Personal Independence Payment:
Second draft of assessment criteria

Department for Work and Pensions

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Available in other formats on request.
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Introduction

Sense Scotland is a leader in the field of communication and innovative support services for people who are marginalised because of challenging behaviour, health care issues and the complexity of their support needs. The organisation offers a range of services for children, young people and adults whose complex support needs are caused by deafblindness or sensory impairment, physical, learning or communication difficulties. Our services are designed to provide continuity across age groups and we work closely with families and colleagues from health, education, social work and housing. This breadth and depth of approach to service delivery helps us take a wider perspective on the direction and implementation of new policies.

Capability Scotland campaigns with, and provides education, employment and care services for disabled people across Scotland. The organisation aims to be a major ally in supporting people to achieve full equality and to have choice and control over their lives by 2020

Introduction

Sense Scotland and Capability Scotland have previously contributed a response to the second draft of the Personal Independence Payment (PIP) criteria, as part of a joint exercise together with Independent Living in Scotland; Inclusion Scotland; Scottish Disability Equality Forum; Scottish Council on Deafness and Quarriers. Both organisations have also provided other responses in relation to the change from Disability Living Allowance (DLA) to PIP.

Having attended a meeting with DWP representatives at Sense Scotland's offices on 12th April 2012, representatives of our organisations agreed to provide further clarification and comment relating to the issues which affect the people who use our services.

We aim in this response to give some practical advice, supported by reasoned argument, relating to an improvement of the assessment criteria. Whatever we say here however, will depend on highly skilled assessors, who have no other target than providing accurate, sensitive and insightful assessments which will have the outcome of improving the life circumstances of disabled people.

General points

<u>The Social Model</u>

We must note from the outset our concern that it was stated at the meeting by DWP representatives that the new assessment will not be based on the social model of disability. We believe that this undermines any of the arguments made previously by both ministers and officials that PIP will be an improvement on DLA. For instance, Maria Miller MP stated in March 2012 that, "*We want to make sure that we put in place a modern benefit that supports people in a modern way based on a social*

model. That's very much why I believe that the Personal Independence Payment is so important for disabled people today[1]."

A great opportunity to demonstrate a commitment to equal opportunities between disabled and non-disabled people will be missed by ignoring the validity of the social model / independent living approach.

This shortfall is demonstrated most starkly within the first activity, which still refers to cooking at above waist height. The outcome is that a person could be completely unable to cook or heat a meal, because they are unable to access storage and equipment which is often at below waist height, or requires stretching. However, despite being in this situation, they could score 0 points on this activity, because in an ideal world they would have a perfectly adapted, spacious kitchen, with everything close at hand at the same time as being of such a size that it accommodates everything.

Cumulative effects of welfare reform

We are seriously concerned that any reduction in eligibility for or spend on DLA/PIP will undermine the right of disabled people in the UK to live independently. However, given the current economic climate, cuts to public services and the rising cost of living, the cumulative effects of reform are potentially catastrophic.

This point was highlighted by the Joint Committee on Human Rights which stated that, "the range of reforms proposed to housing benefit, Disability Living Allowance, the Independent Living Fund, and changes to eligibility criteria risk interacting in a particularly harmful way for disabled people. Some disabled people risk losing DLA and local authority support, while not getting support from the Independent Living Fund, all of which may force them to return to residential care. As a result, there seems to be a significant risk of retrogression of independent living and a breach of the UK's Article 19 obligations."

Combinatorial effects

Consideration must be given to interaction effects where a score on one area coupled with a score in another area will have more than an additive effect. The most obvious example is medication. A second example is communication. Where a person cannot express or understand written or verbal communication they are isolated from information about the world – not just newspapers but the people, places, events, timetables, bills, menus – and have little opportunity to influence it.

The assessment criteria are based around discrete categories each of which is scored along a single dimension. No allowance is made for the co-factor relationships that may exist within and between categories of descriptors. There is a statement in the notes that states: '*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.'* However, if this is not referred to **within every activity**, it is likely to be missed as a factor.

For example, currently, where a person 'needs supervision, prompting or assistance to manage medication or monitor a health condition' (3B), they will be awarded 1 point. If that same person also 'needs to use an aid or appliance to express or understand verbal communication (7C)' s/he will be awarded another 2 points. If s/he

[1] Interview with Able Magazine, March 2012, http://ablemagazine.co.uk/articles/sections/columnists/maria-miller/

also needs 'prompting for all journeys to avoid overwhelming psychological distress (10B)', s/he will be awarded an additional 4 points. Overall this individual will be given a score of 7 points and will not qualify for PIP. However, the cumulative effect of satisfying these descriptors could be devastating. If this person has no support to manage their medication and becomes seriously ill as a result, they may be unable to use the phone to call an ambulance (as a result of their communication difficulties). They will also be unable to make their own way to a doctor, hospital or friend for assistance. The Government needs to give detailed and careful consideration to circumstances such as this where the impact of satisfying several criteria is essentially 'greater than the sum of its parts'. In such circumstances additional points should automatically be awarded. For instance, using the example above, satisfying 3B, 7C and 10D should result in a further 1 point being allocated to ensure the person qualifies for the standard rate of the daily living component.

Heterogeneity

We remain concerned that the approach taken favours a rules-based system and will be unable to cope with the heterogeneity or variability of the effect of disability. A rule-based approach cannot absorb the variety of demand. That can be overcome using highly skilled and experienced staff and we are not convinced that these skills and experience will be available. The effect will not just be on disabled claimants having their claims rejected. It will also drive up costs as those applying the system will increasingly rely on the system's rules, believing them to be right. This in turn will reduce money available to support disabled people through the benefit. Disabled people, some of them the most vulnerable in society, will be the inevitable losers.

As invitations for this work are about to go to tender it will be important that the 'call-off' process builds in the need for any provider to show that it can respond to heterogeneity in demand.

Scoring and testing

We appreciate that in order to test the criteria, scores, however arbitrary-seeming, had to be applied. However, we are concerned at just how way off the mark some of these scores actually are (see our comments below on medication), and what that indicates about the understanding of the impact of certain issues on disabled people.

In some cases, very little consideration appears to have been given to the consequences of points allocation. For instance, three of the descriptors - (3(b), 4(b) and 4(c) - attract 1 point each. Given that the thresholds for qualifying for PIP are all even numbers, it follows that allocation of 1 point will only ever be meaningful (in that it will allow a person to qualify for a benefit they would otherwise not have) if s/he also qualifies for another descriptor which is attributed 1 point. It makes little sense that needing supervision to take medication (3(b)) should only be meaningful when combined with an inability to groom without prompting (4(b)). We are concerned that this is not a deliberate design feature, but rather an arbitrary characteristic of the criteria.

Similarly, in relation to mobility, a person can be allocated 8 points for satisfying descriptor 11(c), or 10 points for satisfying 1(d). Given that the threshold for the Enhanced Rate of PIP is 12 – and that no descriptors have a score of 4 points – in practice it makes no difference to the person whether they score 8 or 10 points. It would therefore be preferable that both descriptors attracted either 10 or 8 points for the sake of clarity and transparency.

Again in relation to the mobility component of PIP, certain activities are allocated 15 points. Given that the threshold for the Enhanced Rate is 12 we are unsure what the rationale behind this higher point allocation is. We are concerned that it is indicative of the Government's intention to raise the threshold for eligibility threshold in the future.

We are also concerned about the approach that has been taken to fluctuating conditions. The draft criteria state that the individuals will be allocated points for the descriptor that applies to them more than 50% of the time. Where 2 or more descriptors combined apply to that person more than 50% of the time, then they will be allocated points for the descriptor which applies to them for the largest proportion of time. However, the regulations fail to mention that it is the *point-scoring* descriptor satisfied for the largest proportion of time that should be applied. The regulations also fail to mention that the descriptors must relate to the same activity.

Given these issues, we are concerned to hear that there is unlikely to be the opportunity to comment on the next version of the assessment, despite the following statement in the explanatory note of November 2011 relating to developing the draft criteria further:

'We view the development of the assessment criteria for Personal Independence Payment as an iterative process and we recognise that these proposals may require some further refinement. We intend to discuss this draft with disabled people and their organisations and to consult formally once we have firmer views on the descriptor weightings and likely entitlement thresholds.'

The Activities

Activity 1 – Preparing food and drink

See our earlier comments relating to the Social Model.

Activity 2 – Taking nutrition

It is not clear whether gastrostomy and other types of assisted feeding would be considered as taking nutrition (2), a therapy (3) or both. We consider these three options.

1. If it counts as therapy only, then someone who requires help with gastrostomy, bolus or pump feeding would obtain 6 points - but without that source of nutrition they would die. In contrast, it is only if a person needs support to convey food and drinks to their mouth that they would receive a maximum of 10 points. Therefore a person who cannot take food through their mouth, but needs support to receive nutrition via another means, receives less points. This is anomalous, and potentially highly dangerous in its impact.
2. If assisted feeding counts as managing a therapeutic source, then even if supervision, prompting or assistance to manage therapy takes at least 14 hours a week (it can take many more hours than this), only 8 points would be awarded. It should be noted that very few people can manage the process of gastrostomy feeding for themselves, taking into account the measuring of

feed; pouring into a suitable vessel (syringe or feed bag); connecting to the tube, setting up the pump; flushing the tube and disconnecting the equipment.

3. If assisted feeding counted as both nutrition and managing therapy the total would be 14 points. Interestingly, this is still less than the points associated with mobility.

4. The need for emergency, immediate support with gastrostomy, or other specialist forms of providing nutrition also needs to be taken into account. It may be necessary to have someone on hand between the times when assisted feeding takes place, to deal with emergencies, such as the dislodging of tubes. Although the reinsertion of a tube may only take a short while if dealt with promptly by a trained person, the timing of it is unpredictable, and the failure to deal with it can result in theatre time for people using gastrostomies. This would justify a score of 12.

5. It should be noted that people using gastrostomies may also take some small amounts of nutrition by mouth, so it will be important that if this is the case, the needs surrounding both aspects of taking nutrition will need to be counted. The safety aspects will also need to be considered, relating to the risk of choking.

6. Gastrostomy and other forms of assisted feeding also have a social impact, and a requirement for privacy and access to hand washing facilities when out and about. See also our comments on mobility.

Activity 3 – Managing therapy or monitoring a health condition

Referring to our earlier comments above about co-factor relationships, particular concern arises with the low maximum scoring possible for 3B. *Needs supervision, prompting or assistance to manage medication or monitor a health condition*

We have particular concerns at the low maximum scoring (1 point) given to being unable to manage medication which is mentioned only once [under 3B]. While for some a low scoring may be acceptable there are many for whom an inability to manage medication will mean they cannot participate in some or all other areas of activities covered by descriptors. An inability to manage medication can result in death, extreme pain, chronic fatigue, withdrawal from society and a host of other conditions that impair an individual's ability to participate in daily life. We recommend that the impact of not being able to manage medication is taken into account. This can be done in one of two ways, either by:

1. Awarding maximum 12 points if condition 3B is met. This would have the disadvantage of resulting in false positives. That is some people would get the higher award even if not taking medication would not affect their results in any other descriptors. Or,
2. Including assessment criteria that build in **impact** of medication / therapy. For example:
    a) [3B] Without supervision, prompting or assistance to manage medication or monitor a health condition, the ability to participate in

daily living activities (Preparing food and drink, Taking nutrition, Managing therapy or monitoring health condition, Managing toilet needs, Dressing / undressing, Communicating, Engaging socially, Making Financial decisions) is adversely affected. Would be awarded **12 points**

b) Without supervision, prompting or assistance to manage medication or monitor a health condition, ability to participate in mobility activities (Planning and following a journey, moving around) is adversely affected. Would be awarded **15 points**

3. Pick up possible variation of the impact of not being able to manage medication with each separate descriptor.

We urge DWP to re-consider this factor and to recognise that an inability to manage medication is associated with high scoring or by introducing a weighting system as mentioned in the first set of draft criteria.

Activity 4 – Bathing and grooming

In relation to both Activity 4 and Activity 5, we are concerned that the descriptors are too heavily focused on specific toileting, bathing and grooming tasks, and do not consider a person's ability to locate, reach and identify the toilet and/or bath. A descriptor to measure the person's ability to physically get to the toilet is potentially vital for people with limited mobility, sensory impairments, or those unable to follow directions.

There is also no mention made of shaving or applying make up in the criteria. Both of these activities are an important part of the grooming process. Both can be vital in terms of a person's self esteem and their ability to look suitably presented for employment and/or social occasions.

Activity 5 – Managing Toilet Needs or Incontinence

Activity 5 also fails to make reference to menstruation. This is clearly a major concern as it does not follow that those who can manage their continence can necessarily manage menstruation. Menstruation is not comparable because, given the possible unpredictability of onset, it requires a greater need for planning and preparation than going to the toilet.

Activity 7 – Communicating

We welcome the additional more detailed requirements on communication. There remain problems with the approach taken. Communication is not a single dimension however the scoring system assumes that it is. There can be adverse impact on **both** verbal communication – either receptive, expressive or both – **and**, separately, adverse impact on written communication – ability to access or produce written information. Written communication and vocal communication are separate entities. Communication should be treated the same as mobility, with separate consideration given to personal communication and written communication.

With the current criteria three disabled people A, B, and C would receive the same 4 points even though:

- A needs assistance to use or access verbal information
- B needs assistance to express or understand complex verbal information
- C needs assistance to use or access verbal information **and** needs assistance to express or understand complex verbal information

(Refer to: Activity 7C*. Needs to use an aid or appliance to express or understand verbal communication.)*

To put the point scoring in context, if the PIP assessment were to be applied to the communication of Professor Stephen Hawking, the world renowned physicist, he would be awarded 2 or possibly 4 points. However, he needs a high tech communication aid to assist with both speaking and writing. It is unlikely that he would be able to repair the aid if it goes wrong. This scoring does not reflect the huge difficulties a person using a complex communication aid must face in their day to day life. It is not only Hawking who has the double disadvantage of needing assistance to communicate and write - so too do deafblind people and many people with autism and learning difficulties. We propose that either the points awarded for this criterion are increased or a graduated points system is introduced to reflect different kinds of aid or appliance.

g. The descriptor "cannot communicate at all", the only communication descriptor to attract 12 points, is ambiguous. Sense Scotland supports disabled people - many of whom have the most complex support needs. If we were asked, or if their parents or carers were asked, if the people could communicate, all would respond "Yes". Most health professionals would respond that the same disabled people could not communicate at all. There is no shared understanding of the term 'cannot communicate at all' and a response obtained from a parent or carer would most likely be that the disabled person could communicate. As a result they would achieve 8 rather than 12 points. People most knowledgeable about the person tend to use the term 'communicate' in a very different way from some professionals (presumably including the professionals who were consulted about this criterion).

With the above in mind we propose the following re-structuring of '7. Communication'

1. Verbal communication	7.Personal communication a. Can express and understand verbal communication unaided	0
	b. Needs to use a **basic** aid, appliance or service to express or understand verbal communication at an ordinary everyday level.	2
	c. Needs to use a **specialist** aid, appliance or service to express or understand verbal communication at an ordinary everyday level.	4
	e. Needs communication support[2] to express or understand complex verbal information.	8

[2] Support might include for example using a complex communication aid, a sign language interpreter, a deafblind guide communicator or other human support.

	We propose that 'complex verbal information' is defined as *[understanding] 'more or less everything that people say (or sign) to them at an ordinary everyday level.'*[3] And *[expressing] 'more or less everything that the disabled person wants to communicate to other people in everyday settings'.*	
	f. Needs communication support to express or understand basic verbal information. ■ We propose that 'basic verbal information' is defined as "two information carrying words" [someone who understands only two information carrying words would interpret *Try not to let the paint go on Jamie.* as *Paint Jamie* - with unintended consequences.	12
	7g. Needs support to communicate and understand intention. See our comments on why the term 'Cannot communicate at all" is ambiguous.	12
2. Written communication	a. Can access written information and express himself or herself in writing unaided, or using **'non-specialist'** spectacles or contact lenses.	0
	b. Needs to use a **basic** aid or appliance other than **non-specialist** spectacles or contact lenses to access written information or to express himself or herself in writing.	2
	c. Needs one or more of – i. Assistance to access written information or to express himself or herself in writing; ii. A complex aid or appliance to access or produce written information; iii. An auxiliary service to provide information in specialised formats[4].	4
	d. Requires all written information to be	6

[3] See Aitken S & Millar S (2004) Listening to children with communication support needs. ISBN 978-1898042266

[4] - **Specialised formats** refer to adapted print materials. Examples would include Large Print, audio, text-to-speech, DAISY versions of the same text as others use without such support.For an explanation see article in Closing the Gap, Jim Kauppila December 2010. (Signposted from http://www.callscotland.org.uk/Blog/Tag/index.php?tag=OCR

	provided as alternative materials[5].	
	e. Cannot access written materials in either specialised formats or alternative materials and cannot express himself or herself in writing.	8

Activity 10 – Planning and following a journey

Please note that support dogs for vision, cannot assist people to go to unfamiliar places!

We propose that the descriptor 10d '*Cannot follow any journey because it would cause overwhelming psychological distress to the individual.*' is re-phrased to read 'is unable to follow any journey', to remove the subjective element for the assessor. It should be incorporated with 10e, and achieve the higher score, as it will involve the person needing to meet the travel costs of others to come to the home – e.g. for social contact, and a range of necessary appointments that would usually be met by the person being able to go out.

We have referred earlier to the issues related to assisted feeding. This has particular impacts on the ability to travel, and move around. We believe that those who require assistance to manage their nutrition in relation to assisted feeding via specialist equipment should receive 12 points for the mobility element, due to the massive impact it has on this activity.

Activity 11 – Moving around

The phrase 'without pain, discomfort or fatigue' should be added to descriptors A to E.

All activities

Descriptors along the following lines should be incorporated **within** every individual activity, with safety being a factor, where these are not already covered. Further, sustaining voluntary or paid employment due to the ability to make spontaneous decisions to react to circumstances as they arise, should be added as an additional activity.

- Is able to make **spontaneous** decisions on issues of mobility; safety; daily living; employment, and social engagement without having to rely on others to enable the person to follow them through
- Requires support from others to respond to **unpredictable** situations relating to issues of mobility; safety; daily living; employment and social engagement.

[5] - **Alternative materials** are re-designed for those who can't use print in a specialised format. The materials may address the same goals but the content of the material is modified or changed in some way. An example would be production of an Easy Read version in symbols so that person can access information.

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