

## Personal Independence Payment: assessment thresholds and consultation

### Mencap response

#### About Mencap

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Mencap is the voice of learning disability. Everything we do is about valuing and supporting people with a learning disability, and their families and carers.

We work with people with a learning disability across England, Northern Ireland and Wales. All our services support people to live life as they choose. Our work includes:

- providing high-quality, flexible services in things like housing, employment, education and personal support that allow people to live as independently as possible in a place they choose
- providing advice through our help-line and website
- campaigning for the changes that people with a learning disability want.

We work with people with a learning disability of all ages. All our services are tailored to the individual so we can provide support throughout their life, ranging from support for a child at each stage of their as they grow up, through adulthood and into old age.

#### **Mencap in Northern Ireland**

Mencap is a voluntary organisation with over 60 year's experience of working alongside and representing the views and interests of people with a learning disability and their families. In Northern Ireland we deliver a range of services, support a membership network of local groups and clubs and campaign for equal opportunities and chances for people with a learning disability.

Through our employment and training services we provide help to young people and adults with a learning disability to prepare for, find and keep a job. We help individuals with a learning disability to explore their options, provide skills training in the workplace and work to remove the barriers to work for each person. We work in partnership with a range of specialist and mainstream employment, training and education organisations and support employers by providing information on the benefits of employing a person with a learning disability; as well as advice on making reasonable adjustments and disability awareness training designed and delivered by two people with a learning disability for their managers and staff.

#### About learning disability

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A learning disability is caused by the way the brain develops before, during or shortly after birth. It is always life-long and affects someone's intellectual and social development. It used to be called mental handicap but this term is outdated and offensive. Learning disability is NOT a mental illness. The term learning difficulty is often incorrectly used interchangeably with learning disability.

### People with a learning disability and DLA

According to the Department for Work and Pensions the number of people with a learning difficulty<sup>1</sup> receiving Disability is estimated to be about 348,000<sup>2</sup>. In February 2010<sup>3</sup>, Mencap undertook a survey to understand better how people with a learning disability use their DLA in order to support the extra costs associated with their disability. Respondents described the following:

- higher laundry costs and higher spend on cleaning products;
- higher than average heating, electricity and phone bills due to medical, physical and personal care needs;
- specialist food as a result of dietary requirements or purchasing of ready meals due to difficulty with cooking;
- higher transport costs;
- paying for help around the home (e.g. cooking meals, sorting bills) and with shopping;
- help to access leisure activities and support with transport.

It is worth noting that for many people, like other sources of income, DLA is often subsumed into the “general pot” and used to pay for things as and when they are needed on a day-to-day basis. People with a learning disability can often find it difficult to single out DLA as a separate resource for a particular purpose. It is also worth noting that for some people with a learning disability, particularly those with lower level needs, any extra costs incurred can be subtle and difficult to distinguish from the everyday activities / costs that non-disabled people face – for example, heating costs. The distinction is that, due to the particular life style of the individual – because of their disability – the costs incurred are greater than would be the case for someone without that disability.

## Context

### **Welfare Reform in Northern Ireland**

The Welfare Reform Bill is expected to be introduced into the Northern Ireland Assembly imminently. Mencap believes that it is vital that MLAs have the opportunity to give the bill full parliamentary scrutiny.

The particular set of circumstances in Northern Ireland in relation to welfare reform, we believe, needs to be considered when implementing any change to the benefits system. This includes the higher levels of disability and poverty and the requirements on public bodies outlined in Section 75.

Mencap draws attention to the proportion of the population claiming DLA, with double the amount of DLA claimants in Northern Ireland compared to the rest of the UK: over 180,000 claimants in 2010.<sup>4</sup> A report by The Institute of Fiscal Studies estimated that in Northern Ireland, because of it has a large population of households with children and higher levels of disabilities, will lose more income than any other region in the UK outside of London. Northern Ireland is likely to be disproportionately affected from the new

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<sup>1</sup> “a significantly reduced ability to, understand new or complex information and learn new skills [impaired intelligence] with a reduced ability to cope independently [impaired social functioning], which started before adulthood with a lasting effect on development.” - DWP definition:

<http://www.dwp.gov.uk/publications/specialist-guides/medical-conditions/glossary-of-terms/#>

<sup>2</sup> PQ answered by Maria Miller, Minister for Disabled People, on 19 July 2010, Figures taken from DWP 5% sample data: <http://services.parliament.uk/hansard/Commons/bydate/20100719/writtenanswers/part018.html>

<sup>3</sup> DLA: *why it matters*, February 2010, Mencap

<sup>4</sup> The impact of tax and benefit reforms to be introduced between 2012-11 and 2014-15 in Northern Ireland, 2012, Institute of Fiscal Studies,

restricted test for Personal Independence Payment than the announced budget in June 2010. Northern Ireland Commissioner for Children and Young people (NICCY) recently produced a report which highlighted the impact of Welfare Reform for Children in Northern Ireland. It said that the benefit changes and the introduction of Universal Credit will impact on children's rights in Northern Ireland. Large families where there is a severely disabled child are at risk of being affected by the benefit cap and this could potentially impact on the lives of 6,500 children in Northern Ireland.<sup>5</sup>

Mencap in Northern Ireland is a member of the Welfare Reform Group and supports their consultation response to the Personal Independence Payment: Assessment and Thresholds document.

### **Approach to reform**

Mencap responded to both the initial consultation on the reform of Disability Living Allowance (DLA) and to the initial draft of the assessment regulations. In both of these responses Mencap emphasised its concern about the approach being taken in the development of Personal Independence Payment (PIP) – in particular, a reduction target of 20% and a focus on those with the 'greatest need'.

Despite the Government commitment to ensure PIP remains an 'extra costs' benefit, those with lower level needs (and most likely to lose their eligibility for PIP) will still have additional costs associated with their disability. The impact assessment accompanying the reform proposals confirms that: "it is likely that some disabled people with lesser barriers to leading independent lives will receive reduced support", and it is acknowledged in the explanatory note to the second draft of the assessment regulations that "across responses [to the first draft assessment] there was a general concern that the proposed approach would result in individuals with lower level needs not being entitled to Personal Independence Payment."

### **Numbers affected**

The consultation document states that the proposed descriptors as they currently stand will see half a million people losing out under PIP by 2015/16. This is a significant number and is extremely worrying for people with a learning disability and their families. Because the three rates for the care component of DLA (low, middle, and high) are being replaced with just two rates under the newly named 'daily living' component of PIP (a standard and enhanced rate), comparing the figures and potential impact 'like for like' is difficult – particularly without knowing the proposed payable amounts for each rate. However, the current estimates – as set out in the consultation document – show the enhanced rate recipient numbers to be similar to the current higher rate for DLA (540,000 and 530,000 respectively), while the numbers set to receive the standard rate are significantly lower than the combined numbers currently receiving middle and lower rate care (690,000 and 1,470,000 respectively). Figures suggest that the majority of people with a learning disability (72%)<sup>6</sup> who are in receipt of DLA receive either the middle or lower rate of the care component. Mencap is therefore very concerned about the potential negative impact of the draft criteria in their current form on this group.

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<sup>5</sup> A child rights impact assessment of the impact of welfare reform on children in Northern Ireland, April 2012, G Horgan and M Monteith (NICCY)

<sup>6</sup> PQ answered by Maria Miller, Minister for Disabled People, on 19 July 2010, Figures taken from DWP 5% sample data:  
<http://services.parliament.uk/hansard/Commons/bydate/20100719/writtenanswers/part018.html>



123 Golden Lane  
London  
EC1Y 0RT  
T: 020 7454 0454  
F: 020 7608 3254  
[www.mencap.org.uk](http://www.mencap.org.uk)

For the mobility component, there will remain two rates under PIP as is currently the case for DLA. There is a significant reduction in numbers across both rates of the component. Again, using the figures as set out in the consultation document, the numbers currently receiving higher rate of mobility are just over 1 million. Under PIP this number will reduce to 760,000 for the enhanced rate and from 900,000 for the current lower rate to 550,000 people receiving the standard rate of PIP.

### **The assessment process and additional evidence**

More generally, the introduction of PIP marks a very different approach to claiming the benefit than was previously the case for DLA. Many people with a learning disability currently receive automatic entitlements to DLA. In comparison, it is the Government's intention that most claimants for PIP have a face-to-face assessment with an independent healthcare professional (HCP). Clearly, it will be essential that the process takes into account the specific support needs of people with a learning disability, and that HCPs have a good knowledge and understanding of learning disability. However, Mencap believes that more emphasis should be placed on gathering additional information and evidence from the people who know the claimant best. It is clear that there are some exemptions from the face-to-face assessment which are reasonable if, based on the evidence received as part of the application process, it is clear that there is an entitlement to PIP.

## Overview

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Mencap welcomes a number of the changes made to the draft assessment since its initial draft, which we believe better take into account the particular support needs of people with a learning disability. In particular:

- The new 'making financial decisions' descriptor; this is an essential part of 'daily living' and acknowledges the support needed for many people with a learning disability to live independently;
- The splitting of the 'communicating with others' activity into two new activities to cover communication and social engagement distinctly; the original descriptor was confusing and tried to cover too many aspects of functioning;
- The addition to the definition of 'communication support' to include 'support from someone experienced in communicating with the claimant'.
- The widening of 'types of support', to include the term 'supervision' alongside 'prompting' and 'assistance'; this will help take into account any issues around safety.

However, we would emphasise the following over-arching points in response to the approach being taken:

- **Definition of eligibility for PIP:** If the Government acknowledges that there will be some disabled people who will not be found eligible for PIP (but may have previously received DLA) it is difficult to comment on the descriptors being proposed without an idea of the sorts of people this might include. Currently the draft regulations state only that an eligible claimant has "limited ability to carry out daily activities" or a "severely limited ability to carry out daily living activities".

A similar suggestion has been made in relation to the Work Capability Assessment (WCA) and members of the work-related activity group of ESA. As was noted in this context, greater clarity around the sorts of claimants intended for this group – i.e. what sort of characteristics, impairments or barriers should define eligibility – would enable a more informed debate as to the descriptors used in the WCA. Along similar lines, clarity about eligibility for PIP given the confusion surrounding the focus on "greatest need", the change to two rates of payment for the 'daily living' component and the continuation of PIP as an "extra costs" benefit, would allow a more productive discussion about the accuracy of the criteria being proposed.

- **Quantifying 'extra costs' of disability:** Mencap supports the proposed focus of PIP on participation and the impact an individual's impairment or health condition has on their daily life. However, we would also stress the complexity of quantifying the extra costs of disability: there is no single factor that can be used that acts as an "adequate proxy for total disability cost."<sup>7</sup> Given this, it is without doubt a challenge to create an assessment that is robust enough to reflect the wide range of disabilities and conditions or whether the 'impact on everyday life' proxy (as opposed to 'care' and 'support' used in DLA) will effectively measure the multi-dimensional drivers that impact on the costs that disabled people incur.

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<sup>7</sup> *Counting the Cost*, Claudia Wood & Eugene Grant, Demos, 2010

- **Focus on impairment and danger of over-simplification:** The draft criteria focus more on the medical impact of an individual's impairment rather than how this interacts with society to create barriers to independence. Further, by measuring a single factor against certain functional tasks and everyday activities, the wider additional costs that DLA is currently spent on – for example, increased electricity bills associated with doing laundry more often or for more expensive specialist clothing – will not be picked up unless we can say confidently that all the other criteria will ensure this 'by proxy'. This is unlikely to be the case in all scenarios.

The technical note which was published alongside the initial draft assessment criteria states that “to provide the best possible proxy [to extra costs of disability], we sought to determine those tasks which are fundamental prerequisites for enabling participation”, as well as “it would not be practical for the assessment to take account of the impact on ALL everyday activities, nor to seek to include all possible areas where extra costs may be generated”. Whilst there is clearly a need for an assessment which is practicable to deliver, there is a danger of over simplification with an approach like this.

- **The approach for those with lower level need:** As is the case now for the Work Capability Assessment (WCA), where someone scores the highest score possible against any one descriptor in the current proposed assessment for PIP, eligibility for the benefit – at least for the enhanced rate – will be met. Someone, however, with a more moderate learning disability will need to score lower amounts across a range of descriptors to reach the 8 point threshold. This is acknowledged in the explanatory notes – i.e. that respondents of the first draft assessment were concerned that the criteria would not accurately reflect the support requirements for individuals with lower level needs across a number of activities, even though their overall need for support may be greater than another individual who scored highly in just one activity. This is why it is essential that there is an appropriate number and range of descriptors included within the assessment, and that the weightings and thresholds are appropriate.
- **Knock-on impact on other services:** As Mencap has previously raised, we are particularly concerned about those people with more moderate learning disabilities, who may currently be receiving lower rates of DLA and may not be eligible for PIP in the future. This group are often unlikely to be accessing support elsewhere – a situation that is worsening as a result of tightening social care eligibility criteria. We do not believe that enough consideration has been given to the potential impact of a reduction in DLA on already stretched social care and NHS budgets. This is a view supported by the Joint Committee on Human Rights in its report into disabled people's right to independent living, which stated that *“evidence that impact assessments of current reforms were not adequately carried out, and did not take into account the likely cumulative impact of reforms on disabled people.”*<sup>8</sup> As we noted in our response to the consultation on DLA reform, it is misleading to suggest that DLA is one part of a wider range of support and services available to disabled people – many people with a learning disability do not meet the threshold for social care.
- **Those with a life-long disability:** There has been a strong focus in the development of PIP on people being able to adapt to their condition over time. This is a simplistic analysis in relation to a

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<sup>8</sup> *Implementation of the Right of Disabled People to Independent Living*, 1 March 2012, Joint Committee on Human Rights, 23<sup>rd</sup> report

benefit that is about providing for the additional costs of disability. For people with a learning disability, support will be life-long and will not lessen over time. Indeed, one could argue that a focus on supporting true independence and participation of people with disabilities could well increase support costs.

## Consultation response

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### **Involvement of people with a learning disability**

Our response focuses specifically on people with a learning disability. To support our response to this consultation, Mencap carried out a focus group session with 16 people with a learning disability. The focus group was made up of people with mild to moderate learning disabilities, reflecting Mencap's particular concern for those people with a learning disability who have lower level need. Six people in the focus group were receiving the lower rate of the care component of DLA and four people were receiving the middle rate. Three of these four were also receiving the lower rate of the mobility component, with the fourth person receiving the higher mobility rate. One additional person who was receiving low rate care was also receiving the high rate mobility component. It is worth noting that both of the individuals in receipt of high rate mobility also had a physical disability.

Of the remaining six participants, three said that they did not receive any DLA payment. A further three said that they knew they were receiving DLA but were not sure which rates they were receiving or whether it was for the care or mobility component or both. It is worth noting that those who were not in receipt of DLA are not necessarily a reflection of non-eligibility for the benefit. Rather, it could well highlight low awareness of the existence of the benefit.

Our intention was to hear the views of the focus group on the descriptors being suggested and to attempt to ascertain where people were likely to score against the new descriptors. The discussion that took place also helped to highlight some wider delivery issues – for example, in relation to guidance for healthcare practitioners. The feedback from this focus group has been particularly helpful in providing Mencap's response to questions 1 - 4.

### **General comments about the descriptors and thresholds**

As noted above, Mencap very much welcomes the inclusion of the three new activities: communicating, engaging socially and making financial decisions, which are particularly relevant to people with a learning disability. Below we comment on each of the proposed descriptors in turn, including the feedback from the focus group. However, as a starting point, we would make the following more general comments:

#### **1. Descriptors aimed at those with 'mental, cognitive and intellectual' disabilities / conditions**

In general, for people with a learning disability, their disability will mean that (to varying degrees) they will need some level of support to fully engage and participate in different aspects of daily living. Related 'extra costs' therefore may be in relation to the support by another person, but will also include things like higher laundry costs, higher transport costs, higher than average heating, electricity and phone bills due to medical, physical and personal care needs and so on. The descriptors concentrate more on the former – levels of support needed – and there are clearly a number of activities which are aimed at exploring the support needs of those with mental health conditions, autism or learning disabilities as opposed to those with physical disabilities or specific health conditions, but these are relatively few: communicating,

engaging socially and making financial decisions, as well as planning and following a journey. As noted earlier, this raises concern about the ability of the assessment to take into account the cumulative impact of a range of different barriers to participation.

## 2. Cumulative impact of a range of different barriers to participation

For those with more severe or profound and multiple learning disabilities or an additional health condition, there are additional activities (e.g. taking nutrition and managing therapy or monitoring a health condition) that are more likely to be applicable – thus, enabling claimants to score against a wider range of descriptors. For those with more moderate needs, there are some activities / sets of descriptors that *may be* applicable – e.g. in relation to choosing appropriate dress (as per the dressing and undressing descriptor) or help with cooking. However, as the focus group found, these were sometimes unclear and difficult to apply to someone with a learning disability. As a result, it was difficult to ascertain what participants might therefore score and whether they would meet eligibility for PIP.

Participants of the focus group tended to pick up points on the communication, social engagement and making financial decisions activities for the 'daily living' component, but these were not always straightforwardly applied. However, it is more likely that these three activities will apply more consistently (to differing degrees) to a wider spectrum of people with a learning disability. As noted, the concern is that, on their own, these activities will not allow for the accumulation of enough points to meet the threshold for PIP.

The Minister for disabled people has stated several times that the Government is committed to PIP supporting participation and enabling disabled people to lead independent lives, and that the new benefit will be about promoting independence and social inclusion. We therefore recommended in response to the first draft assessment, some additional criteria to include 'maintaining a safe and clean living environment' and 'social participation'. These are not included in the current draft assessment but we would re-emphasise their importance.

## 3. Impact on every day activities

We support the stated approach to this second version of the assessment (see paragraph 3.16 of the explanatory notes) to better take into account learning disabilities and other 'mental function' conditions / disabilities. In particular, the recognition of things like a lack of insight, memory problems and support for challenging behaviour are very welcome. Despite this, we remain concerned that the assessment criteria itself, as well as how this is applied by the relevant HCP, does not allow for the subtleties of someone's learning disability and the impact it has on the different aspects of their lives. We hope to draw out these points in the analysis below of individual descriptors, but we would emphasise the challenges of ascertaining levels of support required by an individual with a learning disability without knowing them well – thus emphasising the importance of additional evidence as part of the assessment process.

Additionally, while we would not describe someone with a learning disability as having a fluctuating condition, it is important to recognise that levels of support required by an individual will vary enormously (potentially on a day to day basis) depending on particular circumstances or because of certain environmental and personal / emotional factors. As noted below, we do not believe that this is recognised in some of the proposed criteria, and may also point to some limitations in the definitions of the three

criteria which describe types of support – assistance, prompting and supervision. We go into this in more detail below.

**Question 1: What are your views on the latest draft Daily Living activities?**

**Question 2: What are your views on the weightings and entitlement thresholds for the Daily Living activities?**

- **Preparing food and drink**

A number of the focus group participants felt that more than one of the descriptors applied to them – thus, a high number stated that they felt 1a applied to them (“can prepare and cook a simple meal unaided”), which scores zero points, until they heard 1c (“cannot cook a simple meal using a conventional cooker but can do so using a microwave”). Similarly, a number of participants felt that both 1c and either 1d, 1e or 1f applied – i.e. on their own they could use the microwave, but to cook using a conventional oven they needed someone to be there to assist / prompt or supervise in some way. Presumably the criteria attracting the higher score would apply in these cases.

We would argue that 1c in particular seems out of place at the lower end of the scorings and sits awkwardly above d, e and f – none of which clearly define whether the preparation of a simple meal includes usage of a microwave (although it is implied in the accompanying technical note). By scoring so few points, it is implied that it is acceptable for someone to live on microwaveable meals and without any support to prepare a fresh meal for themselves.

One focus group participant stated that he had never needed to use an oven so had never been shown how to. These points are worth bearing in mind for clarity in any related guidance for those Healthcare professionals (HCPs) carrying out the assessment. Learning from the face-to-face assessment as part of the Work Capability Assessment (WCA), we have found that HCP’s do not always probe or thoroughly explore whether an individual with a learning disability has thoroughly understood a question or what is being asked of them.

*“I’ve never had to use an oven, so I don’t know how to use the one we have. I just heat food in the microwave.”*

Even with an understanding of the definition of a ‘simple meal’, respondents commented that they felt their answer depended on what they were cooking – for example, a baked potato with cheese versus a meal which includes different elements, including fresh vegetables – even though both are made from fresh ingredients. Respondents commonly described finding it difficult to coordinate and time the preparing of a number of different food types at once. Mencap’s response to the initial draft assessment also noted a need to recognise what was ‘appropriate’ food and drink in order to ensure a healthy diet or a diet that is appropriate to a particular health condition – e.g. diabetes. Whilst the definition of simple meal has been amended to take into account fresh ingredients, it does not necessarily equate to a healthy diet or one that is appropriate to a particular health condition.

In the focus group, because of the ‘overlap’ and application of more than one descriptor per person, it became difficult to ascertain where people ‘scored’. Initially, nine of the 16 participants said that they

could 'prepare and cook a simple meal unaided', but with further probing, as noted above, this was not always quite as straightforward. Some felt that (1d) - 'needs prompting' probably applied to them, scoring two points. Arguably, this level of support implies a degree of disability that is likely to have a significant impact on an individual's ability to participate in aspects of daily living, and should therefore attract higher points. The weightings for this activity seem generally low in comparison to some of the others, yet being able to prepare food and drink for oneself is clearly an essential part of daily living.

From the perspective of ensuring safety, it is difficult to know from the descriptions whether 'prompting' or 'supervision' would apply. Again, as noted earlier, the sort of support needed could well vary, depending on what is being cooked or because the individual is distracted for some reason. Additionally, we have concerns about the definition of 'risk and safety' – see question 7/8 below.

Only one person stated that they needed to use an 'aid or appliance' (1b) – in this case, she described using a special vegetable peel because of poor hand / eye coordination. Another participant stated that his vision went 'up and down' so there was some level of fluctuation in the support he needed. From the description of 'variable and fluctuating' as per the explanatory note, it is unlikely this would score him anything under the current descriptors.

*"I have someone who helps me once a week to cook a healthy meal."*

- **Taking nutrition**

This descriptor is more relevant for those people with more severe or profound and multiple learning disabilities, where an individual may need another person and /or some sort of therapeutic source (e.g. a feeding tube) to convey food and drink. The descriptors as they currently stand do not seem to take into account those people who need supervision due to risk of choking as a result of swallowing difficulties.

In the focus group, all 16 participants scored zero points – "can take nutrition unaided" (2a).

- **Managing a therapy or monitoring a condition**

This descriptor does not apply to learning disability *per se*, although clearly it may apply where someone has a health condition in addition to their learning disability.

10 of the focus group participants scored themselves zero points (3a), stating that they did not receive medication, therapy or need to monitor a health condition or managing it unaided, or with the use of an aid of appliance. From discussion, it was unclear where someone might score if they received a prescribed course of medication for a specific reason (but for a limited amount of time) but would need some level of prompting or assistance to remind them to take it. Some clarity is needed about whether descriptor 3b would apply.

The remaining six respondents said that they needed prompting or assistance (1b) to help manage a health condition, therefore scoring one point against this descriptor. This ranged from help with managing diabetes to needing reminding to take medication for epilepsy. One respondent said that his support worker helped him to manage his medication – for example, making sure his medication has not gone past its sell by date.

- **Bathing and grooming**

None of the focus group respondents felt they needed any level of assistance or prompting in relation to bathing, where as six of the respondents felt that they needed some prompting to “groom”, therefore scoring one point. A number of people commented that they needed to be reminded about things like having their hair cut, but from the draft regulations this is not included within the definition of “groom”.

We believe that a score of only one point for this descriptor (‘needs prompting to groom’) is too low. Given that the definition of ‘groom’ as set out in the draft regulations includes to ‘comb or brush one’s hair; wash one’s hair, and clean one’s teeth’, which are all fairly basic, daily activities, someone who needs prompting to do these things arguably needs a considerable amount of support. Similarly, someone who needs supervision or prompting to bathe should surely attract more than two points.

Clearly, participants were less comfortable talking so openly in relation to these more personal issues which, again, would need to be borne in mind by any HCP undertaking the face to face assessment. It is also important to note that there is also sometimes an issue of low self awareness amongst people with a learning disability, including amongst those with fairly low level needs. More generally, there can be an issue with presentation (including clean clothes – as distinct from ‘appropriate clothes’, for example) which does not really get picked up in this or any of the other descriptors but is clearly absolutely central to participation and social inclusion. On the whole, the bathing and grooming criteria appear rather restrictive. We believe further consideration should be given to things like shaving, cutting nails and wearing clean clothes.

Mencap previously raised concern about the wording around ability to wash, bathe and groom to a level “above a level of self neglect”. We therefore welcome its removal.

- **Managing toilet needs or incontinence**

Again, this is more likely to be an issue with people with more severe learning disabilities and all but one of the focus group participants said they could “manage toilet needs or incontinence unaided”, therefore scoring zero points. One person said that they needed to use an aid or appliance to manage toilet needs or incontinence, scoring two points. Participants were clearly less comfortable talking about this activity as a group. It is unclear from the draft regulations whether the ‘aid or appliance’ descriptor includes usage of incontinence pads, which is clearly relevant to this activity and has additional related costs attached.

- **Dressing and undressing**

All but one of the focus group participants could “dress and undress” unaided, scoring zero points. Most of the descriptors under this activity refer to physical assistance to dress and undress, with only 6c referring to assistance or prompting in relation to appropriate clothing. A few people from the focus group stated that they needed some prompting to select appropriate clothing, scoring two points, but again participants found this more personal activity less easy to talk about. Mencap believes that there is too great a focus on the physical act of putting clothes on, allowing people with a learning disability only to score two points against descriptor 6c.

- **Communicating**

During the focus group discussion, a number of points were raised, particularly focusing on (d) “needs assistance to access written information” and (e) “needs communication support to express or

understand complex verbal information”, where it was felt further clarity was needed. For people with a learning disability, the *complexity* of written information is a key point. The focus group felt that the descriptor did not account for this. Additionally, it was clear that some people felt that they could read fairly well, but that this did not equate to understanding the information they were reading. This will apply to many people with a learning disability and needs somehow to be accounted for.

While a distinction between ‘basic’ and ‘complex’ communication is taken into account in the descriptor in relation to verbal information, this is not the case for written information, which appears inconsistent. Further, it is not clear why the definition of ‘basic’ and ‘complex’ communication is referenced in the supporting notes, rather than the regulations themselves.

The majority of participants felt that (d) or (e) would probably apply to them, with an associated score of four points. In response to whether or not people used an aid or appliance to express or understand verbal communication (7c, 2 points), three people said that they used a “read and write” programme on their computers at work. (It is worth noting, however, that the vast majority of people with a learning disability are not in any form of paid employment so this sort of example is unlikely to apply to many.)

Ability to communicate is another central part of being able to live independently and participate fully in society. Someone who needs some degree of support will clearly have needs which will lead to associated disability-related costs. Arguably then, descriptors (d) and (e) should attract higher than four points.

- **Engaging socially**

We welcome the fact that this activity takes into account non-verbal communication, such as understanding body language, which will be very relevant to many people with a learning disability.

All, but three of the focus group participants said that they could engage socially unaided, therefore scoring zero points. However, on further discussion people commented that it would depend on the situation – for example, with familiar versus new people. There could well be need to consider re-shaping this activity to include a descriptor, or several descriptors, which reflect the context of the need for support – for example, needs ‘social support around familiar people’ versus needs ‘social support around unfamiliar people’.

Again, there is likely to be some level of low self awareness amongst this group. It is likely that most people will need some level of ‘prompting’ in some social situations. The example given in the explanatory notes for 8b (this “may apply to people who need encouragement to interact with others by the presence of a third party”) could well apply to many people, including those with lower level support needs. This is potentially a particularly difficult activity for the HCP to judge on a one-to-one basis, with claimants with a learning disability potentially answering positively without understanding the nuances of what is being asked.

We believe that the definition of ‘social support’ to apply only to those “from a person trained or experienced in assisting people to engage in social situations” is far too limiting. This will not be relevant to many people with a learning disability who do not access social care support but, equally, support workers specifically employed to support someone with a learning disability might not be regarded as a person trained in assisting people to engage in social situations.

*"I'm okay with my family, but I don't really feel comfortable with other people and am not always sure what to say."*

The highest score for this activity is eight points, which we believe is too low – there is thus no means of meeting the threshold for the enhanced rate against this activity alone despite its centrality to participation. The descriptor (8d) states that the individual cannot engage socially due to such engagement causing "overwhelming psychological distress" or behaviours which would result in a "substantial risk of harm to the claimant or another person". We believe that this should automatically mean eligibility for the enhanced rate of PIP, with an associated score of 12 points. This would align it with the highest scoring descriptor for the activity exploring communication.

The description of 'substantial risk of harm' implies *physical* harm to one's self as a result of an 'uncontrollable episode of behaviour'. It is also important to consider that difficulties with social interaction can mean that people with a learning disability are often more vulnerable to abuse or being taken advantage of.

- **Making financial decisions**

Thirteen participants stated that they needed support to make complex financial decisions (9b, scoring two points). Initially, a number stated that they "could manage complex financial decisions unaided" (9a, scoring zero), but with further discussion it was revealed that this was done entirely by a family carer who they lived with and there was simply no involvement by the participant. One person who said they did not need any support stated that their household bills were simply set up to be direct debited out of their account. However, on further discussion, the complexities of setting up this arrangement were revealed whereby support was required. Again, this demonstrates the importance of HCPs knowing how to communicate appropriately with people with a learning disability.

Further, participants acknowledged that support could be required with any 'unusual' changes to their budget or bills. One person described getting into debt through credit card usage, while another described going over her overdraft and then owing money to the bank. Both needed support to rectify the problem.

There appears to be an inconsistency in the levels of support by another person outlined throughout this descriptor in comparison to some of the other descriptors which make a distinction between 'prompting', 'supervision' and 'assistance'. 'Prompt' as defined in the draft regulations means to "remind or encourage" but this may not be the most accurate means of describing the sort of support someone may need in relation to making financial decisions.

*"When I lived on my own I needed help to go through my bills so I could understand them. They were bank statements... Budgeting was difficult as I had money coming in and out at different times. It was hard for me to manage on my own."*

The ability to pay bills, go shopping and maintain a budget are central to independent living. The majority of people with a learning disability will need some level of support to do these things and probably

throughout their life. This incurs a significant associated cost. This descriptor should attract a minimum of eight points to be in line with the other descriptors. As it is, the maximum score is six points for someone who cannot make ANY financial decisions at all, complex or simple.

Finally, we would flag up the example case study 12 which states that Elizabeth “does not understand the value of money and therefore cannot go shopping on her own”. This does not seem to reflect the situation for many people with a learning disability who may well struggle to work out how much change they should get, but will still go shopping nevertheless. An example like this supplied to HCPs could well mislead should an assumption be made that because an individual does his / her own shopping, s/he can make “simple financial decisions.”

**Question 3: What are your views on the latest draft Mobility activities?**

**Question 4: What are your views on the weightings and entitlement thresholds for the Mobility activities?**

Only the ‘planning and following a journey’ descriptor is relevant to someone with a learning disability, unless they have an additional physical disability or condition.

It is not clear how 1a and 1cii relate. Nearly all of the focus group participants all stated that (a) would apply to them – i.e. that they can plan and follow a journey unaided, attracting zero points – but this was for the most part based on the assumption that the journey was familiar to them. It may be then the (cii) “needs... a journey to an unfamiliar destination to have been entirely planned by another person” would therefore apply, which would reach the threshold for eligibility for the standard rate. Additionally, a number of participants stated that they could plan and follow an ‘unfamiliar’ but local journey - where they know the local buses and understand the tube system - but that with longer distance journeys, they did not feel they could plan or follow unaided. Others noted that familiar journeys were ‘okay’ if there were no unexpected changes to the journey – e.g. the bus being diverted because of road works.

**Question 5: What are your views on how the regulations work regarding benefit entitlement? [Regulations 1-4]**

Many of the comments already raised in this consultation response go some way to answering this question. The regulations distinguish between eligibility for the standard and enhanced rate of PIP by describing either a ‘limited’ ability or ‘severely limited’ ability to carry out daily living or mobility activities. The issue, as outlined earlier, is a general lack of detail about what these actually mean. How is ‘limited’ defined? At what point does someone become ‘severely limited’ in their ability to carry out daily living or mobility activities?

As noted earlier, without greater clarity about the sorts of claimants intended for each group (or indeed, intended to no longer be eligible for the benefit), there cannot be any informed debate and discussion about the criteria being proposed – i.e. whether they do what they are intended to do and allocate the ‘right’ people to the benefit. As we have found with the WCA, this means that, in effect, the proximate reason for qualifying for a group (i.e. points scored on the descriptors), is also the ultimate reason for qualifying, in the absence of a clear and objective definition or profile of who should qualify for each

group. This presents problems for claimants and representative groups in terms of understanding whether people have been correctly allocated to the benefit – or rate of benefit – and having an objective basis for challenging decisions.

**Question 6: What are your views on how we are dealing with fluctuating conditions?**

As we have seen with the WCA, there are clearly some challenges to getting the process right for people with fluctuating conditions. While it is welcome that the proposals attempt to take into account an inability to perform a task at *some points* of the day, the concern is that for those able to complete activities that amount to less than 50% of the days in the required period – but who may incur significant costs as a result – will score very few, if any, points at all. As noted earlier, while people with a learning disability do not tend to be described as having a ‘fluctuating condition’, levels of support needed may well vary. As the draft regulations currently stand, it would appear that the rule around a particular descriptor applying by ‘satisfying it on over 50% of the days of a required period’, will also apply to people with a learning disability.

As previously noted, the current proposed 50% potentially sets the threshold far too high on a number of descriptors. In theory, for example, it implies that someone who may not need needs assistance or supervision all of the time to prepare food and drink, but who could seriously injure themselves at other times, would fail to score any points. Additionally, the definition of ‘supervision’ is potentially too restrictive. Someone may need to be close by *in case* they are required to ‘prompt’ or ‘supervise’ but not in the room at all times. It is sometimes difficult to establish which, if any, of the three types of support would apply to someone with a learning disability.

**Question 7: What are your views on the definitions of ‘safely’, ‘timely’, ‘repeatedly’ and ‘in a timely’ manner?**

**Question 8: What are your views on the definitions in the regulations?**

As previously noted, it is not always clear why some definitions are included within the regulations themselves, with others set out in the supporting materials. We have given views on specific definitions outlined in the regulations in response to comments on each of the activities / descriptors (above). The definitions of reliably, repeatedly and in a timely manner seem appropriate, but would be more clearly defined within the context of each activity. The definition of safely as it stands in paragraph 7.4 seems adequate – however, the following paragraph (7.5) on ‘risk and safety’ seem to set the scoring thresholds too high, stating that “the risk that a serious adverse event *may* occur due to impairments in insufficient...there has to be evidence that... the adverse event is likely to occur.” How is the *degree* of risk or *seriousness* of an incident defined? And how would this be applied consistently by different HCPs? Surely if there is *any* risk that exists as a direct consequence of someone’s disability, this should be taken into account and an appropriate score awarded.

Mencap strongly believes that these definitions be placed in the regulations themselves to ensure there is consistency in approach, and to emphasise their importance in determining ability in relation to each activity.

### Question 9: Do you have any other comments on the draft regulations?

Mencap would like to make the following comments on other aspects of the draft regulations:

- **Provision of additional information in relation to ability to carry out activities**

It is important that people with a learning disability are supported throughout the assessment process, particularly in relation to the provision of additional information. As we have found with the WCA, claimants (and their supporters) are often unaware of the importance of the provision of additional information and evidence to support their claim. Further, it is more likely to be those with lower level needs who are making an application for PIP without support. With the WCA, Mencap has come across examples of people with a learning disability who are living semi-independently and who are not telling anyone (e.g. family members) about their correspondence in relation to ESA. As a result, they have sent back incomplete claim forms and are completely unaware of the need to provide additional information. The evidence from the WCA process suggests that successful appeals are often as a result of additional evidence provided at the point of appeal. Ensuring claimants are supported to provide information 'up-front' therefore will potentially save the Government money, both as a result of fewer appeals but also by avoiding unnecessary face-to face-assessments, where it is apparent from the range of evidence presented, that there is an entitlement to PIP.

- **Good cause**

The regulations provide little detail about what constitutes 'good cause' for failure to provide additional information or attendance at a face-to-face assessment. 'Good cause' should include a claimant's failure to understand what was expected of him/her, and inadequate support for the claimant in complying with conditions imposed on him/her.

### Conclusion

There have been a number of significant improvements to the draft assessment criteria, since the initial draft was published. These are welcome and we look forward to continuing to work with the DWP to ensure that the assessment is as fair as it can be for people with a learning disability.

Our biggest concern is that the assessment will be too rigid to allow for the particular subtleties of an individual's learning disability and the impact it has on the different aspects of their lives. However, this is an issue that is far wider than the criteria themselves. Learning from the WCA, we know this extends to the assessment process as a whole, including the gathering of additional information, the support / advocacy the individual claimant gets, and the approach, training and knowledge of HCPs. It is vital that all aspects of the process are developed together.



123 Golden Lane  
London  
EC1Y 0RT  
T: 020 7454 0454  
F: 020 7608 3254  
[www.mencap.org.uk](http://www.mencap.org.uk)

#### Respondent details

**Full name:** Jane Alltimes  
**Organisation:** Mencap  
**Your Role:** Senior campaigns and policy officer  
**Address:** 123 Golden Lane  
London EC1Y 0RT  
**Email Address:** [jane.alltimes@mencap.org.uk](mailto:jane.alltimes@mencap.org.uk)  
**Phone Contact:** 020 7696 6916  
**Date of response:** 26 April 2012

#### Contact for Mencap in Northern Ireland

**Full Name:** Jenny Ruddy  
**Organisation:** Mencap Northern Ireland  
**Your Role:** Campaigns Officer  
**Address:** Segal House, 4 Annadale Avenue  
Belfast BT7 3JH  
**Email Address:** [jenny.ruddy@mencap.org.uk](mailto:jenny.ruddy@mencap.org.uk)  
**Phone contact:** 028 9069 0152  
**Date of Response:** 29 April 2012