Activity 11, so they are effectively disregarded entirely in the second draft PIP assessment criteria. **We recommend that consideration of aids be included in Activity 10. It would be appropriate for aids that are required purely to move around be disregarded, as they are considered in Activity 11.**

These key recommendations may be summarised by altering Activity 10's descriptors to those shown in table 3.2. It also incorporates the recommendations of section 3.4.1 on page 33.

Table 3.2: Suggested alternate descriptors for Activity 10

A	Can plan and follow a journey unaided	0
B	Requires prompting to initiate a journey, involving the use of public transport, to an unfamiliar destination	4
C	Requires ongoing prompting, supervision, an aid or appliance, or a support dog to follow a journey, involving the use of public transport, to an unfamiliar destination <b>or</b> requires a journey to an unfamiliar destination, involving the use of public transport, to have been entirely planned by another person	8
D	Requires prompting to initiate a journey to a familiar destination	10
E	Requires ongoing prompting, supervision, an aid or appliance, or a support dog to follow a journey to a familiar destination <b>or</b> require a journey to a familiar destination to have been entirely planned by another person <b>or</b> is unable to undertake any journey due to distress	12

### 3.3.2 Activity 11

This activity seems to be among the most unclear to apply. The meaning of “up to” is particularly unclear. Taking the case studies into account, particularly Richard (case study 6), it appears that some distance below 50m is sufficient to be considered able to walk “up to 50m”. He can walk only 20–30 steps, which we believe approximates to a distance of about 15–23m (taking a generous estimate of a 75cm stride, though an older man in pain is likely to take shorter steps). The descriptor choice given is C, “can move up to 50 metres unaided but no further”. It is easy to see how this conclusion is reached, as he is clearly not entirely incapable of moving around, as required for descriptor G, and there is no aid he can be reasonably expected to use, so he cannot be assessed as if he were using it. Perversely, it appears he would score 15 points as descriptor F if he used a wheelchair, as the difficulties he experiences with his hands would prevent him from self-propelling. Descriptors requiring that a person be able to travel further than a certain distance would make it clear whether a particular descriptor is satisfied, and avoid any misunderstandings leading to attempts to determine exactly how far a person could move with a given aid. **We recommend that the words “up to” not be used in Activity 11 descriptors, but instead each descriptor refer to a specific benchmark distance, requiring that the claimant be able to move further than that distance.**

The fact that wheelchairs are only considered where they are needed to move 50m is a very sharp limitation. We see from the case studies that this would exclude people who need a wheelchair for any significant activity outside the home, as in the case of Andy (case study 7). Andy uses a stick to get around at home, and can walk 40–50m with it, which clearly scores 10 points as descriptor D. However, this distance is so short that he uses a wheelchair whenever journeying out of his home. To any reasonable observer, he would be seen as a wheelchair user. The 50m benchmark for considering wheelchair use excludes him from being considered as such for the purposes of PIP. Indeed, many people have told us that they do not consider 50m a sufficient distance for very much at all. Even assuming that one had access to a car, being limited to 50m would mean only travelling 25m from it, or 50m if one could take sufficient rest; access to a car cannot be assumed, especially as many such people will lose their access to the Motability scheme. **We recommend that the benchmark for considering wheelchair use, and the use of motorised devices, be increased. We suggest it be set at 200m.**

We believe that the costs and barriers associated with wheelchairs may be sufficient to justify a greater distance for their consideration than other aids. However, we agree with the comment sentiment we have noted, that Activity 11 currently does not give sufficient regard to aids and appliances other than wheelchairs and motorised devices, particularly where they are needed only for distances greater than 50m, and particularly where those aids have costs associated, or create greater barriers for their users:

“ if my crutches break or wear out I have to pay to replace them I use lighter weight crutches as they mean I get less fatigued than using standard NHS crutches, and they cost 60 a pair. ”

“ The UK is still widely inaccessible, mobility aids require upkeep and replacement, transport costs can be higher for disabled people. ”

“ I am completely shocked at how the points system is structured on the new PIP. I have spina bifida and an artificial [*sic*] leg yet because I get around on crutches I will only qualify for the lower rate mobility part. I currently get the high rate mobility/DLA which I use for a motability car and this gives me my independence. It is no exaggeration to say that without it I will be virtually housebound. Only able to get out when someone can take me and this will inturn [*sic*] effect my children how will they get to school? ”

Users of crutches must replace ferrules, and may need to buy padded gloves for extended use; these gloves wear out and must be replaced. Users of wheeled walking frames must not only acquire the frames, rarely provided by the NHS, they must also ensure they are maintained and serviced, replace worn-out parts, and likely eventually replace the whole frame. Similarly, users of such aids face access difficulties similar to wheelchair users in many cases; steps are difficult or impassable, curbs present significant obstacles, and doors are difficult or impossible to negotiate. Improvements in access since the Disability Discrimination Act and Equality Act, while significant, have far from eliminated these difficulties. They exclude those using such mobility aids from access to many business premises, restrict their choice of housing, and even present difficulties negotiating public streets, all too often featuring uneven paving, cobbles, absent or insufficient drop kerbs. Public transport is far from universally accessible, even accessible buses and trains being frequently too crowded. This creates additional costs for deliveries, transport, and having restricted choices of providers of goods and services. **We recommend that use of aids other than wheelchairs and motorised devices not be considered equivalent to using no aid at any distance, or at least in the 50–200m distance range. This is most important for aids that require the use of both hands for most of the time they are in use, such as walking frames and pairs of crutches.**

We are also concerned by the juxtaposition of descriptor A or B with descriptor D, especially given the example under D in the explanatory notes, “identifies individuals who can use an aid or appliance to move up to 50 metres but then require a wheelchair for anything further.” If a person requires a significant mobility aid, other than a wheelchair or motorised device, in order to move 50m, it seems appropriate that they score regardless of the distance they may then be able to travel. As explained above, such aids can present a significant barrier and cost. **We recommend that the requirement for an aid to move 50m clearly entitle a claimant to at least Standard rate of the Mobility element in Activity 11. The example in the explanatory notes suggesting this would only be available if a more significant aid were needed to travel further than 50m should be removed or altered. A claimant who can move unaided to some distance shorter than 50m, but requires an aid other than a wheelchair to travel as far as, or further than 50m, should score per descriptor D in the second draft assessment criteria.**

Respondents have also indicated areas of additional costs related to mobility that are not considered in the proposed system:

“ That the way I walk is inefficient means I wear out shoes more quickly than a non-disabled person, so I incur costs linked to wearing out clothing. ”

However, we have no specific recommendations with regard to this problem.

These key recommendations may be summarised by altering Activity 11’s descriptors to those shown in table 3.3 on the following page. To keep in line with all of the recommendations above, it is necessary

to include an additional distance, as we consider distances specified as ranges to be problematic. It also incorporates the recommendations of section 3.4.2 on the next page. Please note, however, that these recommendations are all predicated on a proper treatment of the factors reliably, repeatedly, safely and in a timely fashion, as described in section 3.7 on page 36. Without improvements to those factors, these changes are not sufficient.

Table 3.3: Suggested alternate descriptors for Activity 11

A	Can move over 200m unaided, or using an aid or appliance that requires only one hand most of the time it is in use, other than a wheelchair or motorised device.	0
B	Can move over 200m only by using an aid or appliance that requires two hands most of the time it is in use, other than a wheelchair or motorised device.	2
C	Can move over 100m unaided, or using an aid or appliance that requires only one hand most of the time it is in use, other than a wheelchair or motorised device.	4
D	Can move over 100m only by using an aid or appliance that requires two hands most of the time it is in use, other than a wheelchair or motorised device.	6
E	Can move over 50m unaided, or using an aid or appliance that requires only one hand most of the time it is in use, other than a wheelchair or motorised device.	8
F	Can move over 50m only by using an aid or appliance that requires two hands most of the time it is in use, other than a wheelchair or motorised device.	10
G	Cannot move over 50m <b>or</b> can move over 200m only by using a wheelchair or motorised device <b>or</b> cannot transfer unaided from one seated position to another adjacent seated position	12

### 3.4 Question 4

The Government consultation asks:

**What are your views on the weightings and entitlement thresholds for the Mobility activities?**

In the explanatory note we set out proposals for the weightings of descriptors in the activities relating to entitlement to the Mobility component (activities 10-11). In this document we have set out the entitlement thresholds for the benefit. How well do you think they work to distinguish between differing levels of ability in each activity? How well do you think they work to prioritise individuals on the basis of their overall need? Do you think we need to make any changes to weightings or thresholds?

There was significant disagreement with the scores and thresholds for Mobility in the PIP second draft assessment criteria and consultation document. 84.4% of respondents disagreed with the statement “the scores and thresholds for Mobility are mostly appropriate”, 57.1% strongly, while only 3.8% agreed with it. However, specific disagreements have been harder to establish.

As we outlined in section 3.2 on page 25, we are satisfied with the thresholds announced in the consultation document, in that they may be considered a fixed background to adjust descriptors and scores. It is on this basis that we have made our recommendations regarding scores and descriptors.

### 3.4.1 Activity 10

There is significant concern that the threshold for Enhanced rate is 12 points, but descriptors exist with higher scores. A considerable number of people indicated that they felt this indicated a plan to increase the threshold to 15 in future. These concerns would be alleviated by scoring all descriptors currently scoring 12 or over at 12 points. **We recommend that descriptors scoring over 12 points be reduced to 12 points.**

This recommendation is incorporated in the suggested alteration of Activity 10 shown in table 3.2 on page 29.

### 3.4.2 Activity 11

There is a general feeling that the use of aids for distances over 50m should **not** be considered equivalent to not using any aid. This requires the creation of further descriptors, which can be seen illustrated in the suggested descriptors we list in table 3.3 on the previous page. **We recommend that using an aid for any distance lead to a greater score in Activity 11 than not using an aid.**

There is significant concern that the threshold for Enhanced rate is 12 points, but descriptors exist with higher scores. A considerable number of people indicated that they felt this indicated a plan to increase the threshold to 15 in future. These concerns would be alleviated by scoring all descriptors currently scoring 12 or over at 12 points. It would be even further clarified if the descriptors were merged. **We recommend that descriptors scoring over 12 points be reduced to 12 points, and descriptors merged to remove distinctions that are no longer relevant to assessment, including the distinction between different kinds of wheelchair and motorised device.**

These recommendations are incorporated in the suggested alteration of Activity 11 shown in table 3.3 on the preceding page. As previously noted, these recommendations are all predicated on a proper treatment of the factors reliably, repeatedly, safely and in a timely fashion, as described in section 3.7 on page 36. Without improvements to those factors, these changes are not sufficient.

## 3.5 Question 5

The Government consultation asks:

### **What are your views on how the regulations work regarding benefit entitlement?**

Draft Regulations 1 to 4 set out how the assessment will work to prioritise individuals and determine entitlement to the benefit. How well do you think the draft regulations achieve the intent of the assessment set out in the explanatory note? Do we need to make any changes?

Although this question refers to Regulations 1–4, Regulation 4(4)(c) is specifically addressed in Question 6, and our response regarding that regulation is found in section 3.6 on the following page. Similarly, regulation 2 concerns definitions, the subject of Question 8. Regulation 1 contains nothing relevant to the implementation or function of the assessment. Regulation 3 gives substance to two of the definitions in Regulation 2. We are thus concerned here with Regulation 4, with the exception of 4(4)(c).

Most of the elements of Regulation 4 is quite technical and straightforward. Two exceptions are 4(4)(c), covered in section 3.6, and 4(4)(d), regarding the consideration of aids.

We feel that more clarity is needed over what aids or appliances a claimant “could reasonably be expected to wear or use”. We understand that ministers have already clarified that this would not include a wheelchair. **We recommend that it be clear that aids attracting significant expense not be reasonably expected to be used, in the terms of Regulation 4(4)(d)(ii).** It would also be helpful if clear examples were given in statutory guidance, or other binding form. **We recommend that a set of normative examples of aids that may and may not reasonably be expected to be used, in the terms of Regulation 4(4)(d)(ii), be given, in binding form.**

If one of the factors regarding reasonable expectation is cost and availability, this could be specified in regulation clearly. **We recommend that Regulation 4(4)(d) be supplemented by a new point: “(iii) is either provided by the NHS or is inexpensively and easily obtainable.”**

We are concerned that assessors or Decision Makers may determine that an aid falls under Regulation 4(4)(d)(ii) without full consideration of the claimants circumstance, including whether an aid is suitable for them at all. An aid may already have been considered and dismissed by a relevant health-care professional, perhaps without even informing the claimant. Furthermore, for most aids the only way to determine their suitability is to try them. Grab rails, perching stools, mobility aids—all may be recommended, but found when tried to be unsuitable or give little benefit to the person using them. **We recommend that regulations provide that no aid be assumed to be reasonably expected to be used, in the terms of Regulation 4(4)(d)(ii), without an attempt to determine that it is suitable in the claimant’s individual circumstances.**

We are also concerned that assessors or Decision Makers will overestimate the effect of an aid that could reasonably be expected to be used. As an example, we refer back to the perching stool mentioned in section 3.1.2 on page 14; this is an aid often referred to by DLA Decision Makers as one that may reasonably be expected to be used, but the help it gives is limited. It requires balance to perch, so those with impaired balance will get little or no benefit; it only helps alleviate problems with standing, not any other difficulties. **We recommend that assessors and Decision Makers, and by extension tribunal members, be cautioned in binding regulation or statutory guidance to carefully consider what benefit may be gained from any particular aid being considered under Regulation 4(4)(d)(ii).**

If an aid could reasonably be expected to be used, but is not already in use, it would be appropriate to signpost claimants to a service that could accurately assess that claimant for that aid, preferably before concluding that it would be appropriate. If the aid could be provided with state support, this should be included in the signposting; otherwise, signposting to an index of approved providers of aids to daily living would be appropriate. **We recommend that, where an aid is considered under 4(4)(d)(ii), appropriate signposting be provided for assessment and potential provision of that aid.**

### 3.6 Question 6

The Government consultation asks:

#### **What are your views on how we are dealing with fluctuating conditions?**

Regulation 4(4)(c) of the draft regulations and paragraphs 7.13 to 7.15 of the explanatory note set out how we are proposing to assign descriptors to people who have fluctuating conditions. These are that:

- Scoring descriptors will apply to individuals where their impairment(s) affects their ability to complete an activity on more than 50 per cent of days in a 12 month period.
- If one descriptor in an activity applies on more than 50 per cent of the days in the period i.e. the activity cannot be completed in the way described on more than 50 per cent of days then that descriptor should be chosen.
- If more than one descriptor in an activity applies on more than 50 per cent of the days in the period, then the descriptor chosen should be the one which applies for the greatest proportion of the time.
- Where one single descriptor in an activity is not satisfied on more than 50 per cent of days, but a number of different descriptors in that activity together are satisfied on more than 50 per cent of days for example, descriptor 'B' is satisfied on 40 per cent of days and descriptor 'C' on 30 per cent of different days the descriptor satisfied for the highest proportion of the time should be selected.

What are your views on this approach and how this is set out in the regulations?

These rules were widely considered unclear. 87.3% of respondents disagreed with the statement "the rules for variable and fluctuating conditions make sense and are easy to apply", 59.9% disagreeing strongly; only 3.2% agreed with that statement. Further, few considered that it would be effective, with 70.2% disagreeing with the statement "the rules for variable and fluctuation conditions will always give more points to those most severely affected by their condition", 34.9% disagreeing strongly; only 7.5% agreed with that statement. Given that there was a strong feeling that the rules are unclear, caution should be advised in using these survey results to determine if the results of the rules are appropriate.

While some expressed doubt that 50% was a fair benchmark, there was widespread agreement with the principle of considering those limitations a person faces on a certain proportion of days. There was considerable confusion over the idea that a limitation counts for a day if it is faced at any time on that day, but once it was understood, people felt this was a very strong, sensible way to calculate the amount of time a limitation is faced. For example, these rules would seem to suggest that a person who cannot dress themselves in the morning, but can change for bed at night, will count as unable to dress themselves on that day. Although it was found to be unclear, it was strongly supported.

4(4)(c)(i) and 4(4)(c)(iii) were also generally accepted. However, the meaning of 4(4)(c)(iii) is possibly unclear given that the non-scoring descriptors, labelled A in each activity, are also descriptors. For example, it is unclear what would happen in a situation where someone satisfies descriptor A on 40% of days, B 30% of days, and C 30% of days. **We recommend that 4(4)(c)(iii) be clarified, that if descriptor A of any activity is satisfied on less than 50% of days, one of the other descriptors will be chosen.**

4(4)(c)(ii) presents a very serious problem. As written, it would require that a person who always needs a shower stool, but needs assistance to shower even on 90% of days, only receive points based on needing an aid to bathe - 2 points rather than four. A person who only needed the assistance on 90% of days would score four points, despite the first person having clearly greater needs and facing greater barriers. A worked example of two similar cases showing the perverse results of 4(4)(c)(ii) is shown in Appendix B on page 56. **We recommend that 4(4)(c)(ii) be redrafted such that, if more than one descriptor is satisfied on more than 50% of days, the descriptor that scores the greatest number of points is selected.**



### 3.7 Question 7

The Government consultation asks:

**What are your views on the definitions of 'safely', 'timely', 'repeatedly' and 'in a timely' manner?**

In the assessment an individual must be able to complete an activity descriptor reliably, repeatedly, safely and in a timely manner. Otherwise they should be considered unable to complete the activity described at that level. In paragraph 7.4 of the explanatory note we set out draft definitions for these as follows:

**Reliably** means to a reasonable standard.

**In a timely fashion** means in less than twice the time it would take for an individual without any impairment.

**Repeatedly** means completed as often during the day as the individual activity requires. Consideration needs to be given to the cumulative effects of symptoms such as pain and fatigue i.e. whether completing the activity adversely affects the individual's ability to subsequently complete other activities.

**Safely** means in a fashion that is unlikely to cause harm to the individual, either directly or through vulnerability to the actions of others; or to another person.

What are your views on these? Some organisations have suggested that these terms should be included within the regulations. Do you agree? If so, do you have views on how we should do so for example, as a general provision or referring to them in the detail of activity descriptors?

There is general support to the principle of these factors. There is, however, significant feeling that these factors should have full legislative force, for example by inclusion in regulations. 82.0% of respondents agreed with the statement "Reliably, Repeatedly, Safely and In a Timely Fashion should be given legal force, not just be in guidance", 57.3% agreeing strongly; only 5.3% disagreed with the statement.

We note that the Disability Benefits Consortium, commenting on the first draft, observed that "there is nothing in the criteria (or in the regulations) that would act as a prompt to ensure that individuals must be able to undertake an activity repeatedly, reliably and safely, despite this being mentioned in the accompanying information. Evidence collected from the Work Capability Assessment demonstrates that such considerations are not taken properly into account if not on the 'face' of the test." [14]

The Parliamentary Ombudsman's Principles of Good Administration [15] include as a key feature "getting it right". These experiences all suggest that putting these requirements on the face of the assessment will lead to more right outcomes first time, and fewer cases going to appeal. **We recommend that the factors Reliably, Repeatedly, Safely and In A Timely Fashion have legal force, for example by being included prominently in regulations and training material for assessors and Decision Makers.**

There is a strong belief that these definitions would benefit from being supplemented by normative examples as clarification. It is particularly difficult to understand how Reliably, Repeatedly and In A Timely Fashion will be applied to each activity. The definition of Reliably is particularly unclear. Would

only being able to make barely edible food be “not reliably”? What quantity of food must one be able to successfully get into one’s mouth, compared to the amount that misses, before one is able to convey food to one’s mouth reliably? Similarly, in order to determine what is a timely fashion, there will need to be guidance as to the time an unimpaired person would take to complete each activity, and how often an activity would normally be performed in a day. **We recommend that normative examples be provided to aid in the application of the factors “Reliably, Repeatedly and In a timely fashion”, and that the Government consult widely on these examples. We do not feel it essential that such a consultation be formal, but it must be open to all interested parties.**

Opinion is divided on whether these factors should be mentioned in the activities and descriptors. If they do not have legislative force, it would be beneficial to include those factors most relevant to each activity in the definition of that activity and its descriptors. If they have legislative force and feature prominently in the training of assessors and Decision Makers, it would be less useful, and may be harmful. For example, if some activities specifically reference the question of Safety, it would seem implicit that safety is not an important factor in other activities. **Provided that the factors of “Reliably, Repeatedly, Safely and In a timely fashion” are given legislative force, and feature prominently in training, we recommend that they not be mentioned specifically in the activities or descriptors.**

There is significant concern that pain, nausea, fatigue, vertigo and other forms of discomfort will not be adequately allowed for by these factors, even with the recommendations above:

“ There is insufficient attention paid to pain and fatigue; the regulations should use the phrase ‘without severe discomfort’ to indicate whether someone can do something or not. ”

“ People in horrendous amounts of pain are considered perfectly capable of mobilising. ”

People are not happy that they may be considered able to do something if doing so causes them intense pain, worsens vertigo, induces nausea, and so forth. Instead, they should be considered unable to do something if it causes any form of severe discomfort. We are unsure how this should be handled in the case of people who are in continuous severe discomfort for significant proportions of the time. In many cases it may be appropriate to consider this in terms of the additional discomfort caused by the activity, but those in very severe discomfort most of the time should generally not be considered able to do many activities, as such discomfort can be presumed to prevent the necessary concentration on most tasks. **We recommend that a fifth factor be added to supplement “Reliably, Repeatedly, Safely and In a timely fashion”; the assessment should also ask what they can do “Without severe discomfort”.**

As an observation that may be of use in training assessors, we have found that disabled people do not usually think in the same terms as used in the second draft and consultation. The use of clearly defined, analytical terms in legislation and guidance is understandable, but may lead to a mismatch during the assessment process. For example, we have found that disabled people often think of these factors in terms of ‘struggle’. If a person is unable to do something in a timely fashion, they will often think of it as “struggling to do it quickly enough”, for example, or if unable to do it reliably they may think of it as “struggling to do it well enough”. The compound effect may be thought of simply as “struggling to do it”. **We recommend that assessor training include guidance on the ways that disabled people may**

**think of things, and the terms they might use, as they may not think of things in the same terms used in legislation or official guidance.**

There is concern that Safety will be thought of wholly or primarily in terms of physical harm to individuals. Damage to property should be considered as well, as should emotional harm, such as where an activity is likely to lead to experiences that are triggering of mental health problems, or the risk of damaging kitchen equipment. **We recommend that the definition of 'Safely' clearly encompass emotional harm and damage to property.**

It is important to note that the fact a person does something does not in itself show that they do it Safely. Disabled people, like any other person, are free to decide to do things that are unsafe or unwise for their own reasons. A person who is not generally considered safe to leave their home alone may decide that they are going for a short walk regardless of this, because they feel the risk is outweighed by the benefit of getting out of their home for a few minutes. People who cannot cook safely may decide that the risk is worth it to eat something different, or to have the chance of the possible reward of satisfaction at their own achievement. This is particularly relevant to new claimants, who are likely to be having to manage as best they can without the support or aids that PIP would afford them, but it is also a free choice of those already receiving the benefit. **We recommend that it be made clear to assessors, Decision Makers and tribunal members that people may perform an activity despite it being unsafe, and that performing the activity is not proof that they can do it Safely. Similar arguments hold for the other factors that are to be considered, but Safety is the most paramount factor in this respect.**

There is concern that Repeatedly will be thought of entirely in terms of the effects of an activity on a claimant's ability to perform other activities that day. Many conditions lead to fatigue that last beyond that day, and many individuals find that the full effects of pain and fatigue from exertion are not felt until the next day. **We recommend that the definition of 'Repeatedly' clearly refer to the impact on ability to perform other activities on subsequent days as well as the same day.**

There is concern that Repeatedly will be thought of entirely in terms of the effects of an activity on a claimant's ability to perform the other activities considered in the PIP assessment. Many other activities are essential to life, and while we understand that it would be contrary to the principles of PIP to consider all day-to-day activities, disabled people do still have to Hoover, take out rubbish, do their jobs or voluntary work. Disabled people are also entitled to expect to be able to engage in social and recreational activities on the same basis as people who are not disabled. **We recommend that the definition of 'Repeatedly' clearly consider the impact on all reasonable activities of a person's day-to-day life, not only those activities considered in the PIP assessment.**

There is concern that these factors may only be considered in isolation. For example, it may be possible for someone to do something Safely, and possible for them to do it In a timely fashion, but not possible for them to do both; taking the extra steps and precautions to do it safely can make the task take considerably longer. **We recommend that regulations make it explicitly clear that the activity must be able to be performed Reliably, Repeatedly, Safely and In a timely fashion, as well as any other factors that may be considered, all at the same time.**

### **3.8 Question 8**

The Government consultation asks:

**What are your views on the definitions in the regulations?**

The draft regulations contain a number of definitions in Regulation 1 (Interpretation) and Schedule 1. Do we need to make changes to any of these?

We should first note that it is Regulation 2 that concerns interpretation and definitions, not Regulation 1; Regulation 1 concerns citation and commencement.

There is dissatisfaction with many definitions. 87.1% of respondents disagreed with the statement "the definitions used in the PIP assessment are generally sensible", 52.3% disagreeing strongly; only 2.2% of respondents agreed with that statement. There are a number of areas we have discerned particular concern over.

Many of these adjustments to definitions are essentially duplicative of points made in earlier questions. This is because they are relevant answers to both questions. However, not all altered definitions necessary to implement our earlier recommendations are mentioned in this section. This does not mean that we do not think such changes are necessary. Many of our recommendations in various sections of this submission could be implemented principally by the alteration of definitions.

Point (c) of the definition of "aid or appliance" is a cause for concern. It seems to suggest that any aid or appliance that would not be unusual for an unimpaired person to use will be ignored if it increases the barriers faced by the claimant. This is not clear, however. Even if it we are correct in our understanding of this, we do not believe that it is reasonable. **We recommend that point (c) in the definition of "aid or appliance" be made clear, and then further consulted upon.** We also feel that point (a) in the definition be slightly extended to include the maintenance of a function, so that aids that are used in order to maintain a level of capability are included; clearly, the assessment should not be based on a claimant not using equipment that will prevent their condition deteriorating. **We recommend that point (a) in the definition of "aid or appliance" be extended by the inclusion of 'maintain' in the list of properties in relation to function.**

Bathe is defined as cleaning one's torso, face and underarms. As noted in section 3.1.5 on page 18, there are numerous problems with this definition. Our recommendations in that section outline how it should be altered. For reference the key points in amending it should be the extension of areas of the body washed to include the limbs, specifying that the initial assumption is the use of a bath or shower, and ensuring that the inclusive definition of torso found in the Oxford English Dictionary and anatomical references be used.

We have noted concerns regarding the definition and interpretation of 'cook' in section 3.1.2 on page 14. We would also amend the definition to specify that raw food is being cooked to the point of being safe to eat. **We recommend that the definition of 'cook' be amended to specify that the food is initially raw, and is heated to the point of being safe to eat.**

The definition of "dress and undress" specified slip-on shoes. As explained in section 3.1.7 on page 22, it is inappropriate to specify in this way. Slip-on shoes are contrary to the recommendation of the Society of Chiropodists and Podiatrists, unsuitable for many impairments, and not representative of common practice. As we have recommended, the definition should specify putting on appropriate footwear, in line with general advice, as well as recommendations made to the claimant individually by medical professionals.

Groom is defined very narrowly. We make recommendations for broadening this definition in section 3.1.5 on page 18. For reference, we feel it should include shaving, washing of hands and face, and cutting of fingernails and toenails.

We have expressed significant misgivings regarding the phrase “overwhelming psychological distress”, particularly in section 3.3.1 on page 28. We would prefer this definition no longer be needed. If, however, it is to remain, we do not understand why it should be restricted to a particular class of impairments; the stated principle of PIP is, after all, that impairments should be considered on their functional effects, not their origins. That the distress be psychological already limits the cases in which it will be applied. Removal of the requirement that it derives from an “enduring mental health condition” or “intellectual or cognitive impairment” will prevent the splitting of hairs in assessments and tribunals. **We recommend that, if the phrase “overwhelming psychological distress” is to be used, it not be defined by reference to the forms of condition or impairment that it derives from; if a restrictive definition is to be used, it should be made more inclusive, for example by the addition of the phrase “or the significant psychological impact of a physical impairment or disfigurement”.** We are also very concerned at the phrase “enduring mental health condition” itself. If the intent of this phrase is to remain, we would like that intent made explicit. **We recommend that, if a reference to an “enduring mental health condition” is retained, it have its meaning made explicit.**

As explained in section 3.1.2 on page 14, we believe the definition of ‘prepare’, as used in Activity 1, should be made explicit.

The definition of ‘social support’ seems extremely narrow. As explained in section 3.1.9 on page 23, a disabled person may need many sorts of support that could be seen as falling between ‘prompting’ and ‘social support’, in the context of Activity 8.

In line with our recommendations regarding ‘safely’ in section 3.7 on page 36, we recommend that it be clear that ‘supervision’ should be considered in a broad sense. As it is defined as continuous presence to ensure safety, it is natural that it be considered in a similar way, specifically that it consider all manner of adverse events, not just physical harm. Emotional or psychological damage, reputational damage, and damage to property should also be considered. Furthermore, all of these factors should extend to third parties as well, ensuring that supervision is considered where it is needed to protect other persons, including their property. **We recommend that the definition of ‘supervision’ encompass safety in a broad sense, extending beyond prevention of physical harm to include harm, without limitation, to mental health, emotional state, reputation and property; in all senses, it should extend to the safety of other persons (and their property) as well as the claimant.**

We feel that the definition of “support dog” is unrealistically narrow, as assistance dogs of other kinds enable some disabled people to travel otherwise unaccompanied. For example, seizure alert dogs allow some people with epilepsy to get sufficient warning of seizures to find a safe place. It is unclear how it would be treated, under the current draft, if such a person were to be assessed—would the dog be disregarded entirely, and the assessment conducted on the basis of what the person can do without the dog, or would they be deemed able to travel unaccompanied because they only need a dog that does not meet the definition of “support dog”? **We recommend that the definition of “support dog” be made broader, and the more usual term “assistance dog” used instead. Notwithstanding other recommendations, it would be possible to define in terms of the fact the dog allows the person to travel otherwise unaccompanied. Alternatively, it could be defined by the substitution of the word ‘specific’ for the word ‘sensory’ in the current definition.** We would go further, however, and point out that assistance dogs enable other activities to be conducted, or conducted safely, than simply travel. Assistance dogs may be used for fetching, picking up dropped items, and seizure alert dogs provide warning of seizures to promote safety in other circumstances. **We recommend that support or assistance dogs not be specified in individual activities, but that regulation provide for a general treatment of assistance dogs.** The consideration of an assistance dog may be considered as always

equivalent to help from a person, but that may lead to an unrealistic treatment of the assistance provided by such dogs. Instead, they may be considered equivalent to the form of help that would be needed if the dog were not available; a guide dog for a blind person gives broadly the same assistance as a cane, so could be considered an aid, while a seizure alert dog reduces the need for supervision from another person, so could be considered as supervision. This approach is predicated on our recommendation regarding Activity 10, that aids be considered, as described in section 3.3.1 on page 28. **We recommend, provided that aids are considered in Activity 10, that assistance dogs be considered in all activities based on the form of support they fulfil the need for; where they perform broadly equivalently to an aid, they should be considered an aid, and where they fulfil the need for human supervision or assistance, they should be considered as such.**

Therapy is defined as long-term, but without any indication of what would determine that therapy is long-term. While this can be left to tribunals, and ultimately courts, it seems unlikely that the Department will not be providing guidance to assessors and Decision Makers on this matter, and we would feel better if we knew what this guidance is likely to say, and had the opportunity to comment on it. **We recommend that the Department publish and consult informally on guidance as to what therapy would be considered 'long-term'.**

As noted in section 3.1.6 on page 20, the definition of "toilet needs" should be extended to encompass the washing of hands.

## 3.9 Question 9

The Government consultation asks:

### **Do you have any other comments on the draft regulations?**

Regulations 5 to 10 of the draft regulations relate to elements of the assessment process for Personal Independence Payment, around the requirement to provide information and attend face-to-face consultations, the consequences of failing to meet these requirements and when individuals might have good reason for not meeting these. Do you have any comments on these regulations?

We have a number of concerns around aspects covered by these draft regulations. We have sorted the areas we have identified into separate sections for clarity.

### **3.9.1 Information to be Provided**

We are concerned that Regulation 5(1)(b) gives an open ended power for assessors or Decision Makers to require any information from a claimant, without limit. We do not understand why any information in excess of that covered by 5(1)(a); how can information not related to a claimant's capability to perform the activities of the assessment be relevant to the assessment? We believe that it is reasonable to require the Secretary of State to demonstrate the relevance of the information requested. **We recommend that Regulation 5(1)(b) be removed.**

The ability to provide information is likely to be affected by public holidays. **We recommend that the period of time specified in Regulation 5(2) be specified to take account of public holidays.**

Depending on what information is required, it may be difficult or impossible to obtain in the time scale specified. **We recommend that Regulation 5(2) specify "such longer period as is reasonable", so this may be determined other than by the Secretary of State; for example, when appealing a decision to stop benefit due to information not being provided, a tribunal may then determine whether the longer period was, in fact, reasonable. It would be fair to require that a claimant notify the requesting party of the delay, however.**

Regulation 6 provides that a failure to provide information shall automatically lead to a negative determination. We feel this is inappropriately harsh. It would be most appropriate for an initial warning to be given, or other attempts be made to contact the claimant. It is not appropriate for the burden to fall entirely on the claimant when claimants will, by definition, likely be vulnerable adults. **We recommend that Regulation 6 specify that a negative determination only be made after efforts to contact the claimant have failed, or the claimant does not provide the information even after this contact.**

We are concerned that Regulations 5 and 6 do not appear to be limited to information requested of and provided by the claimant. **We recommend that at least Regulation 6, and preferably also Regulation 5(2), be clarified to only apply to information requested from the claimant.**

### **3.9.2 Face-to-face assessments**

Many concerns surround the use of face-to-face assessments, especially drawing on the experience of disabled people with the Work Capability Assessment face-to-face assessments conducted by ATOS on behalf of the Department. Even following such implementation of the Harrington Reviews' recommendations as has been affected, our respondents report widespread problems with assessors treating the assessment as a 'snapshot', judging their general capability based on observations on that one occasion even where a diagnosis of a fluctuating condition has been confirmed. A failure to take into account evidence from the claimant's own doctors is still widely reported. Conclusions that reflect negatively on entitlement are drawn on inference without giving the claimant the opportunity to explain how that conclusion is not correct. **We recommend the Government take every regulatory, contractual and advisory opportunity to ensure that problems reported with the WCA, particularly those recognised by the Harrington Reviews, do not occur in the PIP assessments. We specifically caution that the assessment is liable to act as a 'snapshot' even where this is explicitly not intended. We recommend that assessors be cautioned against inferring functional capability without checking their conclusions with the claimant, and giving them the opportunity to challenge their inference.**

We are unclear what examinations or questions will allow consideration of the full range of activities called on for the PIP assessment. When this is combined with the obvious limitations of a face-to-face assessment in considering variable and fluctuating conditions, it is clear that the assessor will be reliant on either accepting the claimant's word, or requiring further evidence, on a great many aspects of the assessment. It is unclear what a face-to-face assessment will add in this case. While doctors are often unable to give a clear picture of the effect a person's conditions have on their life, it is unclear what a single face-to-face assessment with a person of any qualification will be able to confirm to any extent greater than asking the patient. This is a particularly vital point when it's considered that claimants will, quite naturally, pace themselves before their assessment, meaning that their condition during examination will tend to be better than average, all other things being equal.

However, if the assessor is presented as, and acts as, completely independent of both the Department and the claimant, this could be a very positive element of the process. This would, of course, require that assessors and the organisations contracted to provide them have no targets, benchmarks or incentives for

the number of people assessed to any level of benefit. If the claimant feels that the assessor is there to determine the correct level of the benefit, including helping them to be awarded a higher level of benefit than they might expect, it is likely to be well-accepted by claimants; this would necessitate this being the objective of all assessors, of course—an attempt to convince the community that this is the intention is going to have significant challenges if it is true, and would be impossible if it is not. If this can be achieved, it is likely to entail the assessors actively searching for reasons to recommend the award of points, rather than the current perception in the WCA, that they actively search for reasons to recommend denying points. We believe this would lead to more assessments giving the right result first time, and thus fewer appeals. Where a system is truly fair, thorough and balanced, people are more likely to accept a negative result. Further, cases that are denied and awarded on appeal cost the Government more overall than if the award had been made in the first place; it is better for the Government to make the award in the first place. **We recommend that contracts and training for assessors and contractors clearly define their position as balanced and independent, there to ensure that claimants get the right level of benefit, as opposed to attempting to deny benefits. This must also be followed-through in practice as well as on paper.**

There is widespread concern that the points-based, descriptor-driven structure of the assessment means that any face-to-face assessment will, underneath any pleasantries that may be included in it, be a computer-drive tick-box assessment that reduces every aspect of their life into what they can or can't do. If it is to be well received by disabled people and the disabled community, it must be more human, more fair and balanced, and more approachable than the Work Capability Assessment. It would be best if extremely limited use is made of pre-populated fields; assessors should be encouraged, in training and by the software itself, to make full use of free writing fields, to ensure the report is tailored to the barriers faced by the individual claimant. **We recommend that any software used to support the assessment be person-focussed on the claimant, rather than any convenient structure that might allow assessors to avoid going into detail and understanding the individual needs of each claimant.**

It is vital that assessors not assume that a given aid can be used, as explained further in section 3.5 on page 33. Most importantly, though, while they may beneficially suggest aids, advise people to consider an aid, or signpost people to services to assess a claimant for or provide an aid, they must not urge a claimant to use a particular aid or class of aids, or criticise their decision not to use an aid. These are personal decisions that people make for a wide range of reasons. If an assessor does not accept a reason to not use an aid, then it is reasonable for them to report scepticism on that matter to the Decision Maker; it is not appropriate for them to push the point with the claimant. **We recommend that the Department ensure that assessors respect claimants' choices to use, or not use, any given aid.**

Important as this point is with regards to aids, it is even more vitally important with regards to treatment. Claimants must not have their entitlement to benefit affected by refusing treatment (except for certain commonly accepted exceptions, which are *very few*). In the same vein, it is very clearly not the responsibility of an assessor to urge a claimant towards any particular treatment or berate them for choosing not to have any specific treatment, or even to refuse treatment altogether. A cornerstone of the principle of informed consent in medical treatment is the option to exercise your right to refuse treatment. It is vital that this option not be eroded by negative consequences in the benefit system or judgemental behaviour from assessors. **We recommend that the Department ensure that assessors respect claimants' right to choose or refuse treatment, and ensure through regulation that benefits will not generally be affected by claimants' choices regarding treatment (notwithstanding the effects of that treatment on the claimant's condition).**

There is particular concern that answering a question “yes, but...” in the assessment will simply be



noted as a 'yes'. It is vital that any such caveats be noted by the assessor, with any decision to disregard them also noted and justified; failing to do this will lead to valid accusations of misrepresentation being made by claimants regarding assessors. **We recommend that the Department ensure, through regulation, contracts and guidance, that assessors must note all caveats given by claimants, and justify any decision to disregard them. This must be part of the formal report filed for each assessment.**

Our respondents have also urged us to remind the Department of the fact that there is no reliable way for an outside observer, like an assessor, to determine the degree of pain, nausea, vertigo, fatigue or any other internal symptom experienced by a claimant. While there are some external signs to most such phenomena, they are not universally present. **We recommend that guidance and training materials for assessors make it clear that they cannot rule out any pain, nausea, vertigo, fatigue or other discomfort reported by a claimant. If they are given any guidance on observable signs of discomfort, it must be accompanied by a clear reminder that these are not conclusive, and in particular that their absence should not be taken to demonstrate the absence of discomfort.**

No assessment takes long enough to determine by observation whether an activity is repeatable in the terms required by PIP, as the impact on other activities for a considerable time must be considered. Standing and sitting during the assessment, or on the way from the waiting area, is not a demonstration that the claimant can generally stand and sit without difficulty, even leaving aside problems with day-to-day variability. **We recommend that the Government ensure that assessors are cautioned against any over-generalisation, and the limitations of observations made during the face-to-face assessment.**

## Chapter 4

# Overarching and Additional Points

While we answer the Government's questions in chapter 3 on page 12, there are a number of points that touch on several questions. While they are addressed in our answers to the questions, we feel that some are important enough to draw attention to as a 'big picture' issue.

There are also a number of points that have been made that do not clearly fit any of the questions asked in the consultation. We feel it is most appropriate to share these, so that the Department may make use of them in some way.

### 4.1 Inflexibility and Narrowness of Conception

There is a considerable feeling from our respondents that the conception of disability reflected in the second draft criteria is narrow and inflexible, considering only those impairments that lead to difficulties in certain, narrowly defined areas, and that these areas are generally defined exclusively, rather than attempting to include the huge variety of impairment found in our society.

“ The criteria as a whole are insufficiently flexible to take account of the variety of needs. ”

“ I feel the criteria is just too inflexible to measure anything but a very specific 'idea' of what disability means. ”

It is also suggested that, while a claimant must demonstrate disability to some objective standard, officials will be able to use subjective judgements to deny eligibility:

“ They are much too vaguely constructed - allowing officials to downgrade eligibility according to opinion rather than objective criteria - and much too inflexible to account for fluctuations in a condition. ”

## 4.2 Impact of Equality Legislation

There is considerable concern that the Government is over-stating the positive impact of the Disability Discrimination Act 1995 and Equality Act 2010. Many 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[16]:

“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[17]:

“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[18] 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[19] on the right to Independent Living, as we consider further in section 4.6 on page 48. 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 would suggest 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.

### **4.3 The Cost of Aids**

We understand the Government's position to be that aids are considered because of their cost. We agree with this principle. However, with the exception of Activity 11, the current draft of the assessment treats all aids within an activity identically. Some aids are extremely expensive, including ongoing costs, but are treated equivalently to much cheaper aids within the same activity. In general, aids award very few points in most activities, suggesting that the Department has underestimated the financial burden of using aids; this is particularly clear in the activities which award no points for the use of aids, though we have made recommendations regarding this in our answers to the consultation questions. **We recommend that the Department re-examine the points awarded for the use of aids, with a view to increasing them in many cases.**

It would clearly be inappropriate to assess the cost of every aid to determine points. However, it should not be difficult to make a general evaluation, prior to finalising the regulations regarding assessment, to determine broad classes of aid within each activity, to determine categories that should attract more points—after the fashion of Activity 11. **We recommend the Department examine different classes of aids that might be used in each activity, to allow for more points to be awarded for aids that represent greater barriers or expense.**

### **4.4 Unsatisfactory Conduct of Consultation**

We are formally complaining about the conduct of this consultation. Appendix D on page 61 contains the text of the complaint we will be sending to the Department's consultation unit. We particularly feel that the Government's code of practice for consultations has not been satisfied in terms of criteria 3, 4 and 5.

Criterion 3 requires clarity of scope and impact. We are not convinced that it is clear what elements of the assessment are open to change resulting from this consultation, particularly given unclear statements about elements out of scope.

Criterion 4 requires the consultation to be accessible. We have received many communications from disabled people expressing feelings from dismay to outrage regarding difficulty accessing or understanding both the consultation document and the documents the consultation was regarding.

Criterion 5 regards the burden of consultation. We believe that a significant burden has had to be met by disabled people in this consultation, that should have been met by the Department.

## 4.5 Handling of Specific Conditions

Many people have complained at the refusal of the Government to specify certain conditions or treatments entitling a claimant to an automatic award for a given rate. While we agree largely with these criticisms, we understand the Government's intention in not making assumptions based on diagnosis or treatment. However, we would argue that there are conditions that should lead to a presumption, pending assessment, of certain awards; further, there are some assumptions that are so safe that they would allow an overall saving, avoiding the wasteful expense of assessing people in cases that are, essentially, foregone conclusions.

For example, if a claimant is severely visually impaired, it is a safe assumption that they will be entitled to Standard rate Mobility, as they will generally need guidance when travelling to an unfamiliar destination. If they use a guide dog, it is arguably inappropriate to challenge them on how they manage without it, as users of guide dogs are recommended to use them generally when out of the house[13], so they may be assumed to be entitled to Enhanced rate Mobility. A person on total parenteral nutrition (TPN) can be assumed to be very ill and in need of considerable care. If these people are to still be subject to a full assessment, it may be worthwhile to do an initial rapid assessment based on these presumptions and award them some level of PIP pending full assessment. This would enable them to begin meeting the additional costs of disability sooner, rather than struggling, possibly incurring debt, and then receiving a sizeable backdated payment. **We recommend that the Government examine conditions that lead to a reasonable presumption of a certain minimum level of PIP entitlement. Examples of levels we consider may be appropriate may be found in table 4.1 on the following page. These levels should be awarded pending full assessment, and if the total benefit awarded after assessment is less than the presumed level, no overpayment should be deemed to have occurred.** In some cases, it would be a waste of assessment resources to subject them to a full assessment at all. **We also recommend that the Government examine conditions that so clearly lead to Enhanced awards that a full assessment would be wasteful, and instead award based on confirmation of those conditions. We anticipate the number of conditions that would justify this would be small.** It is important to consider here that the reasoning is not that the conditions in themselves lead to an automatic entitlement, which we understand the Government's firm position holds as inappropriate. Rather, that the likelihood of such claimants not being entitled to Enhanced rates of benefit is so low that assessing them will cost more than it would save.

## 4.6 Impact on Independent Living, and Other UNCRPD Rights

We note the 23rd report of the Joint Committee on Human Rights in the current session[19], 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 11, their ability to get around independently will be severely curtailed, seriously affecting their quality of life, including the loss of

Table 4.1: Conditions that lead to a logical presumption of a certain level of PIP entitlement; this list is not intended to be exhaustive.

<b>Condition</b>	<b>Daily Living</b>	<b>Mobility</b>	<b>Rationale</b>
Severe visual impairment	Standard	Standard	Mobility is justified by the fact that such persons would almost certainly require guidance to unfamiliar destinations. Daily Living is justified by the fact that such persons are likely to need at least the use of aids, such as tactile labelling, in many aspects of daily life.
Use of guide dog	—	Enhanced	It is not appropriate to challenge a guide dog user on their ability to make journeys without it, as they are generally used for all journeys or none.
Total Parenteral Nutrition	Standard	—	Any person on TPN is likely to be very ill and require considerable care, as is it mainly used in cases of severe illness that will have other wide-ranging effects on the individual. If our recommendation regarding points awarded for therapeutic sources are accepted, it would be reasonable to presume Enhanced daily living.
Full-time use of wheelchair (e. g. inability to bear weight)	—	Enhanced	As such claimants will almost certainly be entitled to the Enhanced rate of the Mobility component, the assessor or Decision Maker should seek to confirm the use of the wheelchair initially, before proceeding with the full assessment, to provide this element of support before taking whatever steps are necessary to determine entitlement to the Daily Living component.

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:

“ A number of people will have to give up work, principally because of the problems with Activity 11, which will leave people without their cars and unable to travel to work or to get out of their homes. ”

A feeling that the reforms are led by a desire to reduce costs, even by removing support from those that need it, is common:

“ they have clearly been drafted (as opposed to drafted clearly) to redefine disability in order to save money, rather than to meet the needs of people living with support needs. ”

“ These changes are about economics, and mean less support for the sick and disabled people who need it. ”

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 recommend 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.**

## 4.7 Indirect Costs of Reform

We share the concerns expressed by Disability Rights UK in their report 'Impact Assessing the Abolition of Working Age Disability Living Allowance'[20], in relation to the costs that will fall in other areas if the second draft PIP criteria are implemented. This is because DLA often provides disabled people with the 'little bit of help early on' that prevents problems from escalating. From our own research among current DLA claimants, we would suggest the following examples of the sorts of costs that may arise:

- Costs to the NHS arising from taking away from less severely disabled people the 'little bit of help early on' that DLA often provides. These costs may include the cost of hospital transport for people with mobility impairments who lose their mobility component, including those who lose their Motability vehicle; greater costs arising from people's inability to visit their GP or to maintain their mental well-being by going out; higher hospital and prescription costs for people

whose condition deteriorates if they are unable to afford therapies and equipment to manage their condition. This is by no means an exhaustive list.

- Costs to the motor industry and the economy due to a smaller number of people being eligible for a car through the Motability scheme. The consultation document[1] provides a prediction that the number of claimants in receipt of the higher/enhanced mobility component will decrease from 1,040,000 to 760,000, a fall of 280,000 or nearly 27%. This does not account for any change in the proportion of Enhanced Mobility awards that will be of too short a duration for Motability, and the movement to shorter-term awards makes it seem likely the proportionate fall in awards suitable for the Motability scheme will be even greater.
- Costs to various local authority services as a result of disabled people's needs no longer being met by DLA. For example, it is likely that disabled people who have difficulties in getting around will be more likely to need services such as Dial-a-Ride if they are no longer able to afford to pay for taxis or cars and are unable to use public transport. Some disabled people will need support, such as domiciliary care, from adult social care if their condition deteriorates due to the loss of DLA support, and some families who rely on the DLA income of a parent may need services if they end up in crisis.
- Local authorities may lose revenue from social care charges, if clients receive less PIP than they do DLA, which most LAs take into account when setting the level of charges.

These are examples only and should not be considered to be an exhaustive list.



# References

- [1] Department for Work and Pensions. Personal Independence Payment: assessment thresholds and consultation. <http://www.dwp.gov.uk/consultations/2012/pip.shtml>, January 2012.
- [2] Hywel Francis. Letter to Maria Miller regarding the right to independent living. [http://www.parliament.uk/documents/joint-committees/human-rights/Maria\\_Miller\\_MP\\_on\\_IL.pdf](http://www.parliament.uk/documents/joint-committees/human-rights/Maria_Miller_MP_on_IL.pdf), March 2012.
- [3] S J Campbell, Anonymous, Sue Marsh, Kaliya Franklin, Declan Gaffney, Anonymous, Mason Dixon, Leigh James, Sam Barnett-Cormack, Rhydian Fon-James, Dawn Wilis, and Anonymous. Responsible Reform—a report on the proposed changes to Disability Living Allowance. Independent report from sick and disabled people, their friends and carers, Diary of a Benefit Scrounger, January 2012. URL [http://www.ekklesia.co.uk/files/response\\_to\\_proposed\\_dla\\_reforms.pdf](http://www.ekklesia.co.uk/files/response_to_proposed_dla_reforms.pdf).
- [4] Department for Work and Pensions. Disability Living Allowance caseload without reform: 2010/11–2015/16. Ad-hoc analysis, Department for Work and Pensions, January 2012. URL [http://statistics.dwp.gov.uk/asd/asdl/adhoc\\_analysis/2012/non\\_reform\\_dla\\_caseload.pdf](http://statistics.dwp.gov.uk/asd/asdl/adhoc_analysis/2012/non_reform_dla_caseload.pdf).
- [5] American Academy of Sleep Medicine. *The International Classification of Sleep Disorders, Revised—Diagnostic and Coding Manual*. American Academy of Sleep Medicine, Westchester, Illinois, 2001.
- [6] Catherine Soanes and Angus Stevenson, editors. *Oxford Dictionary of English*. Oxford University Press, Oxford, revised second edition, 2010.
- [7] NHS Choices. Foot care advice. <http://www.nhs.uk/Livewell/foothealth/Pages/Healthyfeet.aspx>, 2011.
- [8] The Society of Chiropodists and Podiatrists. Healthy feet. <http://www.nhs.uk/Livewell/foothealth/Pages/Healthyfeet.aspx>.
- [9] NHS Direct. Groin or vaginal irritation/infection. <http://www.nhsdirect.nhs.uk/FemaleSexualHealthSelfCare/GroinAndVaginalIrritationAndInfections>.
- [10] The Society of Chiropodists and Podiatrists. Footwear—a guide to choosing the best shoes for your feet. <http://www.scpod.org/publications/>

leaflets-posters-and-postcards/leaflets/footwear-leaflets/  
?assetdet1357310=3501, 2011.

- [11] wearespartacus.org.uk. We Are Spartacus website. <http://wearespartacus.org.uk/>.
- [12] We Are Spartacus forums. <http://spartacusforum.org.uk/>.
- [13] The Guide Dogs for the Blind Association. Guide Dogs UK Charity for the Blind and Partially Sighted. <http://www.guidedogs.org.uk/>, 2012.
- [14] Disability Benefits Consortium. Personal Independence Payment: initial draft of assessment regulations—Disability Benefits Consortium comments. <http://www.disabilityalliance.org/dbcpip.doc>, June 2011.
- [15] Parliamentary and Health Service Ombudsman. Principles of Good Administration. <http://www.ombudsman.org.uk/improving-public-service/ombudsmansprinciples/principles-of-good-administration>.
- [16] Department for Work and Pensions. Public consultation—Disability Living Allowance reform. <http://www.dwp.gov.uk/docs/dla-reform-consultation.pdf>, December 2010.
- [17] Channel 4 News. Full transport access for disabled 'not ever possible'. <http://www.channel4.com/news/full-transport-access-for-disabled-not-ever-possible>, April 2012.
- [18] Department for Work and Pensions. Personal Independent Payment briefing notes. <http://www.dwp.gov.uk/policy/disability/personal-independence-payment/briefing-notes/>, 2012.
- [19] Human Rights Joint Committee. Implementation of the right of disabled people to independent living. Committee Report 23, Parliament of the United Kingdom, Westminster, 2012. URL <http://www.publications.parliament.uk/pa/jt201012/jtselect/jtright/257/25702.htm>.
- [20] Disability Rights UK. Impact assessing the abolition of working age disability living allowance (DLA). <http://www.disabilityrightsuk.org/dlaimpactassessment.htm>, April 2012.

## Appendix A

# A Personal Example of the Need for Expensive Equipment for Management of Condition, Pain, and Sleep

*This section is the verbatim submission of a current DLA claimant who uses expensive equipment to manage pain, control their condition and facilitate sleep*

I currently receive DLA higher rate care and mobility, and I am very concerned that the second draft PIP criteria do not provide proxies for the cost of expensive equipment needed to manage my pain and breathlessness, prevent deterioration in my condition and maximize my well-being. I have had severe ankylosing spondylitis and spinal osteoarthritis for many years and I have a lordotic spine and restricted chest expansion. One of my biggest challenges is to find ways to manage severe chronic pain. I take a number of medications to manage pain, including anti-inflammatories and morphine; the total number of different drugs, including these, that I have to take on a daily basis is currently nine. I also use home oxygen to alleviate breathing difficulties due to restricted chest expansion (which also causes severe pain around my ribcage).

I have to use expensive equipment primarily to:

- control the pain caused by pressure on my spine and joints, and
- provide postural support to enable my body to assume a position that minimizes pain and maximizes respiratory function.

My GP and I have requested help from both health and social care services with the cost of this equipment but our requests have been turned down despite an assessment by the community physiotherapist which confirms my needs.

Since the slightest pressure on my hip joints and my thoracic and lumbar spine causes very severe pain, I have to use a 'dynamic' air mattress, incorporating a pump. This mattress, a 'Breeze' from Arjo-Huntleigh, also provides postural support by moulding itself to the contours of my lordotic spine. The 'Breeze' mattress cost me 3,700 in late 2009 and costs approximately 100 per year to service; it is expected to last a total of 5–10 years, after which time it will need to be replaced. I bought this when it became apparent that a memory foam mattress no longer provided sufficient pressure relief.

Due to the inflammatory and degenerative problems with my spine, I am unable to lie flat without experiencing extreme pain; I have to sleep with my shoulders and my knees raised. This position also helps me to expand my lungs. It is impossible to reliably create this shape with pillows, even with constant assistance from another person, so I have a profiling bed—an Arjo-Huntleigh Minuet 2, which cost 1,200 to purchase and approximately 100 per year to service; it is expected to last about 15 years, after which time it may need to be replaced. I used to have an adjustable bed from a high street store but it did not provide the postural support offered by specialist, hospital-type beds such as the Minuet 2.

Relief of pressure also necessitates the use of 'Varilite' cushions, which contain a cushion of air as well as moulding themselves around the body. I have one Varilite cushion which is fixed semi-permanently to my powered wheelchair and one which similarly replaces the standard seat padding of my armchair. Each of these cushions cost 335 and may need to be replaced after 3–5 years.

In addition to being unable to lie flat, I am unable to sit upright for any length of time and I also need excellent lumbar support. I therefore have a Kirton Fitform adjustable armchair, costing 3,000, which provides an essential tilt-in-space function to enable me to 'sit' in a similar position to that which I adopt in bed. The chair also has an adjustable lumbar support which provides the essential support I need for my lordotic spine. Adjustable chairs from mainstream providers do not provide a true 'tilt-in-space' facility but facilitate a 'reclined' position which is too flat to support my body. I hope my Fitform chair will give me many years of service but it may need to be replaced at some point in the future.

In addition to the above items of equipment, I also have to pay for and maintain my own wheelchair, with a tilt-in-space function, as I do not meet the criteria for a powered wheelchair on the NHS but am unable to use a manual chair. My higher rate mobility component of DLA pays for an internal transfer wheelchair accessible vehicle, for which the downpayment was mainly met by a grant from the Specialist Vehicles Fund. Whilst the rest of my equipment, described above, is extremely expensive, my higher rate care component of DLA makes some contribution to the huge overall expense of managing my condition. The need for expensive equipment should be covered by suitable proxies in the PIP criteria so that I can afford to maintain and replace it as necessary.

# Appendix B

## Illustration of Perverse Results of Draft Regulation 4(4)(c)(ii)

This is a scenario to demonstrate the flaws in Draft Regulation 4(4)(c)(ii). Based on experience of people with fibromyalgia, we consider it a plausible scenario. The principle illustrated, however, doesn't depend on it being plausible.

Let's take two people, Alice and Bob. Both have fibromyalgia, with quite similar needs. Both have typically 3 good days and 4 average or bad days a week, which we can call 40%/60% for clarity.

On all but good days, both need help to shower. Alice also needs a shower stool, even on good days, while Bob does not.

On all but good days, both need assistance to prepare and cook a simple meal. Alice also needs encouragement (which counts as prompting) to overcome the dread of fatigue, on all but the best days (say 95%).

They also both need, on all but good days, help putting on socks.

Bob's points are straightforward to work out, as only one descriptor in each activity applies more than 50

Activity 1	60%	F: needs assistance to prepare and cook a simple meal	4 points
Activity 4	60%	G: needs assistance to bathe	4 points
Activity 6	60%	D: needs assistance to dress their lower half	3 points

He scores 11, qualifying for standard rate of Daily Living.

Now consider Alice. On any reasonable consideration, she has greater barriers than Bob. However, applying 4(4)(c) from the draft regulations, specifically point (ii), we get surprising results:

Activity 1	95%	D: needs prompting to prepare and cook a simple meal	2 points
	60%	F: needs assistance to prepare and cook a simple meal	4 points
	Score used is 2 points		
Activity 4	100%	F: Needs aid to bathe	2 points
	60%	G: needs assistance to bathe	4 points
	Score used is 2 points		
Activity 6	60%	D: needs assistance to dress their lower half	3 points

She scores 7, failing to qualify for any Daily Living rate.

Thus Bob is entitled to Standard Daily Living, and Alice, who faces greater barriers and costs, is not. This is because 4(4)(c)(ii) requires that, if more than one descriptor applies more on more than 50% of days, you apply the one that applies on the greater proportion of days. This problem only occurs for variable conditions; the Government have indicated their intention that, if more than one descriptor applies on all days, the one that scores most points is applied. While it is not clear, we assume that the same principle applies if more than one descriptor applies for an equal proportion of days. Our recommendation on the amendment of 4(4)(c)(ii) would clarify all such situations.

## Appendix C

# The Experience of an Incontinent Adult—A Criticism of the Second Draft’s Treatment of Incontinence

*This section is the verbatim submission of an adult with full double incontinence.*

The continence descriptors for PIP are presently included in the activity for toilet needs, which is not appropriate, as the toilet needs for those people with normal function are very different from those with either bowel or bladder incontinence—these are conditions which are complex and have far reaching consequences. There are several areas of activity which are assessed for PIP and the effects of incontinence are not factored into any of them, which calls into question the validity of those assessments in providing an overall proxy for the costs incurred as a result of disability. For example: incontinence makes it more difficult to engage socially and has an impact on mental health, sometimes resulting in agoraphobia. This brought on by the fear of having an accident in public. This can also impact on mobility and the use of public transport for reasons above and also the necessity to carry the necessary supplies with which to deal with such occurrences—these effects are not taken into account anywhere in the PIP assessment.

For someone with normal function, toileting is about getting to and from the toilet, help with getting on and off the toilet and with cleaning after toilet use. For someone with either bowel or bladder incontinence - or in some cases both—‘toileting’ includes dealing with the effects of leakage/accidents and as accidents can occur anywhere at any time, frequently the cleaning of other areas beside the toilet or bathroom. It necessitates dressing and undressing, bathing or showering. Where a stoma or other collecting device is used, ‘toileting’ includes the changing of bags/collecting devices and associated skin care as well as all the other factors mentioned above.

Whilst I appreciate that bathing and dressing activities are covered elsewhere, I would argue that they are not as straightforward when dealing with incontinence as when undertaken as part of normal everyday ablution activity. Washing/bathing, dressing/undressing would occur at the start and end of each day. Where incontinence is a factor, these activities can occur frequently throughout the day.

Dressing and undressing, for example, after a bowel or bladder accident can involve the removal of wet or soiled padding/clothing and bodily waste from clothing and underwear. Bathing is more intensive as it requires the removal of some from the skin and thorough cleansing to avoid infection and ensure

personal hygiene. The process also involves the cleaning and disinfecting of the facilities to avoid infection. These issues also link in to the fact that PIP activities have to be completed 'safely, repeatedly and in a timely manner'—all of which factor here.

The costs involved with incontinence are probably among some of the easiest disability related costs to quantify and this further calls into question why PIP does not assess it properly. For example, increased showering/bathing and use of washing machines result in higher utility bills—this is ever more relevant as fuel prices rise. Can PIP really claim to provide a realistic assessment of extra cost if this is not factored in? Another example is provisioning of supplies. Due to increased pressure on the NHS, GPs are routinely limiting the supplies available to incontinence sufferers and stoma patients, as they are supplied via free prescription. This patchy provisioning means that DLA is being used by patients to buy whatever is not available from the NHS—including appropriate personal and bed padding, appropriate underwear, antiseptics and barrier creams, to name but a few.

I would also argue that using the present DLA care component, patients are better able to source these things a lot more cheaply than if they were provided via the NHS—examination of any specialist supplier's website will confirm the astronomical price of specialist underwear/padding for example. Cheaper mainstream items which can be modified are widely available and supermarket basics ranges in nappies provide a cheaper alternative than specialist padding. The expected reduction in cost anticipated by PIP will almost certainly be wiped out in providing patients who lose entitlement with alternative support at much higher cost.

On a personal level, let me give you a typical example of how someone with a common neurological condition—spina bifida—is affected by continence issues.

I have no bladder—I have a stoma which replaces the function and empties into a bag attached by adhesive to my side. This condition has never been well controlled due to frequent associated skin conditions which cause problems with adhesion of the bags and results in frequent leakage. Barrier creams help to some extent with the actual skin conditions, but they cause adhesion problems in themselves. The bags have to be attached to clean, dry skin, and in my case whilst lying flat, because I have a kink in the skin caused by scarring, which hinders adhesion. I need help from someone else to ensure the bags are positioned correctly and also to help me sit up afterwards. Leaks result in varying degrees of wetness which require bathing and changing clothes—again requiring help. I have to be careful about sitting positions, moving awkwardly and also the act of walking can bring the bags off—I have an awkward twisting gait which aggravates the problem. I use a night drainage bag which requires help from someone else to manage, and night accidents are frequent—bathing, bedding/clothing changing etc, are frequent occurrences in the small hours.

I have no voluntary bowel control, which necessitates padding and protective underwear at all times. I have no sensation in anus or buttocks and I have to do a 'manual evacuation' daily, for which I require help as I have to assume awkward positions and sometimes lie flat on padding to do the necessary. I have to watch my diet carefully as the bowel is easily irritated—episodes of diarrhoea are frequent and messy. The absence of muscle control and the effects of years of manual evacuations mean that the anus does not close properly after evacuation, resulting in leakage. Most of the time, after an accident the only hygienic way of cleaning up is to get into the bath or shower—again requiring help.

These are stand alone conditions in their own right, but when coupled with mobility problems, life gets considerably more difficult. I have a neurological condition and associated tethered cord syndrome which means that what lower limb function I have is slowly deteriorating. It makes toileting, showering and bathing very difficult even with appropriate seating and aids, and so has a significant impact on the



management of associated incontinence.

I hope this general description of the typical problems I face each day, helps to put into perspective the complex nature of this area of disability and goes some way towards making the point that PIP assessment activity and descriptors for incontinence do not belong in the general category of toileting. The PIP assessment simply does not recognise the extent to which incontinence is a factor across a wide range of disability—the only assessment provided for the condition under PIP is the simple award of points where the condition is not effectively managed. The condition is much more complex than that, and also has an effect in other areas of life, as I have tried to demonstrate here. I do not believe that the present assessment provides an adequate proxy for the significant cost of dealing with the condition and as a result, a significant number of disabled people will be left without support, which leaves the government open to the criticism that the design of the PIP assessment is more about saving money than providing that support.

## Appendix D

# Compliance with Government Code of Practice Consultation Criteria

*This section is the verbatim text of the complaint we are submitting to the Department's consultation unit regarding the conduct of this consultation.*

We believe that the DWP consultation on PIP assessments, as closed April 30th 2012, did not satisfactorily meet the Government Code of Practice for Consultations. We list below the way in which the consultation fell far short of good practice.

### Criterion 1: When to consult

*Formal consultation should take place at a stage when there is scope to influence the policy outcome.*

It is stated in the consultation document, paragraph 5.5, that the Government does “not envisage making significant changes to the broad principles or scope of the assessment i.e. to incorporate social and environmental factors”.

A consultation's purpose is to seek answers that can inform policy. If it has already been decided that no significant changes will be made, the scope of the consultation is limited and the premise is flawed. Participants may feel they are wasting their time, or be dissuaded from participation at all.

While it is positive that the limitations are stated, their specification is imprecise and unclear. **Whilst we understand your reasoning, a consultation needs to be open enough to take into account that some principles and assumption may not be correct. It is not clear what you are really asking or why.**

### Criterion 2: Duration of consultation exercises

*Consultations should normally last for at least 12 weeks with consideration given to longer timescales where feasible and sensible.*

Whilst it is accepted this consultation has had a longer time scale than the minimum, in real terms the time has been shorter, due to the delay in accessible formats being made available. Large print and

easy read versions were not available from the beginning of the exercise.

### **Criterion 3: Clarity of scope and impact**

*Consultation documents should be clear about the consultation process, what is being proposed, the scope to influence and the expected costs and benefits of the proposals.*

Criterion 3 has not been met. As commented under Criterion 1, the scope for influence is limited and, more importantly, unclear.

Criterion 3 states that information about the benefits of the proposals should be included; however, there is little information and justification for developing PIP in the way proposed. The costs have been evidenced, however; it is well known that the stated aim of the PIP proposals is to cut spending.

Equally, modelling an entirely new system on 900 volunteers from an extremely limited cohort when the current numbers of working age DLA claimants is 1.8 million seems to be extremely limited. The sample cannot be representative, as only certain categories of impairment were involved in the analysis.

The impact assessment also makes no attempt to account for consequent costs, such as increased demands on NHS and Local Authority services due to poorer management of conditions; on this point also the consultation fails to meet Criterion 3. In fact, it has fallen to Disability Rights UK to undertake an impact assessment of the proposals for PIP from their research among a large number of current DLA claimants (<http://www.disabilityrightsuk.org/dlaimpactassessment.htm>). In its report, which explains the likely extra cost burden of the PIP proposals on other parts of the public sector, Disability Rights UK makes the point that such an assessment would be expected to have been undertaken by the DWP.

### **Criterion 4: Accessibility of consultation exercises**

*Consultation exercises should be designed to be accessible to, and clearly targeted at, those people the exercise is intended to reach.*

Criterion 4 has not been met. The consultation was not accessible to the target audience, i. e. disabled people and their carers.

There are many ways that the consultation could have been undertaken, including, for example, making a video or spoken word version or commissioning consultation workshops. A number of disability groups independently realised that an online survey was a cheap and effective way to broaden participation yet this facility was not offered by the Department. No extra support has been forthcoming, and the consultation was not advertised to ensure as many people as possible could participate; for example, current DLA claimants were not notified.

Our experience of contact with hundreds of disabled people, particularly via social media sources, indicates that the vast majority of people who will be affected by the introduction of PIP have no knowledge or real understanding of the changes and, if they have seen the consultation documents, find them too daunting and complex to understand, still less comment on. The consultation has been badly thought out, limited in scope and does not meet best practice. It has taken a small group of disabled people with a professional background many hours to support people to access the consultation via a wide range of online support forums and social media groups but this has still not been sufficient to overcome the

inherent difficulties presented by the consultation.

Given that the number of people responding is anticipated to be relatively low, we would appreciate an indication from the Department as to how any future consultations could be organised in a more inclusive way. Groups such as People First are able to provide guidance and support for organisations seeking to make consultations accessible, relevant and meaningful to disabled people.

### **Plain English**

The consultation code of practice requires that plain English should be used. However, the original document was unwieldy, long, complicated and unintelligible. It is full of 'civil-service speak', such that even people familiar with the kind of language used found it almost impossible to decipher.

The following serves as an example:

"Each descriptor in the assessment criteria will have a relative weighting attached to it, reflecting both the level of ability the descriptor represents and the overall importance of that activity within the criteria as a whole. An individual's entitlement to Personal Independence Payment will be determined by the cumulative weightings which apply to that individual. For both the Daily Living and Mobility components, it will be possible for an individual to be entitled to the standard rate; the enhanced rate; or neither."

### **Assumed Knowledge**

The consultation document contains a series of assumptions; some of the questions referred to earlier consultations but did not provide links or guidance, making it extremely difficult to access or answer the questions. Where references were included, they were not clear; simply referring to regulations is not good enough. Reasonable adjustments were not made in relation to the target audience, ie disabled people.

### **Easy Read**

The Easy Read version was simplistic and failed to convey crucial elements of the new proposals. For example, the Easy Read Version showed images of people in wheelchairs using pans at a stove, whereas the draft PIP regulations refer explicitly to using a microwave instead of a conventional cooker. It provided general guidance about the nature of each activity, without giving readers guidance as to the descriptors and their relative scoring. We are particularly concerned that the missing detail concealed some of the most problematic aspects of the proposals.

## **Criterion 5: The burden of consultation**

*Keeping the burden of consultation to a minimum is essential if consultations are to be effective and if consultees' buy-in is to be obtained.*

In relation to buy-in, it is clear that the vast majority of disabled and sick people are extremely mistrustful and fearful of the proposed changes and the consultation has done nothing to allay fears.

Its premise is narrow and unwieldy. Basing the assessment process on a methodology (independent assessment by private sector 'healthcare professionals') that has been seen to be flawed when applied to out of work benefits seems to be placing the consultation on the wrong footing from the outset.

In terms of the burden of consultation, expecting the target audience—i.e. disabled people—to read and understand two long documents written in civil-service speak and jargon and respond to questions which necessitate understanding a complex set of activities, descriptors, scoring and thresholds represents a major burden. Many potential respondents, who may be affected by decreased attention spans and cognitive difficulties due to their impairment, simply found the consultation too daunting to respond, although they are the people most likely to be affected by the proposals.

There are currently three consultations which relate to the proposed Personal Independence Payment; they are all badly advertised beyond the website.

## **Criterion 6: Responsiveness of consultation exercises**

*Consultation responses should be analysed carefully and clear feedback should be provided to participants following the consultation.*

We ask that not only should the headlines and basic narrative be fed back but also that the methodology, the total number and source of responses, whether they are from groups or individuals, the actions to be taken as a result of the consultation responses, and the reasons for those actions, be included in the Government's response to the consultation. It should be clear how the actual points made in the consultation will be implemented and, if suggestions are made by respondents that are not implemented, reasons should be given.

## **Criterion 7: Capacity to consult**

*Officials running consultations should seek guidance in how to run an effective consultation exercise and share what they have learned from the experience.*

We ask for you to reply evidencing the steps you took to ensure the consultation would be effective. Who did you ask? And how did you arrive at a paper based, complicated onerous exercise as the most appropriate method of consulting with 1.8 million working age DLA recipients?