

CSAN Response to:
Personal Independence Payment: assessment thresholds and consultation

CSAN (Caritas Social Action Network) is the domestic social action arm of the Catholic Church in England and Wales.

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General comments

This paper is an improvement on its first draft version; the concerns and opinions of disabled people have been reflected in the refinements and additions. We particularly welcome the inclusion of communication and social/community integration criteria. This criteria has all too often been excluded and as such denied people with permanent and long term disabilities from receiving benefits which will enable them to live well in a world that is ever more complex. It will also enable assessors to have a fuller picture of the lives of people with a disability.

It is important to pay attention to the comments in section 1.2 of the second draft assessment criteria paper, that; *'At the heart of these proposals was the development of an assessment for the new benefit which would enable an accurate, objective, consistent and transparent consideration of individuals.'* If this is to be fully realised, it will not be enough to merely listen and amend criteria, descriptors, thresholds and levels of benefit. If this benefit, which rightly takes into account the advice of disabled people and their organisations, is to be effective, the government must ensure that those who assess needs are fully trained in all areas that affect the lives of people with a disability.

The refined criteria should formulate a benefit that enables a disabled person to live well, thrive, communicate, interact and get around, according to their own individual ability. If this occurs then the new name assigned to this benefit can be fully realised.

We note that the language in the consultation paper is sometimes unnecessarily complex and that this may prove to be a barrier to the paper achieving its aim of *'enabling an accurate objective process'*, which will benefit people whose life experience includes disability.

We also have some concern about the case studies utilised, as the majority of these focus on the life experiences of people who **acquire** a disability. There was no reflection whatsoever, of a person who is born with a physical disability such as cerebral palsy, or who indeed may

have a physical disability as well as an intellectual one. Case studies should provide clarity as to how such cases will be assessed and accredited.

Finally it is important to emphasise that the concept of supervision, often mentioned as an amendment should not totally replace the concept of care, as people with profound and complex disabilities often require care and kindness over and above supervision. Where the concept of respectful care is not mentioned, a hierarchy may result, with the most able at the top and those who experience more profound disability at the bottom.

Specific answers

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 new activities are broadly welcome as they reflect the full scope of the needs of a person with a disability, as they seek to live well. However, there remains a requirement for some acknowledgement of the needs of people with profound and complex disabilities. We feel that some reference to respectful care could also be added as a descriptor; this would be specific for people whose body and intellectual processes are such that they are not able to live an independent life.

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?

The framework given seems to be able to distinguish well between levels of abilities, but further additions should be made for people who have a profound and complex disability, so that we do not discriminate against them by expecting them to have abilities that it may not be possible for them to express.

The new and refined thresholds are better able to assist a person to disclose their needs. However the language in some of the explanations remains somewhat inaccessible and unnecessarily complex.

Not enough attention has been given to highlight the needs of people who are born with a disability, over and above those who acquire disability through illness or mental health issues.

More needs to be done to distinguish between the needs of people with a profound, complex and mild disability.

Dressing and undressing should carry a high weighting as opposed to moderate, as to dress and be dressed comfortably is not a personal choice but a basic human need.

The threshold for activity 7 (as set out in 2nd draft 4.29) should be made more explicit in the descriptor. The threshold must allow for a realistic understanding of the '*levels of support and care*' that is required for those who live with permanent incontinence as part of their life experience. In such cases there would be no threshold possible to distinguish needs. Permanent toileting needs have to be managed and assisted with, whether it is in the day or during the night, as reflected by 4.29 of the 2nd draft. The wording and explanation, concerning the activity of managing toilet needs, should therefore clearly state that no division must be made between night-time and daytime toilet assistance.

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?

These changes are an improvement and we do not feel any further alterations need to be made. The new criteria of moving around correctly identify the needs of people whether they have a profound or mild mobility need or capacity.

Q4. 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?

These changes are an improvement and we do not feel any further alterations need to be made. The removal of '*several hours, after the journey*' is particularly encouraging.

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?

The weightings of descriptors work reasonably well. However, we remain concerned that the complexity of explanations may cause confusion. Clarity is vital when explaining the new regulations otherwise it will be the structure of the questions themselves that take no account of levels of ability.

It is important for attention to be given to weighting levels concerning the lives of people with profound and complex disability and to those who use aids.

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?

This system is currently too complex and should be clarified. It could be interpreted as unnecessarily ambiguous, which would be unfortunate in a process that has involved much time and effort in seeking consultation.

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?

These definitions are an improvement on the first draft and allow the assessor to make judgements according to levels of ability and disability.

Some organisations have suggested that these terms should be included within the regulations. Do you agree?

We agree with the inclusion of these terms within the regulations on the basis that they will make the regulations less ambiguous and more accessible. Clarity must be a priority and future consultation must take differing levels of ability into consideration, if it does not the process will cease to be an authentic mode of obtaining information.

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 should be referred to within the detail of the descriptor.

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?

These are too complex and require significant clarification. Please see responses above.

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?

There must be clear direction given to outline what people with profound and complex disabilities must do if they are not able to engage in face to face consultations. Many people who find such activities challenging and difficult experience a lot of stress due to not being able to understand what they must do. The process must be clear, and accessible.

The skills of the assessors, who will be putting the requirements into practice, must be in-line with current practice concerning the communication skills of disabled people.

The assessors and those imposing regulations should have the skilled use of: Makaton sign language accompanied with the ability to use makaton symbols; Widgit communicate and print symbols supported text; BSL; and Braille guidance.

Face to face interview skills must be developed in conducting interviews with people who have an intellectual disability and information should be made available in symbol format for those who use pictures to communicate.