

Personal Independence Payment: assessment thresholds and consultation

A consultation response from Cymorth Cymru

30/04/2012

Cymorth Cymru is the umbrella body for organisations working with vulnerable people in Wales. Our members work to assist people who are vulnerable, isolated or experiencing housing crisis, including:

- people who are homeless, or at risk of homelessness
- families fleeing domestic abuse
- people dealing with mental or physical health problems, or learning disabilities
- people with alcohol or drug problems
- refugees and people seeking asylum
- care leavers and other vulnerable young people, and
- older people in need of support

This list isn't exhaustive, and individuals may often face a range of challenges that make it difficult for them to find or maintain a stable home and build the sort of lives we all aspire to.

Cymorth Cymru's members help people address these issues, supporting them in finding both emergency accommodation and long-term, secure homes, where they may fulfil their potential and build happy and fulfilling lives.

We have three overarching objectives:

- To improve the links between policy and practice by ensuring that those working in frontline service delivery understand and are influenced by the wider policy context, and those working in policy development understand and are influenced by the experiences and knowledge of those working on the ground.
- To ensure that the sector maximises its contribution to the lives of citizens and the communities in which they live by helping to build and develop the sector's capacity and professionalism.
- To increase public understanding and support for the sector and the work it does in helping people build the lives they aspire to within the community.

1 Introduction

Cymorth Cymru welcomes the opportunity to respond to this important consultation.

Given that there will be half a million less disabled people receiving Personal Independence Payment (PIP) than would be if Disability Living Allowance (DLA) was not reformed, there is understandable concern amongst organisations working to support vulnerable people. Despite the Secretary of State for Work and Pensions stating the genuine sick and disabled have "nothing to fear" from the reforms¹ it is incredibly difficult to determine who the Department of Work and Pensions has in mind when it says that PIP will be targeted at those with the "greatest needs".

The UK Government's stated commitment to support disabled people to exercise choice and control and lead independent lives is laudable and we fully support this objective. However, like many of our partners in Wales, we strongly feel that these proposals will not help achieve this aim but will instead mean that many disabled people will lose their independence and experience further marginalisation, social exclusion and inequality.

2 Consultation Questions

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

Whilst we welcome the addition of new activities on 'Communicating', 'Engaging socially' and 'Making financial decisions', we feel that there are still a number of areas of concerns which are outlined below.

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

Activity 1: Preparing food and drink

We feel that it is important to expand the scope of the activity so that it includes "preparing a simple cooked meal and making a hot drink". The descriptors fail to take account of the assistance that some people need (such as assistance with buying food) and also do not consider the impact of sight impairment (such as not being able to see labels or weight/measure food).

We would support calls for this activity to be more focused on an individual's ability to prepare a simple cooked meal and make a hot drink. We would also like to see more consideration given to an individual's ability to *prepare* food as well as cook food and therefore believe that if an individual's is able to only do part of the descriptor (such as cook food but not able to first prepare the food for cooking), they should be counted as **not** being able to do the descriptor at all.

1 Speech by Iain Duncan Smith, Conservative Party Conference, 5 October 2010.

Additionally, we do not support the downgrading of the role of assistance as unless an individual receives the help they need to prepare or cook a meal, they are at just as much risk of malnutrition or dehydration as someone who cannot cook food or drink at all.

Activity 2: Taking nutrition

We feel that the descriptors fail to take account of the need that some people have for support or supervision with taking nutrition.

Activity 3: Managing therapy or monitoring a health condition

We suggest that the impact of medication management issues needs to be strengthened and that the descriptors need to allow for the additional costs that some people may incur in using specialist aids to manage conditions independently.

We object to the proposal that if someone can take medication by themselves (regardless of how much they have to take and how many times they have to take it) they score 0 points.

Managing significant amounts of medication can impact on an individual's ability to maximise their independence, with the daily life often driven by when and how much medication one has to take. Unlike in other criteria, there is no recognition of the use of aids and appliances (such as dossett boxes and pill timers), allowing individual's to only score points when the assistance of another person is required. We feel that this penalises those who live on their own and must rely on aids or appliances instead.

As such, we believe that the scoring system should better reflect a person's need for medication, for instance by allocating a higher score to individuals where there are significant medicines management issues to be addressed with and without the help of aids.

Activity 4: Bathing and grooming

We feel that these proposals give insufficient weighting to the importance of bathing and grooming in maintaining self-esteem and social relationships. We suggest that the descriptors should be expanded to include nail cutting, shaving and removing facial hair, plucking eyebrows and applying make-up. The descriptors should also allow for some people's need for assistance with safety issues when grooming.

Generally we believe the scoring for this section is very low given that it is important part of ensuring the general well-being and we would welcome the importance of personal care and hygiene being more appropriate reflected in the scoring criteria

Activity 5: Managing toilet needs or incontinence

Many disabled people have increased difficulties with finding and using toilets when away from home and the descriptors need to take account of this fact. The descriptors should also allow for the frequency and severity of incontinence, which can incur higher costs and the clarification would be welcomed regarding on whether incontinence pads count as an aid.

Activity 6: Dressing and undressing

We would like to see the descriptors broadened to include assistance with selecting appropriate clothing and checking if clothes are clean and in a decent state of repair. Additionally, the descriptors do not take account of the additional costs of buying special equipment such a colour identifiers.

We feel that more consideration needs to be given to an individual's need for supervision when dressing and undressing which should be better reflected within the criteria.

Activity 7: Communicating

We feel that the score for needing assistance to access written information is too low, given the frequency and level of assistance that may be required and the impact this may have on capacity for independent living. We suggest that the descriptors are broadened to include accessing information in preferred formats and the scoring should take account of the additional issues and costs arising from this.

We are concerned that this activity only seems to consider specific facets of communication around sensory loss and so is very much focussed on aids and equipment, or the need for interpretation. As an example, there is no activity to express written communication.

We would like to see the criteria award points for difficulty or inability to write, problems with vocalisation and word recall.

Activity 8: Engaging socially

With the worrying rise in disability hate crimes, the stress resulting from having conditions which cause social embarrassment need to taken into account. As such, anxiety and panic attacks should be included in the descriptors and scored appropriately.

We therefore would welcome the activity being reworded to encompass the disabling distress and anxiety that can come from a having a physical condition and symptoms that may cause social embarrassment.

Activity 9: Making financial decisions

We are concerned to see how low scoring this activity is despite the major impact and implications of being able to make financial decisions. As such, we feel that if an individual is unable to make simple financial decisions without assistance they should be scored as being unable to make any financial decisions.

We suggest that this activity needs to include supervision criteria and provide for higher scores given the impact it can have on daily living.

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

10. Planning and following a journey

We would like to see the activity focus on routes rather than destinations. Given the unpredictability of unforeseen hazards (such as cars parked on pavements, wheelie bins, holes in the road/pavement etc.) we suggest that points are awarded to people who find it difficult to cope with unexpected changes.

We feel the activity descriptors need to be reworded here to more carefully capture risk and safety issues. There may be many reasons someone has to have guidance or supervision for planning and following a journey: there is an overemphasis on cognition and mental distress but actually for many individual's the issues will be around risk of falls and needing the support of another person.

We feel that the reference to ALL journeys will make it difficult for individual's living with a fluctuating condition to "score" themselves. We recommend that further consideration is given to the wording and scoring of this section.

11. Moving around

We suggest that this activity should be re-worded so that it explicitly addresses the ability to walk, not the ability to move around, which could be subject to mis-interpretation. We note the change in language from being able to "walk" to in places in the criteria being able to "move". We believe it should be explicit that this is about assessing walking ability.

We also feel that it is important that the descriptors address an individual's ability to walk on steps, uneven surfaces and hills and also take account of the level of discomfort, pain and fatigue when doing so.

The criteria must also be more explicit regarding the physical exertion involved and whether an individual could do the activity repeatedly, reliably, safely and in a timely fashion. On the latter the

amount of time the government estimate the activity to be undertaken should also be explicit e.g. the average non disabled person would be able to walk 50 metres in 36 seconds (based on 5km/hour walking speed). Therefore a person who takes twice as long would not be counted as able to walk this distance in a timely fashion.

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

We endorse the comments made by our partners.

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

Whilst recognising the potential advantages of a points-based assessment system, we are concerned that a computerised system will fail to take account of the whole picture of an individual's circumstances. Much will depend upon the level of "empathy" employed by assessors which places even more emphasis on the need for assessors to be fully accustomed with the needs of disabled people.

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

Further thought should be given to how assessors might be enabled to consider the overall circumstances of those who narrowly fail to meet the 50% of days criteria. We feel that a shorter time frame (e.g. one month) should also be used for assessing the impact of fluctuating conditions, as this is more likely to provide an accurate assessment.

We welcome the proposal that a person will score points against an activity if they are unable to complete or perform it **at some stage of the day** i.e. over a 24 hour period. However, we support calls for assessment to be based on evidence (such as that of a diary) to verify the impact of fluctuations on their lives, as a year's estimate will be almost impossible to recall or estimate.

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

We welcome these definitions on the whole but would like to see more clarification around the term 'timely'. Without such, there is a risk that assessors will revert to evaluating individuals' abilities on the day unless prominence is given to 'safely', 'timely', 'repeatedly' and 'in a timely' manner. The definitions should therefore be given more prominence.

Although these are very welcome there is much to learn from the Work Capability Assessment and the fact that these terms should be on the face of the criteria. It is very apparent from face to face

assessments that assessors have failed to make this judgement call and took the decision on the basis of what a person was able to do in the interview.

This is one of those areas where the language of the criteria is also ambiguous. Reliably is said to mean “to a reasonable standard”. There is no definition of what this means leaving it open for individuals and decision makers to interpret matters very differently.

It is vital to repeat the mantra of “reliably, repeatedly, safely and in a timely manner” in the regulations and the criteria. However we also believe this should go a further step and provide a prompt on the face of each activity otherwise there is a danger this will be overlooked.

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

We endorse the comments made by our partner organisations.

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

3 Conclusion

We feel strongly that these proposals need to be based on the Social Model of Disability in order to fully meet the needs of disabled people. We also endorse the call by Disability Wales for DWP to engage with disabled people’s organisations to consider how the recommendations made in the paper “The Future of PIP: a social model-based approach” can be incorporated into the PIP assessment criteria and procedures.

As Wales has a higher proportion of benefit recipients than other parts of the UK, the introduction of these proposals in their current form will have a disproportionate impact people in Wales. We strongly urge the DWP to take on board the concerns that we have raised together with those of our partner organisations working with disabled people. We fear that these proposals in their current form will not help disabled people maximise their independence but will result in many disabled people losing their independence and experiencing further marginalisation, social exclusion and inequality.

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