

Richmond AID response to DWP consultation on Personal Independence Payment: assessment thresholds

April 2012

1 Who are we?

Richmond AID is the strategic lead organisation (SLO) in the London Borough of Richmond for people with physical, mental health and sensory disabilities but we are a pan-disability organisation. We work with and on behalf of disabled people in our local authority. Our services include: specialist disability-related advice across a range of services via our telephone helpline and drop in service, benefits and welfare advice including casework, employment support, accessibility audits and support with completing social care financial assessments. We also deliver a gardening service to disabled people.

Our services in the round complement formalised care provision and give flexible, community-based support to disabled people living independently in the community and their carers as well as engaging disabled people within the work of the organisation.

Richmond AID has a community involvement group consisting of local disabled people who work with us on directing attention onto key service issues for them. It is members of this group and some others who have worked closely with us through a facilitated workshop on consideration of the latest changes to the PIP draft assessment. At the workshop we had involvement from people with visual impairments, mental ill health and physical disabilities. We have also involved staff members in the discussion of these proposals and have placed information on our Richmond AID website giving information on the consultation and encouraging direct responses to the DWP.

2 General comments

We have read all the associated documents as well as getting responses from local disabled people and although the consultation and explanatory notes have tried to closely define what is open to comment and what is not at this stage, we have to reflect the continuing concerns about the narrow boundaries of PIP and what is excluded from the new benefit.

We welcome that some changes have been made to the assessment criteria from the initial draft and that there is a further willingness to make changes arising from the consultation on this second draft of the assessment criteria. However the feeling is that the criteria remain too narrow and that the scoring is too restrictive and there are omissions around certain needs such as falls and people being able to stay safe in their home.

Looking back at our response in June 2011 to the first draft of the assessment criteria, we would just like to repeat a comment from then:

“DLA was introduced in 1992 in order to ensure that the financial burden imposed by a disability on an individual was mitigated to some extent. It was in recognition that disabled people faced additional costs not borne by others and although the benefit did not cover all costs it has gone some way to reducing the burden on individuals. DLA has been developed since its introduction to cover a fuller integrationist, social model as a disability benefit. With these draft assessment criteria, PIP completely reverses the social model approach and reverts to a medical/health model only. There is no attempt to locate a disabled individual in the context of normal daily living on a par with non-disabled members of society. “

- We remain concerned at the emphasis on a functional medical/basic needs model rather than a social integrationist model.
- There remains a failure to recognise that disabled people have expectations of engaging in normal daily life including employment and the draft criteria still aim at a low personal care/functioning level rather than broader engagement.
- It is ironic that DLA ‘care’ is being replaced by PIP ‘daily living’ yet the assessment criteria seem to emphasise more a care model than a daily living model in the fullest sense. Daily living requires a context, not just discrete tasks: shopping, laundry, housework, maintaining a safe and

hygienic home environment are all part of a disabled person's ability to function as well as engaging in broader community life.

- There is a danger of policy mismatch around PIP and other social changes: the independent living agenda supported by local authority social care does have a broader socially integrated model (currently) in the support it gives to severely disabled people. Our local authority and others are about to change access criteria to social housing to include a category of additional points for those applicants who – if not able to work – are engaged in a minimum number of hours of community/voluntary work per month. Disabled people would then be at a disadvantage if they could not gain these essential additional points to access appropriate social housing. PIP and its narrow criteria on most of the daily living activities would help disadvantage disabled people further.

3a Key areas of omission or narrow definition

- Falls
- Stairs
- Moving around indoors
- Washing/bathing
- Failure to consider the costs of major adaptations to a home to fit the needs of a disabled person
- The cost of purchasing and maintenance of aids
- The use and interpretation of the term 'overwhelming' psychological distress: how is this to be evidenced for the assessment?
- The use of the term 'needs' in relation to supervision/assistance/prompting as there will be a real test or tension in how this is assessed by the contracted health professional. It is not something that family and hospital doctors will necessarily be aware of and offer at first stage of supporting medical evidence. For people with learning disabilities for example, often there is minimal engagement with medical/other support services to be able to offer such supporting evidence.
- The scoring and the thresholds are a cause for concern.

3b Omissions/narrow definitions: in detail

- **Falls** – this is an area which does not appear to be referenced or scored both in terms of keeping safe indoors and outdoors. DWP/ONS MYE 2009 data quoted by Age UK is that there are 8,000 falls a day. A DWP guidance document on falls <http://www.dwp.gov.uk/docs/ch4.pdf> states:

4.2.1 There are certain disabilities which place the affected person at risk of falling. The nature of the disability and the person's age will have an effect on the amount of supervision they will need. In some cases, reasonable precautions can be taken which may avoid the risk of falling, or reduce the risk of injuries resulting from a fall.

4.4.2 Some practical precautions may have been taken to remove the risk of falling. Whilst it is reasonable to expect a disabled person not to undertake activities such as reaching for objects from high shelves, it is unreasonable to expect him/her to spend the whole day sitting in a chair. In addition many practical measures may reduce the risk of falling. If a mentally competent person is experiencing falls for which there is a clinical basis and reasonable precautions have not removed the risk of danger, then they are likely to need supervision and/or attention by day. Moreover the nature, pattern and frequency of falls in this circumstance will have an effect on the person's walking ability.

4.4.3 If the mental state is such that the person is unaware of potential danger and hence cannot take reasonable precautions; and the person is currently experiencing falls for which there is a clinical basis, there may well be a need for supervision during day-time.

Falls were an issue raised with us as something that affects people with a range of physical disabilities where balance is a problem. One individual (who is of working age so affected by PIP) gave us the example where falls are a regular feature for her, leading to severe bruising and even hospital treatment. She needs assistance to be able to get back up and has even had to seek the assistance of paramedics to enable her to do this when the person with her could not safely get her from where she had fallen. She also has falls when using her bath even though this is fitted with grab rails. There are major safety considerations for this person and yet supervision on safety grounds to deal with falls is not covered in the key daily living activities. Another (respondent 6) reported bruising from her falls and says these are a more regular feature now.

i) We strongly recommend that the risk of falls and need for supervision on this are incorporated both within daily living activities and in moving around.

- **Supervision** – it is not clear as to whether this criteria will be met if a need can be shown rather than the existence of physical presence of someone providing this. DLA criteria accept that this is met if the need is shown as it is not possible for everyone to have their own personal carer: this is especially difficult where people live alone or their partner on whom they normally rely is working. Local authority care criteria only make provision for those with critical and substantial care needs within our local authority (as do most others in England and Wales).

ii) We recommend that the assessment accepts this descriptor if the person demonstrates a need for supervision whether or not this is actually provided. The PIP application form must have this properly referenced.

- **Safety** – there is minimal reference to this within the activities especially in relation to people keeping safe within their homes. Unlike DLA which does look at safety within the home, there is no real acknowledgement of this in the PIP activities. Falls - as we have raised already - can be a major issue for disabled people within their home (as well as outside) and can lead to serious consequences, yet this is absent. Confusion and memory lapses which affect people across a range of impairments and can lead to accidents in kitchens/fires on stoves are not encompassed within these assessment criteria. Weak grasp, poor balance, peripheral neuropathy, are some of the physical factors which throw up greater risks to safety in carrying out daily living tasks and moving around the home environment. Cognitive challenges and mental health also create safety risks.

iii) Safety in moving around in the home environment needs to be factored into the daily living activities and have a score of its own.

- **Prompting** – it is important that there now appears to be an acceptance of the role of telephone prompting. It was previously excluded in the initial assessment criteria requiring this to be provided in person yet this is a widely used tool by family members, friends and professional support workers to provide support which is not always available face to face. In fact, telecare is now being more thoroughly developed as part of local

authority and NHS primary care provision to ensure that people get appropriate monitoring and support for day to day care and for monitoring of ongoing health needs.

iv) The clarification of the role and nature of prompting methods and mechanisms to support a person in being able to carry out daily functions must be clearly understood by the assessors and be referenced within the PIP claim form.

- **Pain and fatigue** – there is very little direct reference to these crucial factors in the daily living and moving around activities. These are major limiting factors in what disabled people can achieve in carrying out essential living activities. Pain not only means that an activity takes longer to achieve but it also stops people being able to carry out an activity or give up when they attempt to do it. (See appendix 1 for comments by respondents on how these impact on their ability to do activities.) It may be that the key definitions of safely, reliably, repeatedly and in a timely manner are intended to incorporate pain (and fatigue) but there needs to be much more explicit reference to pain/fatigue within all relevant daily living activities and moving around.

v) We recommend that pain is made an explicit factor for scoring within the relevant daily living activities and in activity 11 moving around.

4 Consultation questions

Q1 – 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?

Activity 1 – this fails to act as an effective proxy for how disabilities (whether physical, mental or cognitive) affect a person's ability through preparing and cooking a main meal for one person in the way that the current DLA cooking test

does. It needs to extend the criteria to include bending (to ovens and below waist storage units), reaching (above shoulders food and storage cupboards), balance and ability to get and carry food from fridge/freezer. We should expect disabled people to be able to enjoy a healthy, balanced main meal (albeit now only one course!) and for some people this will mean using an oven as less demanding and safer than multiple pans on a hot hob with other associated risks. The alternative is not a microwave for everyone because of the nature of ready meals being unsuitable for many health conditions (see appendix 1) and the guidance is for fresh not frozen components for the meal which would require different cooking times for the different types of meat/fish/vegetables which make up a meal.

(Appendix 2: respondents answer to question 1/activity 1 throws up some of the difficulties with where someone with OCD would fall within this category as it currently stands. Appendix 1 has 3 examples which illustrate problems with activity 1 as it stands.)

Activity 2 – the explanatory notes suggest that an ability to take tablets are covered within this activity (eg assistance with ensuring someone can take tablets that may have difficulty swallowing) but this is not obvious from the descriptors currently.

Activity 3 – as this currently stands, it would exclude alternative and complementary therapies many of which are well established but others which have gained credence as treatment for specific conditions but which are not yet mainstreamed or regulated by the Health Professions Council would be excluded.

We welcome the addition of medication and therapies which are recommended not just those actually taken as people are not always able to be compliant with recommendations due say to mental ill health (see appendix 2 example). However, we would also want to see a reference in guidance acknowledging the impact of medication or therapy which is needed to manage a condition but for which there are contra-indications eg NSAIDS for severe pain such as with arthritis but which cannot be taken by someone with severely impaired kidneys. There may be scope to have a section on the PIP claim form to indicate medication or treatment recommended or desirable but which cannot be taken: this would then be taken into account by the assessor when considering the needs level of the disabled applicant.

Monitoring and therapy which takes place outside the home is also apparently excluded yet there are a number of essential therapies which only take place

outside the home environment such as physiotherapy, other musculo-skeletal therapies, hydrotherapy, dialysis, group therapy and one to one sessions for mental health. Richmond AID have recently advised a client who was about to start an 18 month, three day a week, therapy course for a profound mental health problem which of necessity has to be in a non-home setting. The proposal that activity 3 should not take into account medication and monitoring requiring administration by a health professional is an unreasonable restriction as the concept of activity 3 is that a person needs to spend time and be supervised/prompted or assisted to manage a health condition and engage in necessary therapeutic processes to achieve positive management of their health condition/s: whether this is professionally supervised or by others should be irrelevant if that overview and treatment is essential to that person's well-being. B is too low a score as it does not reflect the importance of this function.

vi) We recommend that any recommended therapeutic treatment regardless of who is responsible for supervision should be eligible for scoring in activity 3.

Activity 4 – We are pleased that the entirely inappropriate reference to care above the level of self neglect has been removed. However, within our workshop this activity generated a lot of discussion and dissent particularly in relation to consideration not being given to bathing below torso level. It was felt essential to be able to include washing feet and legs – for many physically disabled people this is really difficult because of inability to bend. It is necessary for hygiene reasons but also for those with or at risk of peripheral neuropathy as the feet must be carefully checked to see if there is damage which could lead to ulceration. Such foot care is recommended by podiatrists to maintain healthy feet. We think that there should be a reference to washing and not just bathing as both these activities are essential. If there is just a reference to bathing, then those who are restricted to washing primarily and have difficulties even with this would not then be able to score in this category. So someone who has to use a perching stool and other aids to wash would not gain points as the perching stool would not apply to bathing.

We also don't understand why shaving is excluded as this is an essential activity in grooming for someone to engage in employment and social participation and requires finer skills than hair brushing and brushing of teeth as well as being a self-care, supervision and prompting need. Cutting finger and toe nails should

also be included in grooming activities. The need to cut toe nails in particular is essential to health management for certain health conditions.

It was also felt that F should attract a higher score to reflect the greater difficulties of managing the task of bathing (and washing) with aids and assistance. Other comments were that the very high cost of adapting a bathroom or having a wet-room installed for someone to be able to safely bathe were not reflected in the scoring and there was a worry that they could be underscored because of the provision of such expensive adaptations. B and C are scored too low and should carry a score of 2 each.

vii) We recommend that the reference to torso be removed and the ability to wash/bathe the whole body is included. We also recommend that being able to wash is separately assessed/scored to bathing.

Activity 5 – The context of the activity should include changing soiled and wet clothes as part of managing toilet needs.

There is no reference to managing menstruation which should be included as this is an ongoing need and could be seen as discriminating against disabled women if not included.

There is a failure to look at night time needs over toileting/access/safety which can be greater and different to day time toileting needs. Also if there are expectations that the person will use a commode at night – not that this mitigates access, assistance and safety needs – what consideration is given as to who will carry/empty and clean the commode?

viii) We recommend that night time continence needs are included in this activity as a separately scored activity.

Activity 6 – Though slightly modified with the addition of socks and slip on shoes, this is still too restricted. Normal or standard dress code including in many work environments would include ties and scarves. Again we have made references elsewhere on the issue of foot care for people with diabetes, arthritis and those with or at risk of peripheral neuropathy: health professionals recommend well fitted shoes with laces, not slip ons: so the reference should be not to slip on shoes but to shoes with laces/fittings (e.g. Velcro straps).

There is also a failure to understand why assistance to dress/undress the lower body should attract a lower score than the upper body: we believe that the score should be the same for D and E or just one category which scores 4 for difficulty/assistance with dressing upper or lower body.

Activity 7 – Respondent 5 in annexe 1 was confused as to how he as a severely visually impaired person would fit in a scoring category here as there appeared to be a crossover for him in activity 9 as a result of his visual impairment for which he uses adaptive software which doesn't resolve his needs and allow independence. Someone with his needs relies heavily on assistance to have information read out to him and to set up phone calls for him. Another client of Richmond AID has both cognitive problems because of her disability but also restrictive use of her fingers due to neurological damage: she relies on others for assistance in using telephones to set up the calls for her as well as assisting her through negotiating the context of the call. This assistance with telephone communication (an essential part of day to day communication) does not appear to be included in this activity specifically on communicating. There is also an absence of being able to write, open correspondence and related activities in this communications category. This same client is unable to write as well as accurately use a telephone or computer because of neurological damage affecting her fingers. Respondent 1 also commented on the difficulties he has with packaging due to peripheral neuropathy damage to his fingers. There should be a score category for people who need assistance to open correspondence and write including form filling on grounds of physical disability not just on intellectual or cognitive disability grounds.

ix) We recommend that assistance to make and receive telephone calls is given a separate score/descriptor in activity 7.

x) We recommend that a need for assistance in opening correspondence and completing written activities (such as form filling) on physical or sensory disability or other grounds be added to the descriptors.

Activity 8 – Is this category too restricted? Although apparently aimed at people with mental ill health, intellectual and cognitive disabilities, should this not also apply to people with other impairments such as those with sight and hearing loss or other disabilities which make it difficult for them to engage socially or where they may be the subject of exclusion? Our respondent 5 who has a severe visual

impairment thought that he met criteria within this activity. So should this activity 8 scope be expanded in terms of who it is intended to apply to or should activity 7 be more inclusive in its approach to communications and social engagement?

Activity 7 and 8 – We have concerns that younger people who have been deaf/visually impaired from an early age will be adversely scored in these categories (7 in particular) as they are more likely to try and aim for greater social independence and rely on friends/social groupings or the assistance of strangers to clarify needs/information and directions rather than restricting themselves to those who are trained or experienced in working with these specific disabilities. For example, our Employment and Involvement Manager has acquired skills in working with the deaf community but he does not have a specific qualification for such work although we do work closely with a number of deaf clients. Our concern would be that this accessing of informal on the spot assistance for those seeking independent daily living does not diminish the actual need for assistance and that people should not be penalised for trying to conduct daily living without an interpreter or professional enabler in tow.

xi) We would want to see guidance reflecting the above concerns and ensuring that people who are deaf or visually impaired are not disadvantaged by their independent efforts.

Activity 9 Referring back to the two examples of individuals we gave in activity 7, we believe that this activity should include assistance and not just prompting. Certainly the second client example we gave would, because of her cognitive difficulties in understanding complex financial decisions, need assistance rather than prompting. Respondent 5 feels that he fits this criteria because of the complexity of the material he is presented with and has to understand via the mechanism of his adaptive technology: we are unsure as to whether this fits in this activity so clarity of where his needs would be met are required.

Q2 – 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?

We have commented on some of the scoring within the different activities above. This is where we feel they are too low or there is a category omitted. From our workshop experience, there was only one participant who felt confident that she would score enough points to retain her current equivalent of DLA higher care and higher mobility. Other disabled participants found it difficult to see where they would score on an equivalence to their current level of DLA entitlement. Concerns were raised about the failure to take into account the cost of aids but also whether these aids would disqualify them from meeting a category. For example, one participant had had to move into a property with a wet room to enable her to manage her showering needs and she was worried that this would disqualify her from sufficient scoring in activity 4.

We are unable to say with confidence that other than those weightings we have directly commented upon that these are right for the range of disabilities and the nature of the impact of these on individual disabled people. We do have particular concerns having looked at the illustrative case studies that people with quite significant levels of needs who would qualify currently for at least the middle rate of DLA care do not score enough to qualify for PIP – this is going to leave many disabled people without any compensatory benefit for their daily needs and support including paying for the cost of aids and adaptations. There is also the particular concern about the scoring proposed to deal with the fluctuating nature of disabling conditions where certain thresholds are required and only one scoring descriptor can be chosen. We think this will mean that people with varying conditions but with intense totally disabling episodes which would get the highest threshold score for those periods would then not be able to show that they meet this for 50% plus of the 6/12month period and thus underscore for their needs. We think that this will also exclude people who suffer from different disabling conditions which attract scores but cannot on each of them go over the 50% threshold to count for the higher scores. We do not have immediate access to DLA/DH data which would show the proportion of people of working age who have multiple or complex disabilities but feel that this needs to be reflected in revisiting the fluctuating conditions scoring as currently proposed.

As to the qualifying threshold at 8 and 12, we would hope that the specialist disability organisations will be able to give guidance on whether they feel these thresholds are appropriate for daily living activities.

Q3 – 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?

Activity 10 It is important that the notes refer to unfamiliar journeys using public transport and we would want to ensure that assessors will apply this criteria even where the person states that they only attempt the journey on foot or by driving/being driven.

We are concerned about the term ‘overwhelming’ psychological distress and the requirement for there to be evidence of an enduring mental health condition, intellectual impairment or cognitive impairment. As we have said elsewhere how will the ‘overwhelming’ part of this be evidenced by the applicant and what will the expectations of the assessor be on this? We believe that the descriptor should apply where there can be shown that it would cause ‘significant’ distress. Also the link should not also be on grounds purely of enduring mental health conditions as there are many other restricting factors (eg access to toilets for people with conditions such as Crohn’s Disease or prostate problem urgency and others experiencing incontinence) or physical disabilities around access suitability for whom embarking on such journeys is a real cause for anxiety and planning.

Is assistance the same as supervision for example for someone with sensory disabilities? We have concerns over whether this adequately captures the situation of safety in emergencies and what can be frequent travel disruptions on public transport. This is especially difficult for people who are anxious travellers and those with sensory disabilities. This is a greater likelihood for those travelling in large city environments with complex travel networks.

We believe that assistance not just supervision and prompting should be included in activity 10 descriptors. It would appear that even including assistance as we recommend that many people who qualified from DLA higher mobility when the rules were changed to allow those with severe visual impairment to qualify, from descriptor C only 8 points would be scored and thus they would not qualify for the equivalent higher threshold in PIP. This would apply to two of our severely visually impaired workshop participants who would be losing their higher DLA mobility on reassessment for PIP.

We are assuming that people with a combination of disabilities which fit into activity 10 as well as 11 will be able to score in both categories but will they be able to combine the scorings or will they remain discrete?

xii) We recommend that the word overwhelming should be replaced by significant, that the distress should not just be as a consequence of enduring mental ill health, cognitive or intellectual impairments but to allow other disability factors which contribute to distress/barriers to planning and conducting a journey to count within this criteria.

xiii) We recommend that assistance should be added to prompting and supervision within these descriptors.

Activity 11 This activity is a matter of great concern to people with disabilities which limit their ability to get around. **We have had sight of the 'wearespartacus' response document and would like to endorse their concerns and recommendations in respect of activity 11.**

In appendix 1 both respondent 2 and 6 have specifically picked up on their worries about their very limited and painful mobility and how they would score under the new descriptors. Respondent 3 (with ME) during the workshop flagged up the problems she experiences where she has a wheelchair as a backup if she cannot get from the car to venue/activity depending on how fatigued she is. However, she needs assistance with the wheelchair. All of these respondents currently receive DLA higher mobility on which they are heavily reliant for their higher disability travel costs both for a motability car in one instance and taxis and paying for use of cars in the others. Respondent 3 also flagged up the problem in reference to daily living activities which would apply equally here that where you have a condition which gives you limited energy that what is used for one task may then stop you doing anything else calling on that energy bank as a consequence.

The notes in the explanatory document do not refer to the need for the activity to be considered repeatedly or to pain, fatigue and severe discomfort. These are all essential factors in a person's ability to be able to make even the shortest of the suggested new distances. Therefore if walking up to 50m with aids leaves a person severely fatigued and in extreme pain, there is no further functionality or meaningful activity that they can then carry out as a consequence. We believe that a person in this instance has such severe mobility limitations that they should be given the highest scoring (which as wearespartacus has suggested should be capped at 12 points). We find the up to 50m a quite meaningless distance both for walking with aids and for wheelchair use and suggest that this has to be doubled to 100m. No consideration appears to have been given to those with disabling conditions generally or of the hands/upper body (eg

MS/ME/arthritis/severe heart/lung conditions) who would not be able to propel themselves on typical terrains including kerbs for any significant distance and then have the capacity to engage in what their end task of mobilising for was intended to achieve. How would the assessment take into account someone whose mobility needs really require a motorised chair but whose accommodation would not allow this to be achieved?

We also have had raised with us the issue of where someone actually needs to use crutches (which support up to 70% of body weight) but only uses a stick (supports up to 25/30% of body weight) as they are too frightened of falling and not having a hand free to save themselves hitting the ground. This participant who is in receipt of DLA higher mobility suffers really severe pain from walking short distances as a consequence and regularly suffers from acute flare ups of pseudo gout in the knees (when they can't mobilise at all for some considerable time) and severe spinal pain. The need to use crutches where recommended by a health professional reflects a higher level of need that should be reflected in the scoring as would someone recommended to use a walking frame as this denotes a higher level of disabling mobility.

Although the explanatory notes (p37) state that activity 11 takes into account a person's ability to move around generally is considered and not just outdoors, we cannot see evidence of that in the actual scoring descriptors.

xiv) We generally endorse the recommendations on activity 11 in the wearespartacus response to this consultation other than their proposed new C and D which we believe they have underscored.

xv) Additionally, we recommend that the descriptors include safely, reliably, repeatedly and in a timely manner.

xvi) We also recommend that pain, severe discomfort and fatigue should be separately referenced rather than just being buried within the concept of repeatedly. These are all essential in considering whether a person is able to mobilise that distance and be functional for other tasks as a consequence.

Q4 – 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?

If we could comment specifically on activity 11 weightings and thresholds. We would understand the purpose of this element of PIP is to acknowledge the higher costs of getting around which their disability places limits on and to grant them a benefit level which enables them to do that. We cannot look at this in a vacuum and will obviously be looking at DLA higher mobility as a comparison point for meeting the needs of severely disabled people. The current proposed descriptors will not give sufficient points with the assumption of 12 points as the threshold to equate to motability and blue badge automatic entitlement. Descriptors B and C significantly underscore in terms of functional mobility especially where Bii is referring to using an aid or appliance – we assume this to be a walking stick/s, crutches, walking frame. Leaving this as it stands would mean that unless proper consideration is given to all mitigating factors as referred to in our recommendations xv and xvi above, this person would not even reach the standard rate leaving them with very restricted mobility and extra costs but no acknowledgement of this through a PIP mobility award. We see this as serious underscoring. We are uncertain as to who category C will apply to other than people with conditions which prevent them using aids such as sticks and crutches and those with severely restricted lung capacity or certain neurological/immune conditions but this surely is equivalent to someone who is unable or virtually unable to walk and requires a higher score of 12? Category D would appear to apply to a significant proportion of those who currently qualify for DLA higher mobility on the basis of their severely restricted mobility – this new scoring would take them onto only the standard rate of PIP mobility and out of entitlement to motability and certainly not reflect the costs of their additional travel needs whether by taxi or renting/owning a car to get around. We believe that D should refer to over 100m and should have a score of 12.

We also believe that where someone can score in both activity 10 and activity 11 that these scores should be able to be combined. This would apply to one of the visually impaired workshop participants who is both severely visually impaired (giving him a score of 8 points) but who also has arthritis restricting his mobility.

Another regular contributor to our community involvement group but who couldn't attend the workshop also has this same combination of disabilities. Both currently receive DLA higher mobility but would only reach the standard threshold under the PIP proposals unless their different disabilities within the two categories could be combined.

xvii) We recommend a complete review of the scoring categories for activity 11, the removal of reference to up to 50 metres being replaced with up to 100 metres; the increasing of the scores in revised categories B, C, D; the consideration of the use of walking aids using both hands generating a higher score.

Q5 – 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?

Reg 2 (1) (a) defines aids and appliance but there is no reference to an **adaptation**. We think that this should also be included in this definition to include adaptation of premises to enable access and functioning for the purpose of someone with disabilities (eg kitchen adaptations, wet rooms, widened doorways etc). We are also concerned as to the inclusion of prosthesis as these are not always a successful aid and require assistance to fit in many instances. Perhaps guidance will clarify their treatment?

Reg 4 (4)(c) we are generally opposed to the current definition and treatment within PIP for the 50% criteria threshold for fluctuating conditions. Please see comments below.

Reg 4 (4)(d)(ii) we don't believe that this should be in the regulations as who will determine what 'reasonably' should be in the context of the individual and their own experience of disability: this is likely to lead to legal challenges at tribunal level and above. Assumptions are likely to be made by assessors that certain aids would be reasonable when that person is not able to obtain or to use a particular aid or (eg commodes) it could then bring further problems managing the aid. If it is to remain, there should be a reference to an expectation that only cheaply available or NHS provided aids should be considered. Alternatively, it

could be rephrased as to that consideration should be given as to whether there are suitable aids to enhance function in a given activity.

Reg 4 (4)(e) Our objection to this regulation is inherent in some of the challenges to the descriptors and the 50% rule. Although ostensibly it is there to ensure that only the highest scoring descriptor should apply, there is a real issue for disability organisations in the design of the separate activities in that there will be people who will have different disabling conditions which would give them different scores for that functionality. This is going to be especially highlighted over the 50% rule but is not solely restricted to that.

Q6 – 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?

We believe that although the general premise appears reasonable to look at how a condition impacts on someone for the majority or greater proportion of the time,

we have concerns about flaws in the process. We know from years of client experience that conditions can remain stable for a time and then become much more severe and that it can be difficult always to predict when, how and for what proportion of time will that person be much more severely impacted by their condition/s. For example, an auto immune condition such a rheumatoid arthritis may go into a flare up unpredictably dependent on stress or other factors. A change of medication may also trigger a major change in a condition: for example anti-TNF treatment for an auto immune condition may produce excellent results initially and then cause an adverse reaction and crisis. Someone with ME/MS may be stable at a certain level of need and then have a crisis in their condition. There are mental health conditions where a short period of therapy can bring improvements especially with high levels of support but once that is removed there is a decline in that person's ability to cope.

There are significant numbers of people who have more than one major health condition and these have different impacts at different times.

xviii) We feel that there must be a way of having a score in the activities which can combine the impact of differing health conditions to consider their cumulative effect on the person's ability to carry out that activity. We recommend that the team responsible for drafting the final assessment criteria and regulations find a way of fairly addressing this issue.

There are also conditions which could fit a high descriptor for a shorter period of time leading to extreme level of restrictions to daily living/mobility activity and then a longer but unpredictable period where the level is less severe: in that period of extreme/highest need the person could be barely functioning and the proposed rule where the descriptor is matched to the proportion of time which is greatest would discriminate against that person being able to function when needs are greatest. It could also have a knock on effect for other passported help available through the benefits system, through local authority support systems and ancillary support services which tie in to using set levels of DLA (now) and PIP (future) as a qualifying gateway to other services.

xix) Regulations need to be amended so that where more one descriptor within an activity is met for more than 50% of the time, the highest scoring descriptor will be chosen. We also feel (as the wearespartacus response recommends) that activity A should be discounted where this would be

satisfied on less than 50% of the days and only other descriptors be selected.

Q7 – 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?

We generally accept that these are essential criteria as to the level of activity which is appropriate when assessing someone for PIP. However we would like to make the following comments:

- Although **repeatedly** is meant to encompass pain and fatigue we believe that this should be separately referenced as a definition or significantly strengthened within this.
- **Repeatedly** should look more holistically at the impact that descriptor would have on a person’s ability to carry out that task but also on other tasks not just for that day but on subsequent days as people who experience pain and fatigue (or distress) from carrying out an activity find

that it can take more than one day to recover from the effort of the activity. (This was specifically referenced in responses at our workshop.)

- **Repeatedly/reliably/safely** should also be considered in the context of whether that person has family/work/employment commitments which mean greater risks and expectations of their activities. Eg if someone is a parent of young children, then there would be a different emphasis on what these factors signified in relation to the well being/safety and care of these children.
- An additional factor should be added which is that an activity should only be selected where that activity action would not cause severe discomfort: where it does, then a higher scoring descriptor would apply.
- **Safety** – It must be understood that disabled people will undertake activities and actions that are not really safe for them but often they have no option or because they resent the restriction their disability places upon them and determine to do it anyway. This does not make it safe for them to do this activity so they should not be scored as though it is safe.

xx) We recommend that these definitions should be in regulations not just in guidance and that they should be referenced throughout the body of the PIP claim form to reinforce the importance of these as to whether or not someone is able to meet a given descriptor or not.

xxi) We also believe that pain, fatigue and severe discomfort should be specifically referenced within the explanation of these terms in the regulations and on the claim form itself so that individuals properly understand the meanings of these when they are trying to establish which descriptor they are able to meet.

Q8 – 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 have already raised concerns on a number of these definitions in the body of the text of this response and would refer you back to those points within the specific activities. However we would like to just summarise those with which we have particular concerns:

- Aid or appliance: we feel that there needs to be greater clarity as to the status of adaptations which are not referenced here but will potentially disadvantage applicants if the existence and cost of these are not treated as 'aids'. There should be consideration given to the initial cost of aids and that of maintenance and replacement (eg mobility scooters/high end software for visually impaired/major home adaptations).
- Assistance and supervision can overlap.
- Bathe – this should include the whole body including feet and lower limbs and cover showering/bathing/whole body washing.
- Cook – this should be from fresh, unprocessed ingredients and include cooking below waist height and encompass the range of activities such as selecting and accessing stored food, accessing cooking implements and equipment. (How does this relate to prepare?)
- Communication support should also allow informally provided support as otherwise it is too restrictive and discriminates against people who are unable to access trained and experienced support for the entirety of the time and in the different environments that this is needed.
- Communication support should also include writing and telephone communications.
- Dress and undress should include culturally, socially and medically (health recommended) items which would include ties, lace up shoes, saris etc.
- Engage socially should be extended to include those who may experience additional needs in this category due to sensory disability or other profound impairments which make social interaction and engagement more difficult.
- Groom should also include a basic wash of key parts of the body which would then allow an aid such as use of perching stool to be considered. Shaving and cutting of finger and toe nails should be included here.
- Manage incontinence should be extended to include night time needs and menstruation plus essential changing of soiled clothing which any of these give rise to.
- Manage medication or therapy should not just refer to home based therapy or exclude monitoring by a health professional.

- Overwhelming psychological distress. Replace or add to this definition by adding a further element to the definition which refers to the significant psychological impact of a physical disability or disfigurement.
- Prompt should make clear that the person doing the prompting does not physically have to be there with the disabled person.
- 'Support dog' should be replaced by the more commonly understood 'assistance dog'.
- Therapy – we strongly disagree with the definition that this should be therapy undertaken at home as there is significant physical and mental health support therapy which cannot be carried out at home and has to be in professional and other medical settings. This still requires time and need for this therapy so we don't see why therapy wherever it takes place should not qualify. We are also concerned as to what constitutes long term as NHS resourcing often means that therapy is not necessarily provided for the length of time reflected by the actual need but rationed by the available resourcing. This needs to be revisited.
- Toilet needs should extend to assistance with any washing of the body and changing of soiled clothing as a result of incontinence/toileting difficulties/menstruation. It should also include getting to/from the toilet and night time toilet needs.

Q9 – 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?

Reg (5)(2) information must be provided under reg (5)(1) within one month does not allow enough time for the communication to travel through the postal system not just at bank holiday periods but in general. This would leave the disabled person or their carer with very limited time to get the further evidence together that is being requested. There should be a modification here that would allow the applicant to respond within one month with an indication that the information will

be forthcoming and thus have this accepted without having to resort to the discretionary role of a Secretary of State decision on extension.

Reg 6 This is too harsh and there should not be a negative decision before a follow up attempt within a further 2 weeks of the initial request is made to contact the applicant and no response has been received. Good reason is critical to employ here also.

Reg 7(1) There is a need to add (d) or a domiciliary visit where appropriate.

Reg 7(3) 7 days is not adequate notice especially if this leads to a negative determination. The person may be temporarily away on holiday/in hospital/recuperating/coping with a bereavement, or waiting for assistance to open or process their mail or too depressed to open the mail or respond. There needs to be a longer period eg 3 weeks and a longer period at Secretary of State decision if reasonable: (this also should apply to Reg 7(4)).

Reg 8 needs an additional good reason category such as Reg 8 (c) any other good reason to be determined by Secretary of State/decision maker.

Reg 9 should this not have added: a re-determination within a reasonable period in respect of the qualifying impairment?

Summary

We have addressed the major issues within the latest draft assessment criteria for PIP. We recognise that specialist disability organisations who deal with a discrete health or disability (e.g. MS Society, RNIB, RNID and many others) will be able to illustrate their concerns with more detailed case examples pertinent to the points raised. We have used our overall experience of a diverse range of clients and those disabled people who choose to engage with our services to compile our response.

There remain many anxieties about PIP including the more restricted model of daily living and mobility which represents a move away from the social model and the lost opportunity to consider the wider costs of utilities, housing, domestic support services that disabled people incur purely as a consequence of their disabling condition/s.

We hope that our observations and comments have sufficient strength of argument and concur with other disability organisations and individuals in enabling those responsible for the design and delivery of PIP to make further adjustments to the assessment criteria and to the regulations.

We recognise how critical the training of the assessors will be in proper application of the activities based on the definitions and the qualifying restrictions addressed in Questions 6 and 7. Both the training and guidance are essential in how consistently activity descriptors (in their final form) and definitions are applied: disabled people and their organisations need to be involved in further contributions and consultation in respect of these. Some of the terms are subjective such as the interpretation of the word 'need' in relation to assistance, prompting and supervision or the choice of the word 'overwhelming' in relation to psychological distress. We have a particular concern as to how guidance and training will be given to the assessors around such significant terms.

We have given 21 numbered recommendations but there are further recommendations in the body of the response. We would wish that these un-numbered recommendations are also addressed.

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April 2012

Appendix 1 Specific contributions from disabled participants following the facilitated workshop

Respondent 1

“Q7: With regard to safely/timely/repeatedly, I would like to say that if a very sick person tries to do a task repeatedly, they are very likely to then suffer later or the following day, due to fatigue or exacerbation of symptoms, which will then in turn make their condition worse. In future it could then mean that they could not do anything at all. I feel that it is vital that these terms be included in ALL the Activity descriptors/regulations, because people such as myself who have a fluctuating condition which can change suddenly and without warning need to be included and such problems taken into account.

It is also essential that as far as safely/timely/repeatedly is concerned, mental health issues are recognized and not just physical harm, and should apply to all the Activity descriptors.

Example: I have an Aids diagnosis which caused me to contract TB; because of that I have permanent chest disease (Bronchiectasis) which means I often have shortness of breath and exhaustion/fatigue. Yes I CAN walk 50 metres unaided (Activity 11) BUT if I do it more than once, repeatedly or on a regular basis, or try to do it when I have a chest infection which I often have, it would make the condition much worse, and I would be in danger.

Example: I suffer from Peripheral neuropathy as one of the side effects of my medication, and severe skin disease which effects my fingers with very painful lesions. Preparing a simple meal (Activity 1) is difficult owing to this reduced manual dexterity. I cannot open packets or tins, cut food etc without help, and have difficulty with switches and appliances. If I struggle to do this activity it would make the condition worse, and I could be in danger with appliances (eg cooker).

Example: Preparing a simple meal (Activity 1). Many people including myself who have serious illness and have to take a large amount of life saving medication, suffer from gastro-intestinal problems, not only related to their illness (eg HIV/Aids or Cancer) but from the medication itself. Having to eat microwave or 'ready meals' in my situation is just not possible, as they just upset my stomach and exacerbate nausea and diarrhea and would make

my health problems worse. Yes I could maybe use a microwave, but eating microwaved/ready meals would be detrimental to my health, therefore such issues need to be taken into account.

Q8 Definitions in the regulations; I do not feel that the government have used the right words to explain things; on the contrary I feel the language used is confusing and difficult to comprehend what they need to know.

Q9 As far as the assessment process is concerned, I feel it is VITAL that the opinions of your Consultant and GP are taken into account, in order to avoid the catastrophic mess of the WCA and ESA. It needs to be fair and needs to be made safe, and treat Disabled and sick people with dignity and respect. Mental Health conditions also need to be taken into account, which has not been the case with the WCA.

It is also important to consider the point of constantly assessing people who have health problems which are just not going to improve and are only going to get worse (ie chronic, progressive and persistent). It should be considered what continually assessing such people will do to their illness in general ie could symptoms be exacerbated because of the stress and anxiety of such a process, and could it mean a deterioration in mental health as a result ? Are the current plans in the draft safe?

I also want to mention some other points which may be of interest; they are also included in both documents which I have enclosed. I will be also submitting my own response to the DWP.

The 'Implications in a reduction expenditure' ie the fact that lower rates of DLA actually have a 'preventative' benefit which helps people with various illnesses (HIV/Aids is just an example) to stay well and manage their treatment regimes etc. The proposed focus of PIP to focus on those with the greatest need will mean that those with lower level needs will no longer have the resources to maintain their health. This will without doubt lead to 'disease progression' and make them more likely to develop health related needs in the future if they deteriorate physically and/or mentally...resulting in much more costly assistance in the future.

Also, the DWP has stated that PIP should support 'participation' among people with Disabilities and long term conditions. However..there is NO consideration of social or leisure activities in the assessment. By contrast, DLA eligibility takes

into account whether the claimant faced barriers to social activities, participating in hobbies or attending places of worship, as a result of their health, and if extra support would increase their participation.”

Respondent 2

“I have completed my own draft assessment form, and I must admit to finding some of the questions difficult to answer regarding my own health conditions, particularly the Moving around section (11). I think section D most refers to me, due to my walking difficulties. However I am still not sure, I do find it difficult to understand because of the way it is worded. I also believe that this section should be graded at 12 points not 10 points for the following reasons:

I have a number of health conditions which vary in severity from day to day, week to week. For example I suffer with Lumbar Spinal Stenosis (which causes pain and numbness in my back through the lower half of my body to my feet)

Osteoarthritis in my knees, Spondylolisthesis, Coccydynia, and Asthma. Any one of these conditions affect my walking from day to day. Some days it is difficult to go out because of back pain, it is painful to walk, or I am breathless.

My ability to walk timely and repeatedly varies from day to day, week to week. I also do not believe I can walk safely; as I have difficulty walking on even and uneven surfaces, up stairs, on slopes, and hills are impossible. I have stumbled and fallen many times whilst walking but I do not use a wheelchair as yet because sitting for long periods is also very painful, walking for long periods is painful. Where do I place myself on the assessment. How am I to assess my walking speed when it varies so much? I believe the government would consider me fit to work, if I wasn't already retired.

The government ought to consider the fact that the impact of many health conditions can vary from day to day, week to week.

I have noticed that there is no mention on the form about walking up stairs, or slopes, or uneven surfaces, not all roads are flat and even.

Pain and fatigue seems not to be mentioned, yet it impacts on many lives.

The Daily living (activity 1) section concentrates on food preparation only. We all know that preparing food is not all there is to our daily living. I cannot see a mention of keeping the areas around you clean and tidy, of bending or stretching to reach things in cupboards, or to carry things. Not everyone has a partner to

help with these activities. There appears to be no mention of shopping, washing your clothes. I find the current draft assessment unrealistic of the daily lives of individuals.”

Respondent 3

“1. Really important that the *reliably, repeatedly safely and timely* bit gets into the regulations as this determines whether people with ME will qualify. The problem is that we can do all sorts of things once but not repeatedly. We have a limited amount of energy in the first place - call it an energy budget - and each activity mental or physical depletes this until we are "over drawn". For example re. mobility - trying to navigate to somewhere unfamiliar will use up mental energy and if we are on foot physical energy **at the same time. Both mental or physical exertion make us exhausted physically and mentally.**

2. For this reason I think there needs to be descriptor for each activity which says something like *cannot do this without suffering fatigue/pain*. The example I gave at the meeting is relevant here - we may manage to cook a meal on a good day but then be too exhausted to eat it. Thus I am concerned about the separate activities in the Care Component as the energy lost in doing any one of these has a knock on effect on doing another one. Another example: if I wash my hair one day I will not try to cook a meal on the same day. Doing one of the activities can therefore use up all the available energy for that day.”

Respondent 4

“Activity one – needs to be much clearer – between hot surfaces (P too scared to use) and MW. She can heat stuff in a MW but not really cook in it. She would need to be supplied with the food, which ever route. The key issue has to be about could the person feed themselves safely (with heat and knives etc.) or not. She could not.

Ten Motabilityit is currently was too woolly. She (P)cannot catch a bus/ train on her own and is uncertain on all her journeys bar 1 (to the local shop)

The key is not physical but about mental – information assimilation (does she fully understand? Often not). And retention (bad memory – yes she has).” (PA supporter to disabled person)

Respondent 5

“Activity 1 – preparing food & drink:

E certainly needs assistance to prepare and cook a simple meal. There would certainly be issues about it being done safely and in timely fashion without lots of help.

Activity 2 – Taking Nutrition: I can really struggle with the mechanics of eating – my wife often has to cut food up for me!

Activity 3 – Taking medication: E noted that he has taken the wrong medication before – so certainly not always done ‘safely’ without assistance.

Activity 6 – Dressing and Undressing: “I certainly need support with choosing my clothing if not the actual physical getting ready and it’s important for people with a visual impairment this distinction is made. For example, I have been out to a hospital appointment before and had on two completely different shoes!”

Activity 8 – Engaging Socially: This is an element of my condition that is largely hidden. Feels that he is between 2 & 4 points on this category. But more than likely a 4 score. It can be very difficult to engage socially when you can’t see very much and I can do this with the support of a third party.

Activity 9 – E has interesting take on this, he struggles with making financial decisions, mostly because he gets overwhelmed by the sheer volume of information. Even with adaptive software he still struggles with the volume and the fact that information starts out in a format that simply does not suit him. He really would not know where to place himself on the points scale.” (Severely visually impaired)

Respondent 6

“I want to know why they do not seem to be taking into account safety in the home. I have real problems as I have so many near falls and falls – my replacement knee can suddenly give way and often I seem to trip myself up with

my feet and catch them on my trousers. I have bruised myself falling and it is a real struggle to get up or I grab onto a work surface or chair to stop myself going down. I can have problems with postural hypotension out of the blue as well so I lose my balance and fall back onto a chair or whatever is there to grab (there is also a problem with one of my medications for hypertension which inhibits renal autoregulation). My balance generally is poor as well and I drop and spill things such as when I am trying to make a drink sitting on my perching stool. I knock things over as well as my judgement seems to be poorer now. I have also forgotten that I have left something cooking and have burnt the saucepan and contents. I manage to burn myself on hot pans like when I am boiling an egg for breakfast. I find it really difficult to bend down to put something in to or get it out of the oven: sometimes it is just easier to put something in the oven to cook as I can't manage two or three different things to cook for a meal and juggling pans as this is too tiring for me. I can't cope with washing up saucepans afterwards either. Because of another chronic health condition, I can't rely on ready meals due to their high salt and fat content so this means the microwave is not an alternative to the cooker for me. It would also be too exhausting if I were to try and cook a meal from different food groups using fresh ingredients in the microwave which would satisfy the guidance from my consultant and dietician.

I think that you have failed to take into account the need for someone to move around indoors including getting to and from the toilet and kitchen as well as going upstairs – I have had stair rails fitted but it is still very slow and painful for me to get up and down.

I am worried about the definition of bathing not including the whole body. I have diabetes as one of my ill health conditions and circulatory and heart problems. I see a diabetic podiatrist for checks and to cut my toenails but I am meant to check my feet regularly and keep good foot hygiene to look out for any damage to my feet as there is the risk of peripheral neuropathy damage. I can't bend so I can only check my feet when I am in the bath as part of my overall hygiene and care. When I was very ill recently and had to have home care support, the carers had to wash my feet and legs for me as I couldn't bathe or shower and I couldn't bend to wash/dry and check my feet (and legs).

The diabetic podiatrist has also stressed that I should not be wearing slip on shoes but lace up shoes because of my diabetes and the need to have proper support for my foot health. This is a real problem as I can't bend to tie up the laces. I don't think you should be restricting shoes to just slip ons as this is contrary to medical advice for myself and other people with diabetes or circulatory problems who could develop or may have peripheral neuropathy damage.

I am really concerned about the activity 11 on moving around. I get higher mobility and have done for a number of years because of my severe arthritis plus I have another chronic back condition which is painful when I am sitting and really severe when I am on my feet to stand or walk. On the advice of the physiotherapist I have to use crutches to support myself walking but can only manage a very short distance before the pain is too great and I have to stop and rest. I get wiped out and exhausted with pain from the effort of walking and have to ask shop assistants or my companions to go and get items for me if I go into a big store as I can't do any more walking having walked from the nearest car parking point.

If I am using my mobility scooter I can get around but I can't take this on the buses nor can I use it in very cold weather (because of my heart condition) or in the rain. I rely on wheelchairs if I am going around an art exhibition or museum as I can't stay on my feet but need someone to push me most of the time because I haven't got the upper body strength and stamina due to my poor health and arthritis to move more than a short distance myself: after a short while I am totally fatigued. I certainly couldn't get myself 50m outside in a wheelchair and don't have the house space for an electric wheelchair. I think this distance is quite unrealistic as a measurement of how severely mobility impaired someone is and it should be at least double this.

Also crutches are a really difficult aid as they use both hands and I am terrified of falling and being unable to save myself: I could not get up from the ground if I did fall outside. I have fallen on a pedestrian crossing locally and a driver had to come out from their car to help me up from the ground while all the traffic waited for me. I have also fallen from my mobility scooter and two people had to help me up on that occasion. I rely on getting friends/family members to drive me to places if these are outside the limited range of my mobility scooter and being able to park as close as possible (directly outside preferably) to the entrance to whatever shop or venue it may be to limit the pain and fatigue of walking. I can't work out from what the assessment criteria are suggesting as to whether I would still be eligible for my blue badge and equivalent of higher mobility. I think the reference to wheelchairs is very confusing in this instance."

Respondent 7

"1 On the low rate of DLA care, you need to show you need 1-2 hours care daily, why does PIP double this to 2-3?"

2 One feeling is that the DLA form, though it is long, it at least allows you to tell your story. The PIP form is more mechanical, like the ESA assessment: it does not allow you to tell your story. Can we add, not necessarily on every section (perhaps with a page at the back), give a large box which says 'tell us anything more you have to say here' – to give people the chance to tell their story

3 DLA is to cover the additional cost of disability which are not covered by health and social services. So, PIP should capture not just your conditions / health information and daily activities but the additional cost to the disabled person from these.

4 There is an overall feeling that re the 20% reduction – we already know that there is not the full take-up of this benefit, so it feels wrong that with this in mind we are trying to cut the benefit

5 PIP doesn't offer automatic qualification for certain conditions/disabilities. This is a passport to so many things. They have put great stress on identifying needs, but seem to be moving away from the passport aspect of DLA

6 Activity 3: therapy and monitoring health: maximum 8 – this seems to be very lowly scored. With the emphasis on prevention this seems strange. It should be ten or 12 points.

7 Activity 6: d) says that you get three points if you need assistance to dress or undress the lower points of your body (3 points). E) is four points for the other parts of your body. One would have thoughts that f) would be for all of your body, for more points (8) . In fact it says can't dress or undress any parts of your body. I don't know why if you can't do d or e you should then go with f. Perhaps it should say you need help to dress or undress all of your body, and the points should be the addition of the previous two. There is a difference between cannot and needing assistance to dress. If you can dress at all, people might not fill this in correctly and won't differentiate sufficiently between these points. We think this could be tidied up.

8 Activity 7: communicating: this doesn't seem to acknowledge the very expensive nature of the varied technology of speech/communication assistance. Should be awarded more points: it is as important as anything else in PIP. It engages very much at the physical level and not social considerations or on cognitive impairments.

9: Activity 9: don't know quite what to make of this. This is all about people with learning or cognitive impairments. Those with sight/sensory conditions are not catered to here. If it is so important, it should attract more points. And why just

financial decisions – why not also understanding independent living, choice, life-decisions, etc.

10: Activity 10: mobility activities: planning and following a journey. For people who use mobility equipment there is often the need for intervention/help/support, getting in and out of inaccessible places, getting onto transport, etc. “ (Local MS organisation and carer)

Respondent 8

“Activity 1 – Preparing food and drink:

Comment: Only seems to address role of small kitchen appliances/aids. A wheelchair user of compact size cannot effectively or safely use a standard height kitchen worktop (90cm high). Restructuring a kitchen is a major expense. Guide notes says -"Cooking food means cooking or heating at above waist height – for example, using a microwave oven or on a cooker hob. It does not consider the ability to bend down . . ."

Activity 4, Bathing & Grooming:

E: Needs supervision or prompting to bathe. , score 2

F: Needs to use an aid or appliance to bathe, score 2

Comment: Having same score for E & F does not reflect cost of procuring specialised appliance or plumbing (such as walk in shower) modifications. Should have score of 4

F: "Needs assistance to bathe" should say "Needs assistance or significant adaptations to bathe" and have a score of 6.

Activity 5 – Managing toilet needs or incontinence:

Descriptor E, "Needs assistance to manage incontinence of either bladder or bowel - 6.

Comment: This sounds too similar to descriptor D. Suggest descriptor E says "Needs significant assistance or specialised plumbing arrangements to manage incontinence of either bladder or bowel".

Activity 6 – Dressing and undressing:

Comment: I think the descriptors should recognise the importance for disabled people to have as 'positive' an image as possible in order to make up for impaired social status.

Activity 7 – Communicating:

Descriptor C "Needs to use an aid or appliance to express or understand verbal communication", (Score 2).

Comments: this score is too low considering the cost of voice synthesiser systems or high-end hearing aids (latter costing £1,000 up to £3,0000).

The process needs to recognise the NHS only provide fairly basic hearing aids (suitable only for quiet or one-to-one communication. If client needs high-end aids for more complex hearing conditions they have to buy themselves.

I suggest descriptor C should be concerned with moderately sophisticated communications technology and descriptor F is rephrased to caters for high-end sophisticated (and much more expensive) technology.

Comment, Descriptors E and F:

They are virtually identical without making clear what level of impairment they are addressing.

Activity 8 – Engaging socially:

Comment:

Because communication problems have a major role in socialising difficulties the descriptors need to make more clear how they are distinguished from communication issues.

Activity 10 – Planning and following a journey:

Comment: "Notes: A person should only be considered able to journey to an unfamiliar destination if they are capable of using public transport (bus or train)."

This note is seriously flawed. Public transport might get a blind person or wheelchair user to the vicinity of their ultimate destination but there is strong possibility of unsurmountable access problems when they get there, e.g. busy road to cross, finding accessible entrances. Or, a blind person or wheelchair user might get to the railway station unescorted, but will need help getting to platforms and getting on trains.

Descriptor C:

Comment: Use of a support dog to get to an unfamiliar destination!

This descriptor shows a fundamental misunderstanding of what a guide dog does. The dog is no more than an 'obstacle avoidance system'. The dog cannot take its owner anywhere if that owner does not already know the route. Once the dog has learned a route it still needs human 'guidance' to select one known route over another.

Finally, a support dog cannot take its 'client' over a busy road where there is no controlled crossing. It can only follow clearly defined paths/pavements - it can't

help in open spaces without such paths. So unfamiliar destinations are out of the question.

General Comments on Assessment:

It is quite strange that the assessment and descriptor system appears to make no allowance for the substantial costs that can be incurred in making a home safe and useable. We can be talking about substantial costs, e.g. stair lifts, security systems, walk in showers, modified kitchens. And it is more than just the procurement. Maintenance of such facilities is also a major charge. Home adaptations can be provided free if the client is on Income Support. If not on IS, it is the responsibility of the client. I thought that this is what my DLA was for and jolly useful it has been.

2. Risk and Safety (Assessment Criteria Explanatory Notes)

Annex B, 7.5

"When considering whether an activity can be undertaken safely it is important to consider the risk of a serious adverse event occurring. However, the risk that a serious adverse event may occur due to impairments is insufficient – there has to be evidence that if the activity was undertaken, the adverse event is likely to occur." Unbelievable! So a 40% chance of being run over or setting fire to the house is OK?"

Appendix 2

Submission from person diagnosed with OCD who attended our workshop.

Q1 – What are your views on the latest draft Daily Living activities?

There seems to be large areas that are absent. eg there is a section on 'making financial decisions' but nothing on making other everyday decisions. What of other decisions like buying essential clothes, what to wear when you go outside. I know a girl with OCD who takes weeks just to buy a pair of shoes. She has to go the shops, look, go home, go back, go home, go back, buy, then take them back again as she's not sure or there's a mark on them or something. It took me about a year to buy an essential ergonomic chair (I have a disc bulge in my neck) and by the time I got it, I'd damaged my neck still further having spent hundreds of hours mulling over and researching chairs due to OCD checking, unable to make a decision. It took me a year to put up shelves (I was so terrified of chemicals in the wood or paint that I spent hundreds of hours trying to find the most non-chemical wood/ paints etc...) It took me several months to put anything on them once they were put up as I was too frightened to put anything on them without cleaning it. These are daily decisions and tasks that can literally take up hundreds of hours of one's life. I took several months to buy a computer monitor, sending it back about three times due to OCD fears (eg I was afraid of a piece of polystyrene in the box that didn't seem to belong to the box), and I won't touch the third monitor as I'm frightened it's been contaminated with radiation from Japan where it was made as it was around the time of the tsunami. This inability to make decisions like this makes my life impossible. My mental health worker wanted me to set up a mental health blog and it took about a year just to decide which hosting company to go with and then I was too afraid to do it. It took two years to edit a ten minute film (part of my back to work support) as I couldn't make editing decisions. It can take me a week to write one letter as it has to be perfect and I can't decide what sounds best. I've really damaged my neck as a result of my inability to make decisions that caused overchecking and researching.

I also really think that keeping one's house clean ought to be in there. Many people with mental health problems can't clean their surroundings and they become messier and messier to the point that they become dangerously unhygienic. I spoke to one girl whose house got so untidy as she was crippled with depression that she left her house and wandered the streets instead. It was

only when social services paid for a cleaning lady that she was able to move back in again. I currently have a vermin infestation in my house as I haven't been able to keep it clean and control the infestation (sometimes I didn't Hoover for three or four months). I will have to throw away all my carpets as a result. It's caused my OCD to get really bad as all I do is think about how to get rid of them all day. I want to move house. I have also had to start throwing away clothes as the beetles got into my laundry basket and now they are in my bedroom. I bought the carpets as I was too afraid to touch the floors in the house, but now the carpets have become infested with these beetles. Vermin like moths and beetles set in when homes aren't kept clean. Being able to clean one's home is an essential part of care. I know a girl who is unable to wash up. This causes her profound anxiety and stops her from being able to cook and prepare food.

Also re: activity 4 washing: I can spend many weeks washing items that I deem contaminated. Eg clothes, bags, pieces of paper. I throw many items away as I can't wear them (eg trainers that I was wearing when I trod on something 'contaminated'). When I moved house, I had to wash every single item before unpacking and also the entire house. I am still doing it four years later. There are whole areas I won't touch and boxes of things I won't touch, all waiting to be washed. I have spent the best part of a decade washing items to the exclusion of all other things in life. It is the reason I had to stop working. Without a cleaning category, this disability is not picked up on at all.

The idea that washing and grooming can be lumped together is absurd as well. People with OCD usually don't have no problem brushing their hair but can have major problems washing. The top mark category, however, requires you to have problems doing both in order to score that mark.

There also ought to be something about getting to sleep. Sleep is essential to life and health. If you don't sleep, you can't do anything during the daytime. There is nothing about aids to get to sleep. I am no longer able to use a pillow as my neck problems got so bad as a result of the OCD checking all the time. I have to use a very uncomfortable roll behind the neck and bedtimes are a nightmare.

Re: Activity 7, 'communicating', all the examples given are for physical health. It's vital that mental health is acknowledged as causing such problems as well. There need to be mental health examples. Communication is something that can be very difficult if you have OCD. People with OCD are often highly intelligent

when it comes to verbal communication, so people overlook the fact that they can have very severe communication problems when it comes to written communication. When I was at university for example, I was unable to read a book as it could take me half an hour to read one page (I had to keep re-reading it and every time a bad thought came into my head, I had to start again). I have letters in my in-tray that date from four years ago that I still haven't managed to read or reply to as the letter has to be perfect or I can't face the information. I tried to join a history course, only to find that I couldn't hand in essays as I spent four whole weeks, working fifteen hour days checking references. Eg changing full stops into commas and back again, checking and rechecking things. I became so unwell physically I can no longer read a book any more as I damaged my cervical discs. When I was at school I would spend all my holidays sometimes writing one essay, just checking it over and over and over again. No teachers knew. I ended up developing varicose veins as a teenager because I wouldn't get up to eat or anything. I just sat checking things and making it perfect for hours and days and weeks. I was once asked to get somebody a couple of facts on alcohol. I spent about 24 hours doing this as I was unable to understand that they meant just a couple of quick facts. Without clarification, I spent 23 hours doing something that should have taken 15 minutes. The end result of all this is that I have very severe disc problems in my back, have osteopenia (the precursor of osteoporosis) and severely low vitamin D as I don't leave the house due to spending hours over information tasks (eg this consultation!)

It sounds ridiculous but I know a girl who is unable to read and write, but with the aid of a special software, she can do so. It takes me several months to do things that she can do in a few hours. OCD was in the World Health Organisation's top ten illnesses for lack of productivity in one's lifetime and this is one of the reasons why. There is a failure to recognise the impact of mental illness since you cannot see it.

Re: activity 2 – Taking nutrition. There doesn't seem to be a category for people who need assistance taking nutrition. South West London and St George's did a survey of their inpatients with OCD as they were finding many people had similar severe health problems. They found that 21 out of 98 patients had developed renal failure as they were so frightened of their own urine they didn't drink water and also tried to avoid urinating. These people even when prompted would find it very difficult to drink water such is their fear. Category F says 'needs another person to convey food and drink to their mouth.' They wouldn't come under that either as their problem only applies to water, not food, even though they have renal failure. Their problem doesn't fit in the categories.

With regards activity 1, it doesn't really capture the nuances of OCD. For example where it says 'cannot cook a simple meal using a conventional cooker but can do so using a microwave.' My OCD means I can't use microwaves as I'm phobic of the microwaves, though microwaves are used in both categories C and E as though nobody has issues with microwaves.

It's difficult to know what to put. Left to my own devices, I'll often not eat at all. I'll only cook if my father comes around as I feel motivated to feed him, but not myself. That kind of falls somewhere between 'needs prompting' and 'needs supervision.' It's difficult to know which to choose therefore. The examples given are not great eg. under 'needs supervision to either prepare or cook a meal' it says 'for example: may apply to individuals who need supervision to prepare...' Isn't that just repeating the question? A practical example would be more helpful. There does seem to be an assumption that the only category for mental health would be 'D.'

Q2 – What are your views on the weightings and entitlement thresholds for the Daily Living activities?

Activity 8 engaging socially has a big jump from 'needs social support to engage socially' (4 points) to 'cannot engage socially due to such engagement causing either overwhelming distress...' (8 points). With OCD, however, I will only go out and engage with others if made to or prompted, as people with OCD have a very strong sense of duty and responsibility, however, that doesn't prevent it causing overwhelming psychological distress. When I go out the house I come home traumatised. I have to decontaminate everything I was wearing or carrying, something that can take hours. I might spend the next day in bed getting over it and frequently am so traumatised by an encounter with another person (eg any unkind or unpredicted act), that I can't leave the house for days afterwards and become reclusive. If my neighbour knocks on my door and I wasn't prepared, or somebody telephones me and I wasn't prepared, I might open the door or answer the phone sometimes, but I will be shaking for hours afterwards. If somebody touches me with a bag or a hand, I am traumatised until I have washed everything. So there is no box for those who *can* engage when supported to, but who are left traumatised by the experience. There needs to be. There are many people who engage socially but have to spend hours or days recovering from the experience. I spend many many hours writing letters to try and put right things that have gone wrong during encounters with the general

public. If I had the money I would want to become a recluse and have no contact with the public at all.

Activity 4. I can't express how disappointing this category is for me. It really doesn't capture even remotely the level of disability caused by one of the main forms of OCD ie washing compulsion. A person with this form of OCD can spend many many hours washing. Or else they won't wash at all in order to avoid spending hours doing so. There really is nothing in this marking that reflects the agony of having to spend hours a day washing one's hands or other parts of one's body. To give only 2 marks for supervising an activity that can take up the best part of one's day is absurd, particularly as people with OCD hide their condition and don't let anyone into their houses to supervise them anyway as then they'd have to wash the entire house. Eight marks are given for not being able to bathe and groom at all, yet only 2 marks given if you spend the entire day washing to the exclusion of other activities.

Activity 6: Dressing and undressing. The marking scheme of this is irrelevant to OCD. I used to have a form of OCD that involved spending about half an hour to get dressed. I had to put on and take off my clothes a certain number of times and if a bad thought came into my head, start all over again. I was late for everything as a result. The division of the body into upper and lower is therefore irrelevant to say the least. The bottom line is that a person with OCD will not let anyone interfere with their rituals so that prompting really doesn't work anyway. All that does is increase anxiety. If there are 2 marks for 'needs prompting' and '4' for needs assistance, neither of these capture the problem. The person needs assistance but won't let anyone assist. Only a trained therapist can carry out such assistance, or else an individual who is not afraid to physically manhandle the individual to stop them carrying out such rituals.

Activity 7 communicating. Given that it can take somebody with OCD several years to write one important letter, three months to fill in a simple form, or a year to read a book, the emphasis on verbal communication as being the only high scoring form of communication really does not reflect the level of disability and distress experienced. If a person is expected by the DWP and those around them to undertake reading and writing eg in work-related activities, filling in forms etc... then to have such a difference between the top marks available for problems with written communication (4) and verbal (8) is not great. If the DWP wants to force people with OCD to work and expects them to be able to carry out such tasks, then it needs to acknowledge those difficulties, else cease from demanding that

they do them. The alternative is that the person ceases all attempts to read and write due to the amount of time these take.

Q3 – What are your views on the latest draft Mobility activities?

Although Activity 10 thankfully does take account of mental illness, I am very concerned about Activity 11. A girl in my block has osteoporosis. I have osteopenia (precursor of osteoporosis). As people with OCD often don't go out for days, they are prone to this due to very low vitamin D levels from lack of sunlight etc...OCD sufferers will often sit on the same chair for hours, or on the floor, without getting up to eat or go to bed, as they are checking something or engaged in some OCD activity (I have varicose veins from sitting for too long as a teenager). There is no box that acknowledges the inability to move from a seated position to another place or further without the prompting or assistance of another person. The examples given are for physical health. There is no recognition that people with mental health problems can have difficulty moving. There are people with OCD that is so severe that most areas of their home are no-go areas. They can't touch them. They only sit in one chair in their house and have bin-liners on the floor to take them to their bed. They won't leave the house. They are too frightened to. It isn't a case of needing an appliance or wheelchair to get around. They need supervision and prompting, but there are simply no boxes for human supervision, only for the aid of appliances (ie non-human help). There are also people with long-term agoraphobia and panic attacks who are housebound and never leave the house.

Q4 – What are your views on the weightings and entitlement thresholds for the Mobility activities?

A person who is not just housebound, but room-bound due to a mental health problem that prevents them getting up or going out the house, would not have that acknowledged by this form. Because they are physically able to walk for 200 metres, even though they don't do it due to a severe mental health problem, they would score no points at all. The 'wheelchair' of the mentally ill person is another human being. The definition of 'aids' or 'appliances' does not include human assistance. This is quite possibly the worst category in the entire form therefore. I know one girl who relies on lifts from other people as she cannot use public transport and is terrified to leave the house. Those people have to wait

sometimes for an hour for her to be able to leave the house (she has a lot of very complicated rituals to perform before leaving). She has several severe mental health conditions. Mobility is one of her greatest problems. She simply cannot leave the house without assistance. There are people with agoraphobia, panic attacks or severe OCD that doesn't respond to treatment who don't leave the house for years. They become recluses. Why does this form not acknowledge that? What use are two legs if a brain won't let a person use them? Should people be penalised for not being able to overcome their severe fears even after decades of therapy hasn't worked? This question appears to think that such mental health conditions can be cured merely by taking away the support.

Q5 – What are your views on how the regulations work regarding benefit entitlement?

It says the PIP assessment is to ascertain whether a 'claimant's ability to carry out daily living activities, mobility activities or both is limited or severely limited by the claimant's physical or mental condition.' However, the severity of a condition like severe OCD just won't register due to the nature of the questions and the marking. eg you could spend eight hours a day washing due to severe phobia, but score only two points, though spending eight hours a day doing one task is utterly crippling. You might not be able to leave your house due to a mental illness but score zero points for 'moving around' as you have two functioning legs even though your mental health problem prevents you getting up from your chair for half of the day.

Q6 – What are your views on how we are dealing with fluctuating conditions?

It can be very difficult to predict with some conditions what those fluctuations might be. Eg disc problems. They can suddenly get worse without warning if you've been engaging in activities that can exacerbate them. I was fine one day, then ill for the next year and it took many months to recuperate. Then I was okay again, then relapsed when I tried to start reading books.

It's not clear whether the rules for fluctuating conditions would work in practice at this point in time.

Q7 – What are your views on the definitions of ‘safely’, ‘timely’, ‘repeatedly’ and ‘in a timely’ manner?

These need to be in with the questions, at least on the first page, though ideally with each question as some people might not read the first page when filling in the form. Without these definitions being present, it is unclear if somebody with OCD who spends eight hours washing would know if they were considered unable to complete the task or not (ie they complete the task but not in a timely manner). Without these definitions being in the question, it is unlikely people with OCD would realise they should tick the box ‘can’t complete the task.’

Ditto dressing. If person with OCD takes half an hour to get dressed as they have to keep taking things off and putting them back on again, what does this count as? Can’t do at all since it isn’t timely? Needs clarification.

Q8 – What are your views on the definitions in the regulations?

Very unhappy about the definition of ‘aid or appliance’ since (re: the ‘moving around’ section of mobility) an aid for a person with a mental health problem would be human support of some description, to help them move around the house and leave the house. Under current definitions a person who doesn’t leave the house for mental health reasons would score zero for this due to the limited definition of ‘aid and appliance.’

Re: definition of ‘therapy.’ Not sure why this only includes therapy undertaken at home. I have been told by a specialist I need to do thirty minutes of weight bearing exercise a week since I lost 20% of my bone mass at an early age. It can only be undertaken outside the home, but the OCD prevents me from carrying it out, so my bones are getting worse. I also have severe vitamin D deficiency, again in large part due to the OCD as I don’t go out the house much to get sun. Another friend with OCD has osteoporosis already though she is young. Many people with OCD have such problems due to being housebound. According to this definition, however, neither prescribed weight-bearing exercise to prevent osteoporosis or going out of the house to get vitamin D from the sunlight would

count as therapy since they don't take place in the house. Osteoporosis kills people though. Many people die as a result of fractures from osteoporosis.

Q9 – Do you have any other comments on the draft regulations?

These represent a big step backwards for people with mental health problems. By only having two levels of care, standard and high, they will result in people with needs in the middle not receiving enough care. The differences between low scores and high scores are too great. The categories are limited and don't reflect the severe impact that a condition like OCD can have in other areas of one's life, like making everyday decisions and cleaning the home etc... These tasks can take up all one's time since one is always obsessively cleaning (or conversely not cleaning at all so the house becomes uninhabitable) and prevent one from doing anything else yet are not included.



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