



national association of
welfare rights advisers

Consultation Response

Personal Independence Payment:
assessment thresholds and consultation

April 2012

The National Association of Welfare Rights Advisers

The National Association of Welfare Rights Advisers was established in 1992 and represents advisers from local authorities, the voluntary sector, trade unions, solicitors and other organisations who provide legal advice on social security and tax credits. We strive to challenge, influence and improve welfare rights policy and legislation, as well as identifying and sharing good practice amongst our members.

NAWRA holds a number of conferences throughout the year across the UK, attended by members from all sectors of the industry. An integral part of these events are workshops that help to develop and lead good practice.

Our members have much experience in providing both front line legal advice on benefits and in providing training and information as well as policy support and development. As such NAWRA is able to bring much knowledge and insight to this consultation exercise.

The response has been put together from evidence collated through an email consultation with members. It is a representation of views from frontline advisers and their clients from across the UK.

Response

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?

The stated aim of Personal Independence Payment is to provide a more personalised, objective and consistent assessment of long term health conditions or disabilities than DLA.

NAWRA does not believe that limiting consideration to specific number of proxy activities, however carefully chosen, is capable of providing as complete or as holistic an assessment as DLA. The DLA bar is set high (e.g. to need frequent attention in connection with bodily functions) but it is open to people with unusual conditions or patterns of difficulties to demonstrate how their particular difficulties can meet a broadly framed test of eligibility.

In deciding to codify these into a points scheme, the objective seems to be to focus in on key proxy activities, which it is hoped will enable the full range of disabling effects to score an appropriate level of points. Such an approach inevitably detached from the specific individual pattern of difficulties that a claimant actually experiences, leads to the risk that a particularly unusual - but genuine and accepted - pattern of difficulties will fail to score the necessary points. There will be widely spaced stools between which many individual claimants may fall.

It may well be that in responding to concerns from a wide range of organisations, the scheme has been improved and that this iteration improves on the first. Certainly the inclusion of three new activities of Communication, Making Financial Decisions and Engaging Socially broadens the range of disabling effects captured.

However NAWRA members have expressed concern that this last activity places an unrealistic emphasis on professional support in the current budgetary climate and conflicts with Government policies on Community Care, a problem highlighted when the two systems meet within for example the Independent Living Fund. Others note the loss of hobbies and pastimes from consideration. That new Activity then represents a considerable narrowing in scope compared with the position within DLA following the Fairy/Halliday decision.

We would certainly take our view from the consensus of the main disability organisations who will have done much more detailed work on this than NAWRA has the resources to do. However, in general it is the experience of Advisers that there is a marked contrast between the ability of points based systems such as ESA and a more general - but still challenging - approach under DLA, to arrive at an overall assessment of a person's difficulties. Can the best designed points system respond as effectively as a test based on a claimant demonstrating a need for frequent attention throughout the day in connection with bodily functions?

The PIP test is essentially a points based "attention" test and a number of NAWRA members working in fields as diverse as mental health and HIV/AIDS have expressed deep concern at the absence of an effective supervision test. We note the changes since the first draft, but in some ways the changes either miss the point or actually make the situation worse. These are:

- the inclusion of new supervision descriptors in relation to supervision in connection with specific activities
- the merger of the former Activities 4 and 5 into the new activity 3 largely because of overlap between taking medication and managing therapy. This is also where "monitoring medical conditions" is placed - the last vestiges of a general supervision test, but which now can only score 1 point as opposed to scores across the range in the old Activity 4.

The current DLA supervision test is not an easy one - it requires a claimant to demonstrate a risk of substantial harm to self or others that requires continuous supervision. There needs to be strong evidence through either a history of past incidents or medical evidence of likelihood.

Actual health crises may be infrequent, but unpredictability or inability to manage the effects of the episode may justify the supervision. This aspect of DLA may be crucial for people affected by falls, dementia, asthma, epilepsy, diabetes, psychotic illnesses, suicidal ideation, severe behavioural problems and so on.

Of course some people affected by such conditions may also score through attention difficulties that are reflected in PIP scoring. For them there is no need for a separate supervision test and indeed there may be a risk of double scoring if they did.

However others may only have significant attention needs during exacerbations or crises, so would fail under the 50% or more threshold. Such claimants may fail the DLA “attention” test as well, but could currently rely on the supervision test to allow benefit to be paid to help with what most people would regard as a severe and debilitating long term health condition with potential significant care needs attached. Under the current descriptors they may score only 1 point.

Points relating to supervision while performing specific daily living tasks, will be of little use to people whose supervision needs are around unpredictable episodes, that may not occur in connection with that particular task and certainly not with sufficient regularity to satisfy the 50% test. In effect these are really just an extension of the attention based tests, rather than any form of separate supervision test.

There may then be a perfectly good case for merging medication and medical therapy, but monitoring medical condition is, as the Guidance suggests, something rather more (including monitoring for intervention around diabetes or suicidal ideation). It was rather clumsily dealt with in the old Activity 4 anyway, but it cannot be right for such a serious need to be marginalised to 1 point in the new Activity 3.

NAWRA would strongly urge an additional Daily Living Activity around supervision to avoid risk to self or others, so that as with Communication, it may be possible to score the necessary points for both rates of the component from that activity alone. The different descriptors within such an Activity would of course need a rather different approach from the other “attention” focused activities - as it is a different but very important support need. Any danger of double counting where there are needs in other areas could be avoided by making the Supervision Activity a semi-detached one, where points are either scored from this activity or from the other attention based activities but not added together.

Without such an alteration, we end up with the unacceptable outcome illustrated in Case Study 4, where an essentially attention based approach denies any Daily Living Component at all to someone with significant risk from unpredictable epileptic fits, each of which can be potentially life threatening. Such a person would need continuous supervision, which in other circumstances might require carers to be around, yet these carers would be unable to claim any Carer’s Allowance.

Case Study 5 illustrates the point that a person with supervision needs might not have significant “attention” needs on the face of it. However a flexible, person-centred benefit could be capable of recognising these needs. Such a benefit would be based on the more realistic proxy of theoretical demand on to a potential carer and might go under the name of - say - Disability Living Allowance.

In the case study there appears to be a case for DLA Lower Care, and possibly, on consideration of the individual circumstances of that claimant, for DLA Middle Care. As the PIP descriptors stand, a 2 point score seems quite likely, reflecting perhaps on the seriousness with which the ability to perform activities “repeatedly, reliably, safely and in a timely fashion” will be taken.

Both cases highlight that important areas of need - with potentially significant costs attached - are ignored by the PIP proposals, excluding those who most reasonable people might consider as having a significant - and potentially dangerous - long term limiting conditions. Pulling all supervision needs into a separate Daily Living Activity rather than the pot luck of whether they can be linked to a few specific activities could considerably improve PIP.

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?

There would need to be a wide level of testing against current awards to get a real feel of how the test works. Because the activities are proxies for, rather than attempts to fully capture the disabling effects of a condition, then a detailed report on a pilot testing exercise comparing outcomes with the current arrangements would be instructive. That is not to say that there may not be a good case for different outcomes than those that DLA delivers - there may be disabling effects that may be under- or over - recognised within both benefits.

There is a danger though that wide gaps in scores and the considerable narrowing down of the issues that can be considered will lead to people with significant needs slipping through the test, both those with significant but lower level needs and those living with more severe limitations.

We are concerned that where the three appear together in a descriptor, “assistance” is aligned with “supervision” against risk in an activity, while “prompting” scores less. We would see prompting and assistance as broadly similar, as in the equality within DLA, even if in a medicalised view and their submissions in Mallinson/Halliday, the Department does not. Of course prompting someone who - having been reminded - gets on with the task unaided may be a lesser need.

However, often it may involve considerable encouragement and motivation effort to get someone to even undertake an activity and/ or significant guidance and monitoring to ensure completion of the task, which may amount to considerably more input than physical assistance. A lower score then seems unfairly discriminatory.

In the end though, the objectivity of thresholds for an assessment of disability is compromised by the main driver of PIP - to achieve the reduction in claimant numbers set out in the tables.

Whatever view may be formed about the proper place to set a boundary between standard and enhanced rates - which is difficult in the absence of any indication of the rates - it is fairly clear that the Government will reserve the right to reset the thresholds or adapt the descriptors, should the assessment either fail to meet the required outcomes or should they wish to make more savings at the expense of those with long term illnesses or disabilities.

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?

It is a justifiable criticism of DLA Mobility that people with significant monitoring or guidance needs that significantly compromised their mobility could only access the Lower Rate, while those with severe physical restrictions just short of virtual inability to walk could not access the higher rate, so the removal of an absolute divide is welcome.

Within Activity 10, putting the dividing line between difficulty in unfamiliar places and in even familiar places seems to sensibly reflect different degrees of compromised Mobility. The purpose of a separate descriptor around “overwhelming psychological distress” is less clear but on the face of it the scoring might seem discriminatory.

Within Activity 11, placing the dividing line between wheelchair use and not seems less defensible as a measure of disability. One wheelchair user may be in constant discomfort when mobilising and be limited by upper body disabling functions, others may not. While these are differentiated within the descriptors, this has no effect as all score more than 12. We believe that to be right reflecting the environmental limitations of access to buildings and particularly public transport requiring the use of cars and taxis.

However someone to who is so severely disabled that their effective walking is limited to getting in and out of a car at each end of a journey may effectively have identical transport needs, while they may actually have considerably more compromised mobility when they get to the destination, because of severe pain, breathlessness, balance problems etc. There needs to be access to the enhanced Mobility Component (and Motability for non-wheelchair users) whose level of mobility restrictions may in practice overlap with wheelchair users.

We are also concerned that other aspects of equal weight in current ‘virtually unable to walk’ criteria (speed, time, manner of walking) are absent from the face of the descriptors. They will to some extent be covered by the guidance of performing the activity “repeatedly, reliably, safely and in a timely manner”, but this does need to come into the regulations.

The current DLA definition of virtually unable to walk has been significantly tightened in recent years, with the distance criteria for example moving down from around 100 metres to 50 metres. This is essentially the level reproduced in Descriptor 10C.

DLA Mobility is harder to get for new claimants and a review of DLA High Mobility customers under current rules is likely to yield significant savings anyway. There is no case for further savings by denying this more tightly defined group access to enhanced Mobility (or the Motability scheme) at all.

A more just and consistent outcome might be achieved by scoring 10C at 12 points, while allowing claimants with severe walking limitations but just outside the virtually unable to walk group access to standard rate Mobility. This might be by uprating 10B to 8 points while allowing a new descriptor above 200m for those with still substantial limitations which would be more appropriate to 4 points, which may, for some, combine with difficulties in Activity 10.

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?

As above in Activity 10 there seems to be a discriminatory scoring for what might appear to be quite limiting “overwhelming psychological descriptors”, compared to other supervising, prompting and guidance. 10B and D might more appropriately be lined up with 10C and E respectively.

In Activity 11, the restricted group under 10C who as under current DLA Higher Mobility case law are to all intents and purposes unable to walk should be enabled to access Enhanced Mobility and Motability, by scoring 12 points to achieve a rough fairness with the overlapping mobility difficulties with some wheelchair users. 10B covers those with not quite so severe but still substantial difficulty and should be allowed access to the standard rate. A new descriptor should be developed that would be more appropriate to a 4 point weighting.

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?

Regulations 1 and 2 are fairly uncontroversial definitions of basic PIP terminology.

Regulation 3 refers to the list of Daily Living Activities - as above we suggest there is a need for the addition of a distinct Supervision Activity

Regulation 4 sets out the terminology used to define enhanced and standard rates. The devil lies more in the detail discussed elsewhere, but the experience of advisers in NAWRA members in dealing with the ESA gives little confidence that a medically based PIP Assessment will lead to an objective, accurate personal assessment of the disabling effects that a customer faces.

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?

The position in DLA is summarised in case law around “any period throughout which” . The starting point is to count needs the majority of the time but people who may fall outside the definition can still qualify

R(A)3/90 & R(A)2/74 suggest taking a broad view, based on whether in ordinary English usage, someone could be said to have those needs (looking at lengths of remission, frequency and the severity of the disability). *“Some but not all days or nights is sufficient”*

Award may still be appropriate even if periods of remission lasting over a week, depending on their length and frequency. Alternatively it is open to suspend an award during remission and restore without a qualifying period. Overall then a normative not arithmetical approach is required.

This has the irritating fuzziness of reasonableness and individual determination that does not fit well with the aim of a more defined list of descriptors. The third bullet point does at least allow for awards where a descriptor is not made the majority of the time, but would exclude customers where only one descriptor applies in a specific area. We believe the DLA approach allows greater flexibility.

NAWRA members have highlighted potential problems with requiring 50% of a 12 month period, as claimants may find this very difficult to allocate days over the past year. DLA allowed a more flexible approach based on the pattern of variability for a person. Some may be able to express variation better over a typical week, or month, although allowing up to 12 months is a useful option for conditions which have periods of remission. The current wording focussing on 12 months only may increase uncertainty in decision making - and the number of appeals - for people with more recently emerging illnesses or disability at the time of their claim, even if a fairly typical weekly pattern has emerged during the qualifying period.

Variability - together with the qualifying period - can make decisions particularly difficult in situations where people may face severe but unpredictable difficulties ahead - for example following a diagnosis of cancer or a stroke or similar significantly disabling condition. There may be significant immediate and dramatic additional needs. However, it may only be after a year or so of treatment and recovery or speech/ physiotherapy that a longer term pattern of disabling effects emerges. It may be only then that an application of the normal tests becomes sensible or that a consultant can offer a long term prognosis.

At periods the disabling effects may satisfy tests for Higher or Enhanced rates of DLA/PIP and indeed be potentially life threatening. At other times there may be good days at the end of, for example, a chemotherapy cycle.

While on the whole NAWRA feels that moves to an ESA style descriptor based system is likely to reduce the flexibility that an experienced DLA Decision Maker can bring to this situation , there is a provision within ESA that might usefully be carried over into PIP. ESA regulations at least allow people to be treated as passing the normal assessment in certain circumstances e.g while awaiting, receiving or recovering from chemotherapy. There may be potential to import this concept into PIP - extending to a limited range of similar serious debilitating conditions, more than likely to produce significant disabling effects over the 12 month period for an award, but where variability and uncertainty as to the longer term level of disabilities that a claimant may face. At present wise Decision Makers can make use of flexibility to make a short term award, but the more restrictive nature of PIP may require such a “treated as” approach.

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?

These provisions are vital to give some flexibility to what may appear a detached set of descriptors, however carefully crafted to fit the real lives of people living with disabilities. Their status as guidance means that they are more persuasive than binding. Assessments will be more effective if these are included as regulations.

The very similar provisions under ESA have moved from guidance to case law, but as such may be less obvious to assessing health professionals or ESA Decision Makers.

It may be easier to highlight these as an overarching regulation - and key principle in the training of DMs and assessors, whilst giving specific examples of the application of these principles in guidance within each descriptor.

It seems that it is often the failure to consider these aspects that leads to unsatisfactory and incomplete snap shot assessments. A hard pressed examiner may rely too much on the apparent ability to perform an activity once in the examining room, the appearance of the customer in front of them, or their apparent responses. Too often there is a failure to take account of the fact that most customers will actually underestimate their difficulties and may have taken considerable doses of painkillers or other medication to be able to attend, or may have been getting ready from before the crack of dawn. Others may appear to cope with the assessment only at the expense of being physically or emotionally drained for the rest of the day.

It is very often failings here that lie at the root of incorrect ESA decisions, that are currently overturned at the rate of 40% of those appealed, with much higher rates where customers are advised and assisted to obtain evidence from professionals who have known them over a longer period of time. The application of the descriptors may appear more objective, but in fact can often reveal an incomplete, partial and subjective process.

Anything that can raise the visibility and status of these provisions and ensure that they are highlighted in training may help such unnecessary expense and customer distress being incurred by a systemic failure to get the right decision first time.

We would further suggest that the Appeals Service is used as an effective quality process with judges able to feedback concerns of breaches in individual cases and empowered to require a response, while periodic general reports can help identify systemic patterns again with a duty on the Secretary of State to respond. This may sound rather radical, but is no more than the normal quality processes in successful private companies - or even advice agencies!

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?

Again we would be very interested in any concerns raised by disability groups around any of these definitions as a result of their more detailed work.

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?

These regulations are almost a carry over from the similar ESA provisions. These can cause difficulty to vulnerable people or those with chaotic lives. Difficulties often come down to inflexible application as much as the content of the regulations.

NAWRA has concerns over the effectiveness of many medical assessments within ESA or even within DLA. While many will succeed in giving an effective overall assessment of the disabling effects of a condition, others will be prone to an incomplete snap shot picture especially in assessments of disabling effects with a less clear cut presentation mental health, conditions causing fatigue and difficulty rather than inability to complete a task.

While there have been some assurances that perhaps a greater consideration will be given to other evidence from professionals with a perhaps more informed understanding of a customer's difficulties, we would like to see a matching duty on the Secretary of State to consider a range of sources of evidence and whether a consultation with a health professional is, truly, the most appropriate source in a particular case.

Conclusion

If the objective of a new scheme is really to offer a more personalised, targeted, objective, efficient and consistent assessment of disabilities then NAWRA would welcome a constructive dialogue about DLA reform. The basic principles of that benefit have been well matured through caselaw resulting in a benefit that is capable of a cost effective, holistic and individual assessment, even if this is not always achieved in practise.

While we recognise the hard work by all stakeholders and are grateful for the genuine willingness of the Government to consult on the design of the criteria, the record of the similarly structured ESA suggests that PIP will introduce significant new areas of subjectivity into a far more expensive and de-personalised assessment process.

The stated intention was to '*develop criteria which are clear to understand and apply; consistent in their outcome; consider the impact of impairments rather than what the impairments are; fairly take account of all impairment types*'. However improved and tweaked the grid may be, we remain concerned that it will be very difficult to develop a set of points based descriptors that can achieve this as effectively as the current test.

Advisers' experience with ESA - and Incapacity Benefit before that - suggest that a points based approach can miss out significant areas of relevant difficulty, both in valid "attention needs" that fall between the widely spaced bars of the test and in the complete absence of an effective "supervision" test. We have concerns that a more medicalised approach based on assessments by health professionals will merely extend the problems of a "snap shot" approach that bedevils both ESA assessments and EMP reports under DLA. The systemic failure - in too many cases - to consider both the wider context of how disabling effects impact on people's lives or to properly take into account the ability to undertake activities repeatedly, reliably, safely and in a timely fashion is what lies at the heart of so many wrong determinations and appeals.

PIP does though have the one virtue - that in ripping up the existing system it dispenses with all those irritating tests of reasonableness developed by case law over the years, and allows easy adjustment to secure whatever level of cuts are required.

In our submission to the first consultation, NAWRA felt that the arguments for the abolition of DLA were poorly made and expressed fears that the history of ESA suggests that any points based scheme is less likely to arrive at a holistic assessment of disability. We cannot accept that the current benefit is “out of control” when the DWP’s own research suggests that the benefit is significantly *underclaimed*. We feel the Department were right to abandon a previous pilot of a points based system - Activities for Managing Life - in favour of plans for better training and a tiered approach to Decision Making to seek more consistency within the current benefit.

We are moving away from simplicity rather than towards it, as there will now be three benefits - DLA (for children), PIP (for working age) and AA (for 65 and over), when DLA could effectively serve as a single universal disability benefit. There is certainly scope to reform DLA - to improve assessments, achieve better consistency and encourage its potential as a crucial back to work benefit. There are some good features within PIP that could usefully be brought into DLA. However, we remain convinced that despite all its shortcomings, DLA offers a more modern, person centred benefit, better able to achieve the stated objectives for PIP than the more narrow points based medicalised assessment that is proposed.