

Final Response to the second PIP consultation re assessment criteria

With contributions from NCODP Independent Living Group members and the Disability Rights Norfolk team

General comments

The groups felt that individuals should be allowed to see the criteria before the assessment (without the scores perhaps) so that they knew what the assessment was about.

The groups felt that the document needed better wording, and there were too many notes which were not included in the main part of the guidance. They felt it was overly complicated and misleading, which could lead to people answering the questions but not understanding them. They also wanted an easy read version of the activities.

Because of the complexity, they felt that they would need the support of an advice agency to complete the form. They thought that there would be a lot of anger because it is seen as so difficult. They felt that the benefit should be based on care needs, not on points being aggregated to qualify for benefit – there was a risk of not capturing information with the use of ‘tick boxes’.

Question 1 – what are your views on the latest draft Daily Living Activities?

Activity 1 – the groups were happy with descriptors apart from (b) which they felt required the word ‘special’ in front of the word ‘appliance’, and (f) where they felt the wording was not clear re preparing and someone reading and understanding a recipe or instructions especially when cooking something which they have not cooked before. The descriptor assumes a great deal as above, i.e. chopping ingredients is ok, but some people would not be able to understand a method of cooking/ preparing a meal. It is also difficult to cook a reasonable and nutritious range of simple meals just using a microwave and this seems unfairly detrimental to a claimant’s health. Not everyone has an expensive microwave capable of a range of tasks, and it is not reasonable to expect that they are able to purchase one. It is not at all easy to get a range of different types of food all cooked at the same time just using one microwave.

Activity 2 – the groups were happy with descriptors and scores for (a), (d) and (e). They would like to see the word ‘special’ before the word ‘appliance’ in (b). There should be another activity reflecting need for supervision when taking nutrition.

Activity 3 – They were happier with the descriptors and scores for (a) and (b), but for (c) (d) (e) and (f) commented “what about needs that are 24/7” and also felt there were issues around ‘waking’ that had not been taken into account. The monitoring of a health condition seems to be associated with physical conditions only (nebulisers and oxygen being mentioned) and someone with a mental health condition might fail to recognise that the descriptors could apply to them and not report on this

Activity 4 – some of the language was meaningless to the group, e.g. ‘grooming’ and if this is going to be recorded from tick boxes it will make no allowance for people to expand on a particular situation. Why is no mention made of legs or feet? Surely it is just as important to clean there too?

Activity 5 – there is no mention of hoisting – which descriptor applies to people who require this type of support? Surely a hoist should not be classified as an aid or appliance, as people using hoists often require considerable support with toileting. For (e) and (f) it was noted that assistance to manage incontinence of bladder or bowel is often interchangeable, and a person may be able to manage on one day but not the next. A question was raised regarding the definition of assistance, because it could mean taking a person to the bathroom door, or it could be they need assistance to take off lower garments inside the toilet and use wipes etc, so this needs to be clarified. Also, why are cleaning and changing clothes not included within this activity? It may be that someone has to have a shower because of the state they can get into.

Activity 6 – it was felt that the descriptors were unrealistic, and that (d), (e) and (f) should be the same. Why are lace-up shoes not included? Does everyone with a disability have to use slip-on shoes? This may not be possible or suitable in winter, and doesn’t take account of the fact that lace-up shoes or boots may offer much more stability and support.

Activities 7-9 – generally the descriptors were felt to be generally very confusing because of lack of description. It was felt that there was no descriptor which adequately covered need for supervision to prevent self-harming, suicidal ideation or other self-neglect problems as well as danger from delusional or hallucinatory behaviours associated with mental health problems

Activity 7 – it is not clear how the use of Braille is taken into account or what is meant by complex as opposed to basic verbal information.

Activity 8 – the groups asked for examples of an event so that people knew what it meant. The use of words such as ‘overwhelming’ and ‘uncontrollable’ need clarification because it gives no reference point as to how high the assessment bar will be set. Will it be as perceived by the claimant, or as perceived by the assessor (i.e. needs to be clearly visible)?

Activity 9 – a client's level of understanding around financial issues needs to be clarified with regard to complex or simple understanding. The groups wanted examples to be given in the guidance notes to make it easy for clients to understand what is needed when they answer the questions. There is no descriptor that seems to cover a claimant who can only do their own shopping with support because they cannot deal with money; they would hand over their purse and expect a shopkeeper to work it all out and give them the correct change – do they count as someone who cannot make any financial decisions at all?

Question 2 – what are your views on the weightings and entitlement thresholds for the Daily Living Activities?

Activity 1 – no comments were made by the groups.

Activity 2 – they felt that descriptor (c) should be given 4 points. Also, if descriptor 2(f) gets 10 points, why does 3(b) only merit 1 point?

Activity 3 – see above. It does not make sense that someone who may require constant monitoring of their health condition for safety may only score 1 point. This will put many people out of the range of entitlement when their condition may at times be life-threatening.

Activity 4 – the scoring seemed mainly to be 1 or 2, and only 2 descriptors gave 4 or 8 points – the group felt that there were insufficient points allocated to the first 6 descriptors, and overall the scoring was too rigid.

Activity 5 – people may have a commode but this still requires emptying – however using a commode only seems to award 2 points. There should be an additional point – 'do you require assistance to empty commode or portable toilet?' For (e) and (f) the level of support may still be the same regardless of whether it might be incontinence of bladder or bowel (or both) and yet it scores less if only one applies. This does not make sense.

Activity 6 – a question was raised as to why fewer points are given to a person who requires assistance for upper body – this was seen as gender discriminatory: women may find that the need for support to dress or undress their upper body is just as great as for their lower body; (d), (e) and (f) should all get the same points

Activities 7-9 – generally the scoring was not felt to be allocated fairly, and the scale from top to bottom of points was inadequate and 'very black or white', there was no room for discussion and the thresholds were unfair.

Activity 7 – is there going to be a penalty for people with high intelligence (score 8 if you can't express or understand basic verbal information, but only 4 if you can't express or understand complex verbal information – no help to take a signer to university)?

Activity 8 – the groups felt the score for (b) was inadequate, and also especially so for (c) because it implies you already need a carer, so why is the score so low? There seems potentially to be no eligibility unless a claimant is assessed as a visibly quivering wreck or a dangerous psychopath (everything else is less than 8 points) – this does not seem right.

Activity 9 - a client's understanding around financial issues needs to be clarified with regard to complex or simple understanding – and yet being unable to make any financial decision only scores 6. This does not seem right. Also the use of 'prompting' as the only requirement for this activity is seriously inadequate, as many people will require more than reminding or encouragement; they won't need someone to take over, but they will need someone to intervene as appropriate.

Question 3 – what are your views on the latest draft Mobility activities?

Activity 10 – the groups felt that a client may have the ability to plan a journey, but they may have had to undergo many hours of extensive training before this is possible, and this is not captured. Many people need specialised and costly adapted motor vehicles to get out and about, and again this is not addressed.

The descriptors do not take into account clients who suffer with Alzheimer's, depression, or dementia. Clients with visual problems are excluded if they are able to get around using a white stick rather than a support dog.

The word 'overwhelming' needs clarification because it gives no reference point as to how high the assessment bar will be set. Will it be as perceived by the claimant, or as perceived by the assessor (i.e. needs to be clearly visible)?

There is no clear reference to being unable to plan and follow a journey due to depression affecting motivation and interest, and it wasn't clear what descriptor applies when a journey is interrupted due to panic attacks, perhaps when crowds are encountered. Also, why does the entire journey have to have been planned by another person? It may be that a claimant is familiar and confident with one small part of the journey.

Activity 11 – The wording of some of these descriptors could be clarified – instead of 'up to' in (c) (d) (e) and (f) could the words 'as far as' be used?

There is still a reference to 'walking' in the guidance notes – does this infer that there is still an expectation that moving takes place by putting one foot in front of another and weight-bearing? Also, what account is taken of the need to lean on another person?

There is nothing about the manner in which someone walks, i.e. type of gait when walking, number of falls or episodes of dizziness, using a stick, needing to rest (e.g. although they may be able to walk 50 metres plus, they might need to take medication such as use an inhaler to continue on).

Question 4 – what are your views on the weightings and entitlement thresholds for the Mobility Activities?

Activity 10-11 – the groups felt that the scoring omitted clients who are on their own with no support from friends, family, neighbours etc; also that it did not take into account the level of danger the client may be put under e.g. from increased depression, adverse weather conditions etc, even if they could plan their own journey.

It was felt there should be an additional score somewhere between 0-4 for Activity 10.

For Activity 11 the score of 10 for (d) seems to seriously under-represent the level of difficulty that would be experienced.

Clients who were disallowed because of the scoring would become socially isolated (as described above with no immediate support from another person) so that it will increase their needs from moderate to high over time, putting increased pressure on local services and councils, including increased demand for Personal Budgets, and increase NHS pressure and costs.

Question 5 – what are your views on how the regulations work regarding benefit entitlement

The groups felt that people with social difficulties were excluded, e.g. those with autistic spectrum disorders, where even a regular journey followed by a client has to be meticulously planned so that they can follow this on their own. They would not be able to follow other journeys without the help of another person. Even on regular known journeys clients may be unaware of dangers e.g. other people abusing them, taking their money etc. They also felt that where conditions/disabilities are progressive more support would be required, and that removal of benefit for someone with moderate needs could exacerbate their needs in the future increasing the pressure on other services, i.e. NHS, local authorities etc.

The groups unanimously said that the assessments did NOT successfully prioritise those in most need. Many statements seemed to be insufficiently inclusive or people would fall between two descriptors and lose out as they would potentially be awarded the lower score of the two. There is no clear guidance as to what people should do if their condition gets worse, or when they should take action, and the groups wanted to know if there would be a specific number of times that a person could apply for PIP. If lifetime awards exist, how meaningful is that, since these people now find they will be reassessed.

Question 6 – what are your views on how we are dealing with fluctuating conditions?

They felt that assessing someone with a fluctuating condition over 12 months was too long a period, and suggesting that people try to work out what they were like 50% of the time over that period was too difficult for many to assess. Also the 50% rule does not take into consideration people whose ability may be impaired or fluctuate at different times of each day. Lots of disabled people will look only at what they *can* do, and they may end up being penalised. One person made the point that they did not even know how the 50% should be calculated.

There was a unanimous view that fluctuating conditions were not taken into consideration sufficiently and limited scope appeared to be given to represent this, with very arbitrary guidelines.

Question 7 – what are your views on the definitions of ‘reliably, safely, repeatedly and in a timely manner’?

They did not like the use of words ‘reliably’ or ‘in a timely fashion’, feeling they were too old-fashioned and meaningless. The standard should be qualified for each activity, e.g. twice the time, or the average between x and y.

However they are eventually worded, these concepts should be incorporated in the Regulations, not simply stated as guidance.

Question 8 – what are your views on the definitions in the regulations?

Comments on the Regulations in general (Part 1):

s.2(1)(c) The phrase explaining the boundaries to ‘aid or appliance’ is unclear

s.3 – surely mobility is part of daily living?

s.4(4)(c) – how is 50% to be calculated?

s.4(4)(d) – who decides if a prosthetic is too uncomfortable to wear, when on the surface it may be deemed ‘suitable’?

s.4(4)(e) – this is very unclear

s.7(3) – it was felt that 7 days was not enough time; it should be at least 14

s.7(4) – would a failure of electronic means be a reasonable excuse for non-compliance?

Should there be a receipt required notice?

s.12(1)(a) – could it use the word ‘throughout’ rather than the words ‘at every time’?

What does at every time mean exactly?

Comments on the definitions in Schedule 1:

‘bathe’ should include lower limbs

‘cook’ should not just be at or above waist height; it seriously limits the range of food that can be eaten as part of a nutritious diet, as well as in some cases increasing the effort that has to go into the task of cooking, and is unfairly limiting the style of cooking that many people are used to, perhaps for cultural reasons.

‘dress and undress’ should not just specify slip-on shoes; this is an unrealistic reduction in potential footwear requirements as during winter it may be essential to wear boots, and lace-up shoes are far more supportive. Tights should also be included rather than just socks.

‘engage socially’ (c) should be ‘establish and maintain relationships’

‘groom’ (b) should include drying hair; it is not reasonable for anyone with long hair to sit around with wet hair as many people with mobility problems will already struggle to keep warm. If they are unable to wash their own hair they are certainly unable to hold a dryer for the required length of time. It should also include shaving for men and women.

‘manage incontinence’ should include managing menstruation as it will involve a very similar set of tasks to managing incontinence of bowel or bladder. It should also incorporate the act of cleaning where appropriate.

‘monitor health’ should be amended to incorporate the words ‘without which the claimant may be at risk or their health is likely to deteriorate’

‘overwhelming psychological distress’ is defined with no guidance whatsoever as to the level of severity which will be expected to meet the criteria; the word ‘overwhelming’ needs to be clarified

‘prepare’ should include getting raw ingredients and equipment from cupboards

‘prompt’ should make clear that physical presence is not required

‘simple meal’ should incorporate the words ‘as part of a balanced and nutritious diet’

‘social support’ should include use of informal carers; it is completely unfair to expect that the claimant has access to someone who is ‘experienced in assisting people’ rather than experienced in helping them in particular

‘supervision’ expects continuous presence but the word ‘continuous’ requires clarification

‘take nutrition’ should incorporate a level of supervision to ensure safety when chewing or swallowing

‘therapy’ requires a definition for long-term

Question 9 – do you have any other comments on the draft Regulations?

There are a number of low-scoring descriptors; if a claimant doesn't have multiple problems they may be excluded from PIP and yet it may have major consequences – for example if someone would not eat without continual encouragement and motivation, they will only score 4 points and receive no help, also needing assistance to bathe only scores 4 points – is a person not supposed to ever bathe if this is their only problem?

All of the guidance notes need to be part of the Regulations, not something added on in an informal manner.

Case Studies

These comments should be read in conjunction with the above comments on specific activities.

The groups looked specifically at the case studies provided and would like to make the following comments:

2 – awarded too little

3 – fair

4 – fair on mobility, but the daily living component does not account for the unpredictability of epilepsy *or risk that he would hurt himself without monitoring*. Also the assessment fails to take any notice of supervision needs beyond cooking a meal or bathing. If seizures could be daily and without warning, surely they would need supervision when eating, as the risk of choking could be great, as well as there is a real risk of injury, particularly head injury, during any falls. Someone might need to raise the alarm. Also if someone is having uncontrolled daily fits, surely they should be awarded points under 3(a) because they would, in all likelihood, have emergency medication which would need to be administered if seizures became too frequent, or claimant went into 'status'.

5 – Although this case is less severe than (4) above as the claimant does get some warning, they would still have significant supervision needs particularly with eating and bathing, but also in the wider description of activities, because of risk of head injury, need to administer medication or raise the alarm.

6 – awarded too little. This claimant appears to have huge legs if they can walk more than 50 metres in the 20-30 steps he can manage before pain forces him to stop. Inability to grip will also limit ability to cook for himself to a greater extent than the 2 points awarded would suggest.

7 – no account is taken of how he walks, risk of falls or instability. He cannot walk more than 50 metres but seems to be penalised because he tries to walk rather than rely on using a wheelchair.

8 – no entitlement to mobility is fair, but as far as daily living is concerned there is no information about recovering from the operation or if help was needed for applying medical dressings which may be relevant. The client stressed she could manage with dressing etc if she had shoes with Velcro etc, but how difficult was this for her? Did it take her more time than a standard amount of time to dress? No account taken of this.

9 – Some felt it was fair. But his ability to plan and follow a journey unaided was queried, because he can't hear many of the signs of danger that the hearing population take for granted.

10 – if this claimant is dependent on her insulin being administered for her, is she at risk of hypos? If so, can she bathe without supervision? Assistance may be required for social interaction and also in unfamiliar toilets.

11 – no comments

12 – daily living enhanced rate is fair, but for mobility there were concerns around safely/without supervision when she was on journeys on her own. She gets confused, has transport to the day centre she attends, only goes out in her neighbourhood, but may not be aware of dangers around her, e.g. strangers taking advantage of her.

13 – correct, although the categories were barely described and much of the scoring is low but at least he still qualifies for full rate

14 – fair if the problem is a mild one of 'low mood', but claimants with depressive conditions need problems to be fully investigated as they often do not fully understand, concentrate on, or fully engage with a questionnaire

15 – as expected

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