

**Personal Independence Payment:
assessment thresholds and consultation**

Consultation Response submitted by:
ARChive (a coalition of adults with Autism Spectrum Disorders in Glasgow).

Consultation questions

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There are a number of specific areas where we are particularly seeking feedback on the second draft:

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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?

OUR RESPONSE: In relation to “Communicating”, we feel that there should be an additional descriptor between descriptor (c) and (d) for Activity 7 (e.g. something similar to (e), only referring to written information.) There also needs to be some definition to exemplify what is meant by “complex” at (e) and “basic” at (f). It is important that the scoring also reflects the fluctuation in functioning that even people at the so-called higher functioning end of the autism spectrum can experience - sometimes for days at a time, depending on their stress and anxiety levels. We also feel that the descriptors relating to communication support should not solely be related to the learning disabled or similarly cognitively impaired, but also recognised as being valid for people on the autism spectrum in terms of their functioning rather than their IQ.

In relation to “Engaging Socially”, we feel that an additional descriptor is required between (c) and (d) - something that reflects that people on the autism spectrum can engage socially, but that they require knowledgeable (often specialist) support services to do so - and also to reflect that they can only engage with a very limited number of people at any one time (usually one or two at most) and that they can only engage with other people in a limited way.

In relation to Activity 9 - “Making Financial Decisions” - again, there needs to be a specific definition of what is meant by ‘complex’ and ‘simple’ financial decisions. What exactly do these terms mean and what measures will assessors use to determine which applies? Does ‘financial’ refer to using money, banking, paying bills, budgeting or all of these? These are all areas of difficulty for people with autism, regardless of intelligence, due to difficulties with personal organisation, ability to prioritise tasks, recognising what is important, making calculations, and problems with impulse control (re spending). Again, it is important that these are

not only seen as problems for people who are learning disabled or of low intelligence. In the case of Autism Spectrum Disorder (ASD), it is more a problem of organisation and decision-making difficulties and the current descriptors do not reflect this. We would suggest that, while there is a role for the use of the word 'prompting' in descriptors (b) and (c), the word 'organising' or the phrase 'help with personal organisation' should also be included.

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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?

OUR RESPONSE: We feel that the entitlement thresholds require further work, both in terms of the number of descriptors (insufficient) and the points awarded for each (not enough at the lower levels). This applies particularly to the mobility descriptors. Going from 0 to 4 points and from 4 to 8 points with nothing in between could disadvantage people on the autism spectrum to whom (a) does not apply, but who are not quite a (b), or not (c), but not quite (d).

While we welcome the inclusion of a specific "Planning a Journey" activity category, the "Moving Around" category still fails to reflect that not all 'moving around' difficulties are due to physical limitations. Some are also related to mental, emotional and motivational difficulties - as in the case of autism. For example, people becoming psychologically overwhelmed and 'stuck' in one place, unable to move or engage in tasks without prompting or reassurance. This can be very disabling, as it prevents people from attending to things that they need to do, resulting in low motivation and possible self-neglect.

We also feel that the large incremental increases in the points awarded between descriptors and the wide applicability of the descriptors themselves for both of the two mobility activities could disadvantage people with cognitive difficulties who are not learning disabled (and therefore don't currently qualify for statutory funded social care support) and who do not have physical disabilities, or whose physical problems - such as co-ordination disorders - are not compensated for by the use of aids or appliances.

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?

OUR RESPONSE: Further to our response to Question 2, we would advise that a descriptor that does not relate solely to physical limitations be included in the “Moving Around” activity category. For example “Needs prompting to move around and stay active; needs encouraged/reminded to move around.” There also needs to be, we feel, a category reflecting that people with certain cognitive disabilities - including autism - can require supervision when moving around, indoors and especially outdoors, because they lack awareness of danger and common risks. It is not obvious to us how this fits into the existing descriptors.

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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?

OUR RESPONSE: Please refer to the answers given for Questions 2 and 3. We believe that there are obvious gaps in terms of entitlement thresholds - both in the points awarded and the levels of functioning described - and that there is still an apparent bias towards physical causes as an explanation for mobility problems, which disadvantages people on the autism spectrum.

As such, the individual descriptors within the mobility activities are insufficient to distinguish between different levels (and types) of ability in each activity. In prioritising the purely physical - particularly walking difficulties - claimants whose cognitive functioning limits their mobility will find it difficult to find a descriptor that fits their own situation. The fact that there is no mention in the descriptors of the effect of co-ordination problems or tiredness caused by cognitive overload increases this likelihood.

In addition, some of the superlatives used - such as “overwhelming” psychological distress (Activity 10, descriptor (d)) are open to misinterpretation, which could disadvantage claimants who might otherwise be eligible. We recommend the inclusion of some kind of glossary explaining what degree of disability these terms are describing. (We note that there is already a glossary defining the terms used to describe the activities, but require something that explains how much/to what extent.) With specific regard to descriptor (d), we feel that, if an individual cannot undertake an activity without it causing psychological distress - overwhelming or otherwise - the score should be 12 points and not 10.

The difference in points awarded from one descriptor to the next within an activity are arguably too large in the mobility section and perhaps an additional descriptor between (a) and (b) in Activity 11 (“Planning a Journey”) should be included to reflect that someone might require regular support or supervision, but not for all journeys.

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?

OUR RESPONSE: We have a concern that - as has been the case for some in relation to Employment and Support Allowance - the system of assessment for Personal Independence Payment does not show due regard for the fact that conditions such as autism are lifelong, incurable, untreatable by the use of medication and therefore unlikely to improve and any fluctuations that occur usually relate to a worsening of the individual’s functioning, not an improvement, or one that is sustainable. Subjecting people to regular reassessment - especially those for who do not have co-morbid physical illnesses, amenable to improvement - can cause unwarranted distress. This is especially the case if the claimant’s limited responses, lack of detail or lack of expressiveness (particularly of distress) are repeatedly misinterpreted as indicating that the individual is less disabled than they really are. This could lack vulnerable (and unsupported) individuals into a cycle of assessment-appeal-reassessment which could be detrimental to their mental health and wellbeing.

We also feel that the reduction to two rates of award - standard and enhanced - in the case of care (or “Daily Living”, as in PIP) could unfairly reduce eligibility in people whose difficulties are less obvious to assessors and don’t fit within the limited number of descriptors across Activities 1 to 9. This could include people currently assess as having low level care needs under Disability Living Allowance.

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?

OUR RESPONSE: We feel that the system described in the explanatory note - on assigning descriptors to people who have fluctuating conditions - is biased in favour of those who have physical and not mental disabilities. We do not understand how the system described can be used in the case of complex cognitive conditions such as autism, where fluctuations can occur on a daily basis, throughout the day, and vary dramatically from one day to the next and that core impairments associated with the condition are permanent and not something that is likely to improve. On this basis, we feel that it would be extremely difficult - not to say impossible - for someone with autism or Asperger Syndrome to quantify or explain how much their condition fluctuates, so we fail to understand how the assessor would be able to determine this.

Remember, also, that if such divinations are based on self-report responses during assessment, then will be compromised, as people on the autism spectrum perform badly under stress (and having to answer questions that they don't know in advance is stressful). They also lack the ability to understand and explain accurately how they are really feeling. How will the system cater for this? We imagine that this will also be a problem for people with mental health conditions.

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?

OUR RESPONSE: While definitions of this type might well be necessary, the examples given above raise more questions than they answer, which surely defeats the purpose? For example, “reliably” refers to a “reasonable” standard, but what is meant by reasonable is neither defined nor quantified. Ditto “in a timely fashion”. How long is “twice the time it would take for an individual without any impairment?” These terms would be confusing for most people and completely baffling for someone on the autism spectrum. Specifying the time taken in minutes, so that a valid comparison might be made, would be more meaningful.

There also needs to be an acknowledgement that the reason for taking longer (in the case of those who have autism) might have nothing to do with physical disability and everything to do with cognitive impairments. How, then, can a valid comparison be made?

In the case of the word “repeatedly”, examples need to be provided to explain what is meant by this; also in the case of “as often during the day as the individual activity requires” (we have no idea what this means in relation to any task that we can think of). In addition, it isn’t just the cumulative effects of pain and fatigue that need to be considered, but also the cognitive processing deficits that affect people with autism and the related impact of stress and anxiety. Stress can have a domino effect in terms of a person with autism’s ability to carry out subsequent tasks, as can difficulties in stopping/starting, recognising when a task is complete and how and when to start the next task, etc.

Again, in the case of “safely”, further clarity is required, as well as an acknowledgement that many people with autism lack awareness of danger and non-specific references to safety will mean nothing to them.

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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?

OUR RESPONSE: We are unable to comment on these, as we were unable to locate the required information (it would have been helpful if a link to the relevant part of the DWP website had been included next to Question 8).

Speaking in general terms, and with reference to comments made earlier in this response, it is crucial that there is no ambiguity or scope for misinterpretation in any of the language, terminology or definitions used in the descriptors or the activities overall, as this would disadvantage people with cognitive disabilities such as autism, as would descriptors that are solely or mostly applicable to physical rather than non-physical disabilities.

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?

OUR RESPONSE: We feel that the scope of assessment should be extended to cover social and environmental factors in as much detail as possible, as these are significantly disabling factors in the case of autism. Autism is primarily an impairment of social understanding and communication, while environmental factors that can't be controlled for such as change, newness, unfamiliarity and sensory overload in terms of noise, speed, light, etc. can cause distress and cognitive and emotional meltdown. Failure to include these areas within the assessment criteria would significantly disadvantage people whose disabilities are most affected - and best explained - in the context of such factors.

